

'Setting the Scene': A More-Than-Representational, Participatory Action Study Exploring the Wellbeing Benefits of Participatory Arts for People Living with Dementia and their Carers

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*'And when there are enough outsiders together in one place,
a mystic osmosis takes place and you're inside.'*

– Stephen King, 'The Stand'

*'I wandered lonely as a cloud
That floats on high o'er vales and hills,
When all at once I saw a crowd,
A host, of golden daffodils;
Beside the lake, beneath the trees,
Fluttering and dancing in the breeze...'*

– William Wordsworth, 'I Wandered Lonely as a Cloud'

Declaration

I declare that this doctoral thesis is all my own original work and any sources used within it have been acknowledged as references. All of the images displayed throughout this thesis have been captured, by me, using video camcorders or cameras during the research fieldwork period and have received ethical permissions to be shown. None of the contents of this thesis have been used for fulfilment of any other higher degrees or awards. This research project was funded by the Economic and Social Research Council (ESRC) and received partial funding from CASE partner Theatre by the Lake.

Meghánn Ward

22nd June 2021

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Abstract

Community-based participatory arts are being increasingly promoted for the wellbeing of people living with dementia and their carers. Yet, there remains variability in the arts-based programmes available, inconsistencies in how they are evaluated, and ambiguity around wellbeing definitions. Moreover, the voices of people with dementia are lacking in the research process. This ESRC-funded CASE project collaborated with Theatre by the Lake, Cumbria, to examine the effectiveness of their '*Setting the Scene*' participatory multi-arts programme. The project involved a participatory action research (PAR) and sensory ethnography design, with qualitative and visual multi-methods. An 'in the moment' theoretical lens was developed by integrating more-than-representational theory, therapeutic landscapes and relational wellbeing concepts. Four resulting empirical chapters illustrate how people with dementia and carers contributed to, and were benefited by, *Setting the Scene*'s arts, objects, people and landscapes. The first chapter explores person-centred, 'in the moment' and strength-based engagements, elicited by the programme's multi-arts, multi-modal, and thematic design. The following chapter examines the plurality of communication and participation in art-making through more-than-verbal, more-than-human tenets. The final two chapters examine the nuances of therapeutic landscapes and acts of caring within the programme, respectively. Overall, this thesis considers participatory multi-arts for enabling socio-spatial-material therapeutic encounters through emergent, non-judgemental, creative landscapes. *Setting the Scene* is understood as producing important 'in the moment' relational wellbeing benefits for people impacted by dementia, alongside the joint respite potential for carers. New contributions are made to a more-than-verbal reconceptualization of 'voice' to support the inclusivity

of people with dementia in research and practice. Through novel integration of 'more-than' theories and methods so far lacking in dementia research, this thesis demonstrates how people with dementia can be acknowledged as 'more than' their symptoms through the arts; being recognised for enduring skills, narratives and authenticities that contribute to 'being' and 'doing' well.

Dedication

To all the participants, carers and families involved in Theatre by the Lake's *Setting the Scene* programme, who showed what it meant to live well with dementia through their eagerness, openness, creativity and generosity.

In memory of the *Setting the Scene* members who sadly passed away during my time researching the programme.

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I wouldn't be where I am today if it weren't for my first teachers – my parents Deborah and Patrick – and the love and sacrifices made by my whole family – including my sister Erin and her boyfriend Dillon – to help me pursue my education. I am so thankful for them all, for their care packages and virtual get-togethers that uplifted me when I missed them. Whilst COVID-19 brought many challenges, I am eternally grateful for the comforts of my family home during the Christmas lockdown while I wrote the first draft of this thesis. Lastly, I want to say an incredible thank you to my fiancé Aaron for taking the leap of faith and moving to England with me; for mentally supporting me throughout the course of this PhD, even when times were tough; and for never failing to make me laugh with your optimistic outlook on life.

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Chapter 1: Setting the Scene: An Introduction

1.1 My Motivation

As a pianist and singer-songwriter, I consider music and other creative outlets to be my preferred communication mediums over everyday speech. When public speaking seemed overwhelming in my youth, music and poetry enabled me to express emotions, tell personal stories, and ultimately encouraged me to perform on stage, in regional shows, and weddings. Unbeknown to me, these personal experiences around creative communication would re-emerge as underlying principles of my doctoral study of participatory arts for people living with dementia. Having explored ageing, emotion and creativity within my previous BSc Psychology degree and MA Social Anthropology studies, I longed to delve deeper into art's contributions to wellbeing. In 2016, I began volunteering at Alzheimer's Society 'Singing for the Brain' workshops in Belfast, Northern Ireland, where I observed first-hand the 'in the moment' benefits and communication opportunities that music created. Feeling passionate about contributing towards this field, I fortunately found, and was accepted onto, this ESRC-funded CASE studentship with Lancaster University and Theatre by the Lake. The result of that studentship is this thesis, which takes my passions for creative arts, dementia and wellbeing, and aligns them with a social, geographical and 'more-than' theoretical lens of study, to better understand wellbeing, selfhood, and creative engagement processes in dementia.

1.2 Current Status of Dementia

Recent statistics suggest that there are between 850,000 and 920,000 people in the United Kingdom living with dementia, with diagnoses predicted to rise to over 1 million by the year 2025 (Alzheimer's Society, 2021a; Social Care Institute for Excellence [SCIE], 2020). Worldwide, an estimated 55 million people are living with different forms of dementia, rising by an additional 10 million new diagnoses each year (World Health Organization [WHO], 2021). The most common cause of dementia is Alzheimer's disease, accounting for between 60-70% of worldwide cases (WHO, 2021), with the remaining diagnoses including vascular dementia, dementia

with Lewy bodies, frontotemporal dementia, and other rarer dementia-related syndromes and conditions (Alzheimer's Society, 2021a).

The daily impact of dementia symptoms on an individual is dependent on the specific disease causing them and the parts of the brain experiencing degeneration (Alzheimer's Society, 2021a). As an example, Alzheimer's disease is primarily caused by a build-up of amyloid beta proteins (plaques) and tau proteins (tangles) occurring throughout the brain, leading to potentially wide-ranging cognitive and behavioural symptoms (Kent, Spires-Jones & Durrant, 2020). Contrastingly, frontotemporal dementia is caused by a different mixture of protein build-ups specific to the brain's frontal and temporal lobes, primarily impacting regions responsible for emotional processing, personality, and language (Alzheimer's Research UK, 2021). Yet, regardless of the specific physiological profiles of different dementias, most dementia experiences will share broadly similar symptoms affecting memory, information processing, and overall cognition. One method of categorising these symptoms, irrespective of the specific form, is by acknowledging the stage of symptom progression as being early, moderate, or later-stage. Outlined by the Alzheimer's Society (2021b), individuals in early stages of dementia can maintain relative independence alongside mild symptoms of memory loss, mood changes, or difficulties with language processing and/or planning. Middle or moderate stages of dementia typically last longer, during which individuals display more noticeable symptoms, may show new behavioural or physical changes, and require more day-to-day support. Finally, individuals in the later stages of dementia have advancing memory loss, increasing communication difficulties and behavioural changes, eventually requiring full-time care.

While biomedical research is dedicated to investigating the interplay of different risk factors and pathologic causes of dementia, a lack of consensus exists on how it develops and on how to effectively treat or prevent it (e.g. James & Bennett, 2019). Until reliable clinical developments are made, there remains no cure and no reliable method of reversing dementia's progressive course; only limited pharmaceutical interventions are available to temporarily manage day-to-day symptoms (Alzheimer's Association, 2021). With limited biomedical options, it is important to

move beyond the medicalisation of dementia and towards social models of living – specifically ‘living well’ – that contemplate psychosocial, cultural, societal, environmental and/or economic factors that impact community-dwelling people with dementia (e.g. Oyebode & Parveen, 2019).

Outside of a biomedical lens, the daily experience of having dementia is acknowledged for both its cognitive and social implications. Whilst primarily affecting memory and cognition, people with dementia are also impacted by how they communicate with others, and indeed how those others view them (Dewing, 2008), affecting their everyday relationships and community inclusion (Ryan, Bannister & Anas, 2009). This ‘symptom-focused’ or ‘loss/deficit’ approach can overshadow how wellbeing and personhood are understood with dementia (Clarke et al., 2020, p.3). Subsequently, recent research, care practices and dementia campaigns have been reconsidering the person-centred work of Kitwood (1997), considering ‘the person *with dementia*’ (Thomas & Milligan, 2015, p.5); the roles of inclusion, autonomy and identity in health and wellbeing experiences (Clarke & Bailey, 2016); and a strength-based approach that attends to enduring skills and capabilities (McGovern, 2015). These new developments in person-centred dementia care, research and policy collectively contribute to the internationally acknowledged ‘dementia-friendly community’ initiative.

1.3 The Development of Enabling, Dementia-Friendly Communities

The dementia-friendly community initiative seeks to promote inclusive places for people who live with dementia, within which social stigma is reduced (Shannon, Bail & Neville, 2019) and people with dementia can feel empowered to ‘remain active, engaged, and valued members of society’ (Woodward et al., 2019, p.67). This initiative was developed to address findings that identify people with dementia as being at higher risk of isolation, more apprehensive about carrying out regular tasks, and subsequently withdrawing from their social activities and immediate communities (e.g. Birt et al., 2020). Whilst approaches and definitions of dementia-friendly communities vary within and across nations, Alzheimer’s Disease International (2021) has identified the four key tenets that link dementia-friendly communities across the world. They comprise *people* – those living with dementia

and those who have an informed awareness about dementia; *communities* – such as physical and/or social landscapes that make person-centred adjustments to meet the needs of people with dementia; *organisations* – be it a business, care provider or charity, with their own appropriate dementia-related strategies, initiatives or activities in place; and *partnerships* – the forming of alliances between different organisations to establish wider dementia-friendly changes in a specific location or region. Whilst vague, these four elements should be involved in some manner for each case of dementia-friendly community development.

In practice, a dementia-friendly community should ensure that the lived experiences of people with dementia are positive, involving ongoing opportunities for wellbeing and belonging through inclusive, socio-cultural, meaningful and embodied engagements (e.g. Rahman & Swaffer, 2018). Yet, dementia-friendly communities typically vary and remain more regarded as a physical, as opposed to social, presence (Ward et al., 2021). This is exemplified in The British Standards Institute guidelines (BSI, 2015; *in* Ward et al., 2021), which recognise a dementia-friendly community as ‘a geographical area’ fluctuating in size from small businesses, cafés or neighbourhoods, to larger villages, towns or cities. Indeed, this does not consider the potential for dementia-friendly communities to also have virtual or digital features (Rahman & Swaffer, 2018). Moreover, it can become difficult to effectively oversee dementia-friendly policies and infrastructure, with greater weight given to spreading their application and less on how such practices unfold in the intimate, everyday lives of individuals and families. New alternatives to dementia-friendly frameworks are being developed by researchers including Clark, Campbell, Ward and Keady, through their ongoing work on ‘enabling neighbourhoods’ (e.g. Clark et al., 2020; Ward et al., 2021). As an alternative, this framework looks beyond what can be done for inclusion in specified physical boundaries. Instead, it promotes the embodied and social practices that people with dementia not only experience within particular settings, but also contribute to places, neighbourhoods and other social activities.

This thesis continues to reference ‘dementia-friendly’ frameworks, in accordance with the terms used in the work of CASE partner Theatre by the Lake. However, awareness of the emerging literature helps to draw attention beyond the physical

boundaries of dementia-friendly landscapes, inspiring perspectives that consider the enabling or empowering relational and social factors in the everyday geographies of people with dementia. Outside of healthcare settings, various psychosocial community interventions and creative programmes have the potential to promote the skills and enabling needs of individuals and families affected by dementia. The most commonly researched activities are nature-based or gardening groups (Milligan, Gatrell & Bingley, 2004; Bossen, 2010; Gonzalez & Kirkevold, 2014; de Bruin et al., 2017; Noone & Jenkins, 2018; Wu et al., 2021) and arts-based programmes (Sherratt, Thornton & Hatton, 2004; Beard, 2012; Zeilig et al., 2014; Dowlen et al., 2018; Milligan & Mossabir, 2018; Ward et al., 2020). Themes of arts, nature and self-expression are all relevant to the CASE project as presented in this thesis, conducted in partnership with Theatre by the Lake, a dementia-friendly organisation based in the Northwest of the infamous English Lake District.

1.4 The Lake District, Theatre by the Lake and ‘Setting the Scene’

The English Lake District has long been revered for its therapeutic potential, in terms of the aesthetic beauty of its lakes and woodland landscapes (Donaldson, Gregory & Taylor, 2017) and the wellbeing experiences they afford (Tolia-Kelly, 2008; Jepson & Sharpley, 2015). Yet, as highlighted by Rose (2012), the Lake District was not always viewed this way, originally comprising ‘wild, inaccessible, barren, dangerous and frightening’ landscapes that contrast with picturesque, present-day descriptions (p.1383). The transition of impression is often attributed to notable works of the eighteenth century – including writers such as William Wordsworth and painters like JMW Turner (Kemal & Gaskell, 1995; Tolia-Kelly, 2007; Rose, 2012) – that offered new literary and visual narratives of the Lake District. This insight shows how art can influence impressions of place in popular culture, as well as demonstrating that place-based experiences also inform the arts. Similarly, but on a meso level, this study engages with how place and community are entangled in the creative arts-based activities of Theatre by the Lake’s *‘Setting the Scene’* programme.

Theatre by the Lake (Figure 1.1) is based in Keswick, in the northwest of the Lake District National Park. It is built along the perimeter of Lake Derwentwater (Figure 1.2), opposite to a public green, Hope Gardens public park (Figure 1.3), and encircled by mountains and fells (Figure 1.4).



Figure 1.1: Theatre by the Lake building.



Figure 1.2: Lake Derwentwater at sunset.



Figure 1.3: *Hope Gardens, Keswick.*



Figure 1.4: *View of the peaks from Theatre by the Lake.*

Prior to the COVID-19 pandemic, Theatre by the Lake were running a range of seasonal theatre productions and community activities, amongst them their 'Living Well with Dementia' initiative; this was developed in response to local demand for dementia-friendly services.¹ The *Setting the Scene* participatory arts programme forms a central part of this initiative, comprising 'a series of creative sessions enabling people to share, create and connect' through theme-based multi-arts

¹Cumbria County Council found their prevalence of dementia to be 12% higher than the national average (Cumbria County Council, 2017, p.13). This is associated with the 'Super-ageing' Cumbrian population, where approximately a quarter of local residents are 65+ years (p.34). Theatre by the Lake is a member of Keswick's Dementia Action Alliance, a group of organisations and businesses working towards dementia-friendly community services.

activities (Theatre by the Lake, 2020). Designed by theatre staff and a freelance creative practitioner approximately six years ago, the programme delivers to both people living with dementia and carers, aiming to create ‘peer support’, promote ‘feelings of well-being’ and ‘respond to participants’ interests, personalities and requests’ within an ‘accepting environment’ (Theatre by the Lake, 2020). Offered freely to participants, the programme has received partial funding from different organisations over its lifespan, including Arts Council England, Cumbria County Council, Keswick Town Council, and The Lottery Fund. Though it is now well-established, *Setting the Scene* has received no formal evaluation from participants or external researchers; to do so could contribute to new learning about dementia, enhance the programme’s effectiveness and aid the theatre’s overall objective to ‘share [our] learning with other organisations and businesses to create a dementia friendly community’ (Theatre by the Lake, 2020).

1.5 Research Summary

Considering the *Setting the Scene* programme, the current status of dementia, and the impressions of The Lake District, this thesis endeavoured to explore the wellbeing experiences of engaging in participatory arts for people living with dementia and their carers. Centred on CASE partner Theatre by the Lake’s programme and current members, the thesis employed a participatory action research [PAR] methodology to conduct collaborative and participatory research alongside theatre staff, participants with dementia, and carers. Informed by sensory ethnography and ‘more-than’ human geographies, this thesis aimed to build upon existing literature to gain in-depth understandings of creative and sensory arts engagement; participation and communication; objects and artefacts; self-identity and group relations; and to further illuminate how to live well with dementia. The research objectives will be outlined at the close of Chapter 2, contextualised by the knowledge gaps of existing literature in dementia and community-based participatory arts.

1.6 Thesis Overview and Chapter Breakdown

Comprising 10 chapters, this thesis addresses the empirical, theoretical and methodological influences that guided the subsequent design, data collection and interpretation of the fieldwork and findings.

Following this introduction, Chapter 2 presents a thematic modified scoping review of the existing literature on community-based participatory arts for the wellbeing of people living with dementia. I examine the varied personal, relational and socio-spatial benefits as drawn from relevant literature, in addition to methodological and theoretical considerations. I argue that whilst recent papers are beginning to address socio-cultural-material tenets in participatory arts settings, there remains an opportunity to expand on the enquiry of place, objects, identity, group relations, and participatory arts design. Furthermore, I acknowledge the lack of direct involvement of people with dementia in research processes and address the opportunity to resolve this using participatory frameworks and multi-sensory data collection.

Chapter 3 follows on from Chapter 2's insights by outlining a holistic social and geographical theoretical framework, to guide the research conduct and interpretation of the empirical findings of this thesis. This chapter first presents the concept of relational wellbeing and recent literature advocating this approach, informed by Deleuzoguattarian assemblage theory. Building on identified knowledge gaps in Chapter 2's review, the framework draws together more-than-representational and therapeutic landscapes theories, to aid exploring more-than-verbal, 'in the moment', material, sensory and place-based experiences of people with dementia and their carers attending *Setting the Scene*.

Chapter 4 presents the chosen methodology, which integrates participatory action research [PAR] and sensory ethnography principles. After considering methodological and theoretical insights from existing literature, this chapter addresses a chronological overview of the study design, *Setting the Scene* participant sample, and each data collection method adopted for the four fieldwork phases of the research. The chapter highlights the importance of finding methods of data

collection that uphold the personhood and voices of people living with dementia, including using visual data and adapting qualitative techniques.

Chapter 5 is the first of four empirical chapters, addressing the impact of *Setting the Scene*'s programme design on the engagement and wellbeing of participants. This is presented according to three distinct components – multi-arts, multi-modal designs, and thematic contents. The empirical evidence is further exemplified through three participant vignettes that demonstrate the heterogeneity of people with dementia and the varying opportunities that multi-faceted programmes can offer. This chapter aligns with the first objective of this project: to better understand the role of *Setting the Scene*'s multi-arts approach, underlying processes, and facilitation methods.

Chapter 6, the second empirical chapter, presents extensive insight into how people with dementia communicate through, and engage with, participatory arts activities using tangible (physical/material) and intangible (imaginative/discursive) means. This chapter broadly addresses the plurality of communication and participation, to explore how to sustain the attention and engagement of people with dementia in arts contexts. The findings illustrate the flexible, more-than-verbal ways that participants expressed themselves during sessions, advocating for the central role of objects in the enablement of participants' interactions. Overall, I address the effectiveness of blending person-centred needs of individuals within group-centric arts participation, touching on the 'relational self' concept (Conradson, 2005).

Chapter 7 examines the place-based factors that impacted participation at the programme, which offer better insight into how the setting within, and landscape beyond, the intrinsic art activities can influence arts and wellbeing experiences. This smaller empirical chapter touches on the natural landscapes outside of the session venues, the interior busyness and spaces within which sessions took place, and the social atmosphere that unfolded during sessions, pertaining to the community-based context of participatory arts. Informed by the therapeutic landscapes concept, this chapter acknowledges the ways that wellbeing can emerge in particular places or spaces, and through relations with people within them.

Chapter 8 closes the findings section and dedicates consideration to the concept of 'care' at sessions. Given that the *Setting the Scene* sessions did not distinguish between carers and people with dementia, this chapter presents evidence of carers as facilitators, as participants in their own right, and the importance of their dyadic relationships. Furthermore, the capacities of people living with dementia to care for/about others is also presented, blurring the roles of participants. Overall, this chapter exemplifies the benefits and challenges of making sessions carer-inclusive and presents how participatory arts settings offer an empowering outlet to people with dementia to show their care to others.

Chapter 9 discusses the overall contributions made by this thesis to the field of dementia and participatory arts research, making connections between the evidence presented in the previous four chapters and the existing literature explored in earlier sections. Split into four main sections, this chapter considers the empirical, theoretical and methodological research contributions, in addition to the research limitations. The thesis is then closed by Chapter 10's conclusion, with a brief overview of the thesis and its implications for dementia policy, arts practice and the future of participatory arts for the wellbeing of people living with dementia or caring for someone with a diagnosis.

Chapter 2: Community-Based Participatory Arts for People with Dementia: A Thematic Modified Scoping Review

2.1 Introduction and Objectives

2.1.1 Rationale

As suggested in Chapter 1, people living with dementia are being increasingly supported to maintain active lifestyles and promote their enduring skills by attending community-based activity programmes (Alzheimer's Society, 2021d). These programmes most often engage with nature or the arts, the latter of which is the focus of this chapter. Whilst there is a considerable body of evidence indicating the health and wellbeing benefits of creative activity, there is a continued 'lack of clarity' in the literature when making distinctions between different art forms, practices and wellbeing outcomes in dementia research (Leckey, 2011, p.501; Pamelia, 2015). This makes it more difficult to draw conclusions across the evidence base about what type of activity is of most benefit and what its distinctive features or intentions are. This review chapter forms an outline and synthesis of participatory arts literature for people living with dementia, concentrating on community settings as characterised by CASE partner Theatre by the Lake. Building on a modified scoping review I previously published in the Journals of Arts & Health (Ward et al., 2020), this review chapter sets the foundation for the remaining thesis, establishing an understanding of participatory arts, their benefits and shortcomings, the methods used to evaluate them, and their underpinning theoretical frameworks. The knowledge gaps identified in the existing dementia and participatory arts literature guide the exploration of *Setting the Scene* according to research objectives as outlined at the end of this chapter.

2.1.2 Dementia and the Arts

There has been a widespread 'flourishing' of creative arts-based dementia services and programmes within the past 10 to 15 years, both in the United Kingdom and globally, all of which contribute to the drive towards 'living well with dementia' (Castora-Binkley et al., 2010; Zeilig et al., 2014; Bellass et al., 2019). Commonly

adopted activities – used in isolation or in combination – include visual art, music, dance, drama, storytelling and poetry (e.g., Beard, 2012), while more innovative programmes can include participatory filmmaking (e.g. Capstick & Ludwin, 2015) and photography (e.g. Dooley et al., 2020). Broadly speaking, these arts programmes in all forms have shown to feed into ‘the creative, imaginative and emotional parts of a person’, thereby contributing to experiences of wellbeing for people living with dementia (SCIE, 2015). Depending on their design and setting, creative activity groups can also foster social and relational benefits to their participants (Leckey, 2011). Given that people with dementia commonly experience social isolation and displacement from their communities (Alzheimer’s Society, 2018), in addition to various changes to skills or abilities, any opportunities that provide both creative and social benefits can be valuable to this community. Influenced by the needs of people with dementia and informed by the approach adopted in Theatre by the Lake’s *Setting the Scene* programme, this review chapter focuses on one specific approach to creative activity: participatory arts.

2.1.3 Defining Participatory Arts

Participatory arts programmes involve art-making activities that are led by creative practitioners or professional artists in group-based community settings (Zeilig et al., 2014). As suggested in the name, their broad intention is to promote the participation and joining in of its members in creative processes. Indeed, other participatory arts studies define them as ‘intrinsically social’ with an integral emphasis on peer support (Stickley, Wright & Slade, 2018). Participatory arts therefore reveal the ways that creative ‘personal development’ and community ‘social cohesion’ can together be met to promote wellbeing outside of therapy contexts (Carey & Sutton, 2004, p.124).

It is important to differentiate participatory arts approaches from other art-based methods, which vary on content and intent. Firstly, conventional arts-based therapies require trained therapists and usually have associations with clinical settings (Castora-Binkley et al., 2010). They traditionally remain centred on the health and wellbeing outcomes of a client and the end goal of ‘psychological’ or ‘physical change’, irrespective of art skill or completion of an art piece. In contrast,

recreational arts and crafts are more ambiguous regarding the setting, the number/type of participants involved, and the facilitator (Leitner & Leitner, 2012), with a primary aim to complete an artwork (Schoenwald, 2012). Comparatively, participatory arts are more concerned with the process fostered by activities as opposed to creative or psychological outcomes (Dix & Gregory, 2010); a process that is centred on the accessibility of the arts and taking part alongside non-artists and arts professionals. Whilst subtle, this varies to the emancipatory social engagement principles underpinning community arts (Matarasso, 2019).

Participatory arts may encompass performing or auditory arts activities – such as drama, dance, singing and music-based activities – the less performative but albeit participatory literary arts – comprising fictional literature, creative writing, storytelling and oral histories (e.g. Mar et al., 2011) – and visual arts – art-making using different mediums or forms such as painting, drawing, sculpture and textiles (e.g. Rose & Lonsdale, 2016). Given the broad range of activities, art forms, settings, and processes that fall under ‘participatory arts’, it would be insightful to conduct a thorough review on the insights of existing literature specifically investigating dementia experiences with participatory arts.

2.1.4 Recent Syntheses on Dementia and Participatory Arts

Before conducting this participatory arts review, an initial exploration of the literature revealed four recent papers that have studied the application of participatory arts to dementia, but from different standpoints. Zeilig et al.’s ‘participative arts’ review (2014) critically explored the variety and accessibility of arts programmes for people with dementia in the UK and Ireland, whilst Young et al.’s review (2016) studied international literature for the cognitive benefits of community-based participatory arts. Further reviews have since been conducted specifically looking at participatory visual arts (Cavalcanti Barroso, 2020) and the methods used to evaluate participatory arts programmes (Bazooband et al., 2021), the latter review hinting at a greater need for attending to social behaviours within participatory arts evaluation. Evidently, existing literature has so far been reviewed with varying criteria and perspectives guiding the inclusion criteria, in addition to limited consideration for the theoretical underpinnings of the research in this field.

Additional useful insights can be taken from other reviews, such as recent work by Dowlen et al. (2018), focusing on the active participation of people with dementia within musicking activities. Whilst including therapy literature, Dowlen et al. thematically analysed qualitative studies to ascertain the psychological, social and emotional benefits of music activity; components of dementia health and wellbeing that can be undervalued in favour of investigating cognitive benefits (e.g. Young et al., 2016). Dowlen et al.'s review (2018) also flagged a gap in using inclusive research methods in dementia musicking literature, suggesting a need to investigate this across all participatory arts. Indeed, it is timely to conduct an updated and broader review of internationally researched, community-based participatory arts, with a greater emphasis on thematic, social, and theoretical tenets of the overall literature.

2.1.5 Aims and Objectives

Influenced by considerations and gaps in the most recent literature syntheses, this thematic and modified scoping review aimed to explore the in-depth effectiveness of participatory arts - inclusive of performing, visual and literary arts but exclusive of therapy approaches – on the health and wellbeing of people with dementia in community-based settings. To gain an efficient scope of the evidence base, an openness to research locations, community settings, research methods, outcome measures and theoretical frameworks was adopted. Given the variability of health and wellbeing interpretations within the literature, this review adopted a holistic perspective on what it means for participatory arts activities to be effective, considering physical, psychological or cognitive, emotional and social benefits collectively across literature. Relating to the overall aims addressed, this modified scoping review had the following objectives:

- To offer a descriptive overview of the different participatory arts implemented for people with dementia;
- To consider the overall holistic benefits of participatory arts activities for people with dementia by exploring the roles of:
 - the 'individual' in the programmes;
 - the 'group' in the activities;
 - space, place and objects.

- To consider how methodologies, theoretical frameworks, and data collection methods have been employed.

2.2 Method and Criteria

This review sought to gain a broader scope of the topic of dementia and community-based participatory arts, for which previous reviews have explored under stricter inclusion criteria. Of the 14 review types outlined by Grant and Booth (2009), a scoping approach was deemed most suitable for supporting this broader insight, using 'systematic, transparent and replicable' methods for summarising and collating the overall range of literature (p.101). Scoping reviews can help to 'identify knowledge gaps, scope a body of literature, clarify concepts or to investigate research conduct', all of which are relevant to the aims of this review (Munn et al., 2018, p.1). While the aims and objectives of this review are most attuned to scoping review approaches, the strategy and methods chosen to conduct database searches and quality assessments of papers were modified from the comprehensive systematic review approach (see Section 2.2.2). Whilst uncharacteristic of scoping reviews, a systematised strategy to reviewing and appraising the literature was chosen after preliminary grey literature searches indicated a lack of clarity regarding participant samples, art approaches, and overall research conduct; this contrasted to the transparency sought in this review. The resulting hybrid review method is referred to as a modified scoping review and has been adopted in recent literature on dementia and other health studies (Gonzalez & Kirkevold, 2014; Holmberg Fagerlund et al., 2017). This modified scoping review was conducted in accordance with guidelines from Arksey and O'Malley (2005), regarding the identification, selection and collation of the relevant literature.

2.2.1 Inclusion Criteria and Search Strategy

Prior to conducting the main database searches for this review, preliminary literature searches were conducted across Google Scholar and other research databases, to determine the key terms in literature and to differentiate between those that are relevant or irrelevant to this review's scope. This process led to the development of a table of inclusion and exclusion criteria for the main database searches (Table 2.1) and a systematic list of database search terms (Table 2.2).

Table 2.1: Inclusion and Exclusion Criteria

	Inclusion criteria	Exclusion criteria
Population	Adults of any age with a diagnosis of any form of dementia in early or mid-stages. Carers or partners of people living with early or mid-stage dementia.	Advanced dementia stages. Research where dementia is not the primary focus or where specific results for dementia are not reported.
Programme/ Intervention	Participatory arts-based that may include, but are not limited to, singing, music, dancing and movement, drama/theatre, storytelling, creative writing or visual arts.	Therapy or clinical-based interventions. One-to-one interventions not conducted in a group setting.
Outcomes	Outcome measures broadly related to effectiveness, participation and wellbeing.	Invasive/biological testing or measurements using blood sample, x-rays or scans. Studies focusing on arts practice over effectiveness for people with dementia.
Setting	Community or semi-public settings e.g. theatres or community centres, multi-purposeful and dedicated safe spaces for the art activities.	Healthcare settings i.e. residential homes, hospitals, hospices, given their association with therapy, recreation and advanced dementia.
Study design	Any empirical research design including quantitative, qualitative or mixed methods.	-
Additional features	Papers published in English language. Research publications between 2008 and 2021. Search period is based on previous publication start dates up to the current period.	Non-English language publications. Book formats, reviews, commentaries, literature reviews/meta-analyses, or dissertations.

Table 2.2: List of Database Search Terms

Search terms:
<p>dementia OR Alzheimer* OR “memory loss”</p> <p>AND</p> <p>participatory* OR performing* OR "community-based*" OR art OR arts OR "community*" OR "dramatic art*" OR drama OR music* OR singing OR dance OR dancing OR movement OR storytelling OR acting OR arts-based OR reminiscence OR art-making OR “literary art” OR “visual art” OR creativ*</p> <p>AND</p> <p>“quality of life” OR wellbeing OR "well-being" OR "well being" OR health OR happiness OR behaviour OR expression OR social* OR communicat* OR engage OR engaging OR cognit* OR therapeutic OR interact* OR carer OR caregiver OR spouse* OR partner*</p>

Literature dedicated to people living with more advanced dementia was excluded given that it was commonly conducted in nursing, residential or specialist care settings and frequently featured therapy approaches, trained therapists or untrained care staff (Wall & Duffy, 2010; Sampson et al., 2018). Furthermore, people living with advanced dementia often have different needs to those with early or moderate dementia, given that they are prone to additional illness, hospitalization and more pronounced cognitive decline (Mitchell et al., 2009). For these reasons, this scoping review focused specifically on people living with early to moderate stages of dementia in the community. The listed terms in Table 2.2 aimed to represent the wide variety of participatory arts activities that exist and outcomes that may be measured. In addition to search terms, database filters were planned to be used, where available, to manually exclude some subject areas, publication dates, formats and languages. However, this was not always possible, with an awareness that this would lead to a larger number of record results.

2.2.2 Searching, Screening, Quality and Selection

Searches were conducted on the following databases on three occasions between July 2018 and February 2021 (including one original search and two search updates): *PsycINFO, Scopus, SocINDEX with Full Text, CINAHL Complete, Medline Complete* and

Web of Science. The databases were chosen for their representation of arts, humanities, social and health sciences. Hand searches were also conducted using the complete volumes of the Journal of Arts & Health – Volume 1 (2009) to Volume 13 (2021) – and the Journal of Applied Arts & Health – Volume 1 (2010) to Volume 11 (2020). These journals were of relevance to the review due to their interdisciplinary contributions to arts and health. Further to this, and indicated in the Section 2.2 introduction, preliminary book and grey literature searches did not meet the inclusion criteria due to missing key details (or difficulty in verifying them), the presence of therapy approaches, and noncommunity-based research settings. Whilst some of this literature may have added value, it was too difficult to judge against criteria and was subsequently excluded in preference for peer-reviewed published literature.

O’Mara-Eves et al. (2015) have previously stated that research in public health, arts and social research can often lead to vast numbers of records in database searches, given the large scope that topics in these fields can span. This occurred during this review, with 22,922 records solely from databases. To ensure no accidental exclusion of relevant literature, all database records were exported to an EndNote Library where 9 hand searches were added, and duplicate papers were removed (Figure 2.1). Simultaneous title and abstract screening processes were conducted on the remaining 14883 papers, aided by searching in bulk for terms irrelevant to the review, including ‘therapy’, ‘pharmaceutical’, or ‘advanced dementia’. 314 papers were identified as meeting the criteria for full text screening, including papers with inconclusive titles and abstracts. Given the high volume of records, full text screenings were more efficient by beginning at the method sections of papers, since these contained most of the relevant information for decision-making. If a paper was identified as suitable after a method screening, it was subject to a full text screening. After this process, 52 papers underwent scrutiny with quality assessments. These were conducted using an appraisal tool developed by Hawker et al. (2002), designed to aid in the methodological assessment of disparate forms of data and exemplified in previous reviews (e.g. Milligan et al., 2016). The resulting quality scores in this review ranged from 20 to 35 ($M = 26.53$) out of a total possible score of 36 (Table

2.3). Whilst this tool is well-established, some papers can receive lower scores due to publication constraints and word limits as opposed to research quality; hence, scores were not considered final, but as an additional judgment process for the review.

Input from a second reviewer was sought at the end stages of the full text screening, for papers that remained inconclusive. After conducting solo scrutiny on the remaining papers, the second reviewer and I met to discuss our decisions, using a Kappa coefficient of concordance as a form of inter-rater reliability check. Full agreement was achieved and a perfect coefficient of 1.0, with 30 papers finalised for the review.

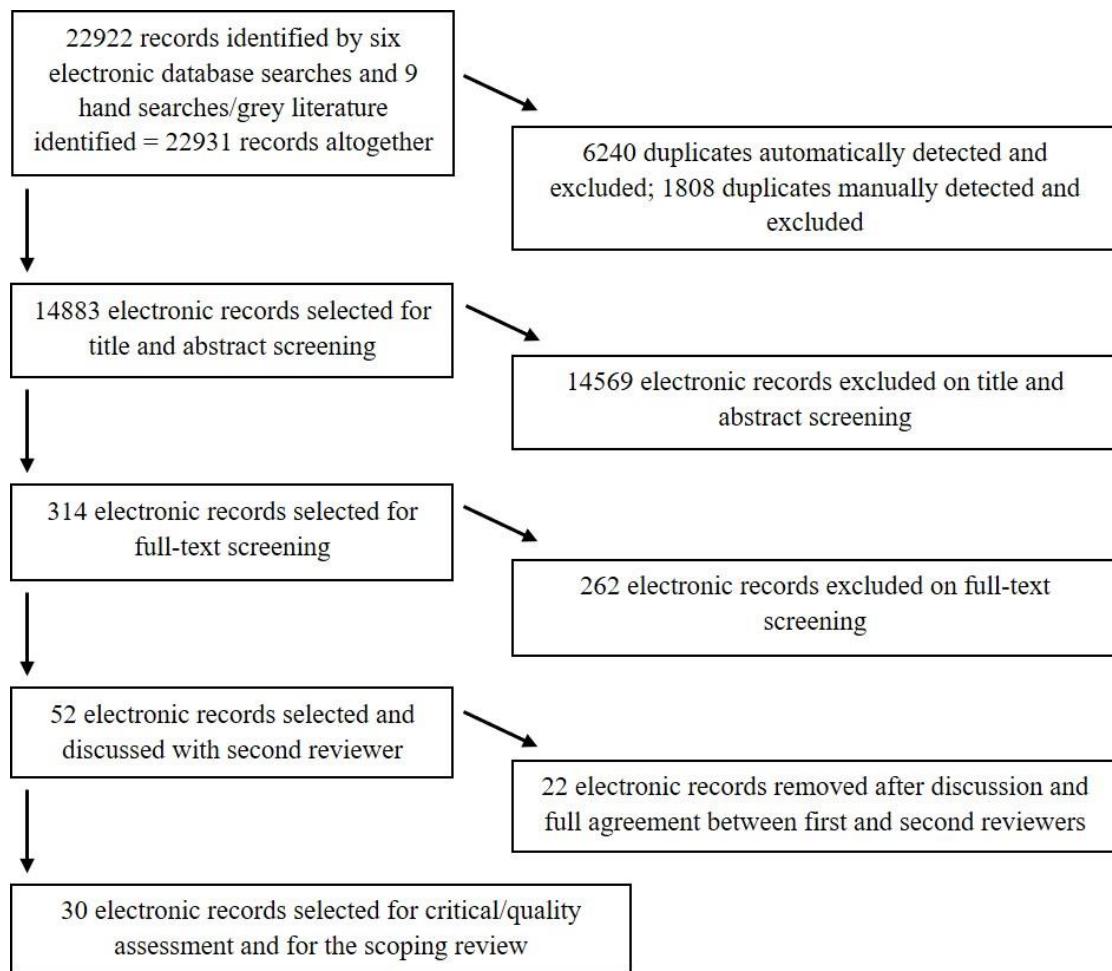


Figure 2.1: Flow Diagram of Literature Search Process

2.2.3 Data Charting and Analysis

Data charting was guided by Arksey and O’Malley (2005) and included publication and author details, research aims/objectives, intervention or programme type, methodology, sample, important results and review-specific features such as setting or location, facilitator type, inclusion of carers, demographics and dementia type. A simplified version has been included in this thesis (Table 2.3). Influenced by the recent thematic synthesis on musicking by Dowlen et al. (2018), a thematic analysis was chosen to develop an in-depth understanding of participatory arts and the overall effectiveness, holistic benefits and design features of programmes in the selected 30 papers (Braun & Clarke, 2006). Each paper was read in full and coded by hand, producing a thorough coding bank on Word Excel, within which patterns were iteratively developed and refined to meet the objectives of this review.

Table 2.3: Summary of Reviewed Papers

Author/s, year and country	Study aims/objectives/research questions	Participant sample	Arts-based programme	Study design and data collection	QA score
Bannan & Montgomery-Smith (2008) Australia	Assess the benefits of group singing activities and the participation of people with dementia and carers	21-25 participants per session, (including people with dementia and carers together)	Music: Alzheimer's Society 'Singing for the Brain' musical reminiscence sessions	Mixed methods pilot study: Video and audio recordings Carer-completed questionnaires	26/36
Belver et al. (2017) Spain	Design and evaluate the effectiveness of an arts activity programme for people with dementia	12 people with dementia 4 family carers 2 professional carers	Visual art-making: 'We Have a Date with Art' – MoMA-inspired model in Prado Museum	Qualitative, ethnographic study: Participant observation Field journals Photographs Video recordings	31/36
Burnside et al. (2017) USA	Explore the impact of an experiential museum-based arts program on people with dementia and carers	21 people with dementia 21 family and professional carers	Visual art-making: ' <i>here: now</i> ' visual art MoMA-inspired model in Frye Museum	Qualitative, grounded theory study: Semi-structured telephone interviews	31/36
Camic et al. (2013) UK	Determine the impact of a community singing group on wellbeing and daily functioning of people with dementia and carers	10 people with dementia 10 carers	Music: 'Singing Together Group'	Mixed methods pilot evaluation study: Semi-structured interviews Standardised measures Observational scales Carer diaries	28/36
Camic et al. (2014) UK	Understand the impact of an art gallery intervention on social inclusion, carer burden, quality of life and daily living	12 people with dementia 12 carers	Visual art-making: Programme in traditional and contemporary art galleries	Mixed-methods pre-post study design: Standardised questionnaires Interviews Fieldnotes	29/36

Camic et al. (2019) UK	Determine the impact of object-handling on the subjective wellbeing of people in with different dementia diagnoses	80 people with dementia	Visual art-making: Object-handling programme, in an Alzheimer's Society centre and museum	Quasi-experimental study design: Pre- and post-intervention questionnaires	31/36
Chauhan (2018) UK	Examine the creative potential of people with dementia artistic engagement in sculpture-making	7 people with dementia	Visual art-making: Dynamic sculpture-making programme using multiple mediums (clay, papier mâché and virtual means)	Practice-based investigative study: Observations 'In the moment'/audio-recorded interviews Questionnaires Video recordings	26/36
Evans et al. (2019) UK	Explore whether a music-based programme can enhance quality of life for people with dementia and their carers	20 people with dementia	Music: 'My Musical Memories' Reminiscence programme designed by Alzheimer's Society England	Mixed methods pre-post intervention design: Creative/Expressive observation tool Focus groups Feedback from volunteer observations	25/36
Flatt et al. (2015) USA	Gather the subjective art activity experiences of older adults with early-stage dementia and carers	10 people with dementia 10 carers	Visual art-making: Session based on the MoMA model, at The Andy Warhol Museum	Cross-sectional qualitative study: Focus groups Satisfaction surveys	27/36
Hafford-Letchfield (2013) UK	Explore a community-based comedy/drama project to communicate with people with dementia	12 people with dementia 4 family carers 8 staff members	Comedy: The Grange comedy project of unscripted, improvised acting, humour and parody, in a community day centre	Mixed methods study: Interviews Video recordings	20/36
Harris & Caporella (2014) + (2018) USA	Evaluate an intergenerational choir [for combating dementia stigma] and lessening social isolation for people with dementia	22 people with dementia 21 family carers 62 undergraduate students	Music: Intergenerational choir music programme based at a university	Mixed methods study: Qualitative questionnaires for students Focus groups for people with dementia and carers Observations	30/36

Hendriks et al. (2021) Netherlands	Examine how an interactive creative programme is experienced and appreciated by people with dementia and carers	95 people with dementia 104 carers	Visual art-making: The 'Unforgettable' visual art programme of guided art viewing and art-making, inspired by Meet Me at MoMA	Single-group design: Bespoke questionnaire with open and closed questions Pre- and post-intervention evaluations	32/36
Innes et al. (2021) UK	Explore the health and wellbeing impact of a heritage programme on people with dementia and carers	24 people with dementia 24 carers	Multi-arts: The 'Sensory Places' heritage programme for creative, multi-sensory storytelling and site-specific explorations	Mixed-methods design: Mood questionnaires Face-to-face and/or telephone interviews Demographic data	27/36
Johnson et al. (2017) UK	Compare the impact of two museum-based activities and a social activity on the subjective wellbeing of people with dementia and carers	36 people with dementia 30 carers	Visual art-making: Museum object-handling and art viewing programme with refreshment break in-between activities	Quasi-experimental study with mixed 2 x 4 repeated-measures crossover design: Four-stage visual analogue scales Post-programme evaluative questionnaire	33/36
McCabe et al. (2015) UK	Evaluate outcomes of a creative musical project for people with dementia and carers	44 people with dementia and carers	Music: Development of a musical production, led by Scottish Opera company	Qualitative participatory study: Interviews	26/36
Osman et al. (2016) UK	Explore the experiences of people with dementia and carers at 'Singing for the Brain' sessions	10 people with dementia 10 family carers	Music: Alzheimer's Society 'Singing for the Brain' musical reminiscence sessions in community setting	Qualitative study: Semi-structured interviews	28/36
Petrescu et al. (2014) Australia	Test the effectiveness of poetry-writing for psychological functioning in people with early stages of dementia	4 people with dementia	Poetry: Poetry writing workshop	Qualitative study: Structured interviews	20/36

Richards et al. (2018) USA	Investigate the benefits of a visual arts program on the quality of life, self-esteem and activities of daily living	27 people with dementia 26 carers	Visual art-making: Visual Arts Education programme	Randomised controlled single-blind trial design: Quantitative outcome measures	31/36
Schall et al. (2018) Germany	Assess the impact of an arts-based intervention on health and wellbeing outcomes	44 people with dementia 44 carers	Visual art-making: ART Encounters: Museum Intervention Study (ARTEMIS) visual art programme, including control group	Randomised wait-list controlled study with mixed-methods design: Standardised measures (self-reported) Subjective evaluations by informal carers	32/36
Selberg (2015) USA	Investigate the connections between dementia, art and personhood during a museum-based arts program	People with dementia and carers (insufficient detail)	Visual art-making: 'Meet Me at MoMA' New York Museum of Modern Art Alzheimer's programme	Qualitative, ethnographic study: Participant observation Interviews	21/36
Stevens (2012) Australia	Investigate the benefits of a stand-up comedy improvisation workshop for people with mild dementia in the community	6 people with dementia 6 carers	Comedy: Stand-up comedy and improvisation workshop intervention	Qualitative study: Fieldnotes Semi-structured interviews	24/36
Swinnen (2016) The Netherlands	Examine the inclusion of people with dementia and key strategies for enabling participation in poetry performances and improvisations.	15-35 people each session (insufficient detail)	Poetry: Alzheimer's Poetry project including slam poetry, call and response, rhythm and rhyme, and memorised song	Ethnographic case study: Participant observation Fieldnotes Audio and video recordings Photographs Semi-structured conversations Corpus of poems	24/36
Synnes et al. (2020) Norway	Explore a poetry group as a form of alternative expression, linguistic possibility and sharing of self-narrative	11 people with dementia	Poetry: Practical poetry writing groups	Multi-methods qualitative study: Semi-structured interviews Focus group interviews Fieldnotes Linguistic/narrative analysis of 66 poems	25/36

Tan (2018) Singapore	Examine the impact of a pilot participatory visual art, multi-sensory dementia care programme	8 people with dementia	Visual art-making: 'Let's Have Tea at the Museum' programme using art-making and storytelling, conducted in Peranakan Museum	Mixed methods study: Observations Fieldnotes and journal writing Video recordings Photography	26/36
Tsekleves et al. (2020) UK	Explore how co-design can be implemented into the participation of people with dementia in arts-based activities	12 people with dementia and their carers (insufficient detail) 2 support workers	Multi-arts: 'Ageing Playfully' programme of multi-arts, playful participatory activities	Multi-methods qualitative study: Participation observation Audio recordings Photography and video recordings Post-workshop focus group	26/36
Ullán et al. (2013) Spain	Determine the impact of a contemporary artistic educational program	21 people with dementia	Visual art-making: Visual art Education programme using contemporary photographic cyanotype methods	Mixed methods study: Participant observation Focus groups Observational assessments by educators	25/36
Unadkat et al. (2017) USA	Understand the benefits of group singing for people with dementia and their partners across different singing interventions	17 people with dementia 17 spousal carers	Music: Five community music /singing groups attended by the participating couples prior to/during the research	Qualitative, grounded theory study: Interviews	33/36
Windle et al. (2018) UK	Investigate whether visual art can improve the wellbeing, quality of life and communication of people with dementia	54 people with dementia in community settings (site 3)	Visual art-making: Programme disseminated across three sites (library; arts centre with gallery; music and arts venue) with control group	Longitudinal mixed methods design with repeated measures: Questionnaires and self-evaluation forms Qualitative open-ended interviews Behavioural observations	35/36
Zeilig et al. (2019) UK	Investigate how music and dance co-creativity can impact wellbeing from the subjective perspectives of people living with dementia and their carers	5 people with dementia 3 spousal carers	Music: 'With All' multi-activity, co-creative art programme of improvisatory music and dance	Intrinsic case study methodology and mixed methods approach: Dialogic interviews Video recordings Wellbeing questionnaire	24/36

2.3 Findings

The 30 selected papers for review were published in eight different countries, 13 of which were in the United Kingdom, seven in the United States, and three in Australia (Table 2.3). The remaining papers range from across Europe, with only one deriving from South East Asia (Tan, 2018). Though this may, in part, be due to restrictions on English language publications, it also may indicate that participatory arts activities are less developed in South East Asian regions.

As identified in Table 2.3 Column 4, the 30 reviewed papers comprised visual art-making (N = 14); singing, music and/or dance (N = 9); poetry and creative writing (N = 3); comedy and drama (N = 2); while others were more characteristic of multi-arts (N = 2). Some of the programmes were based on unique designs, whilst others were identified as, or inspired by, transferrable models including 'Meet Me at MoMA' and 'Singing for the Brain' programmes (see Table 2.3 for further details). Only six of the included papers described their activities as 'participatory' arts, although all were screened as eligible for this definition (Hafford-Letchfield, 2013; Flatt et al., 2015; Swinnen, 2016; Richards et al., 2018; Tan, 2018; Tseklevs et al., 2020). This hints at the variable ways that arts-based programmes define their approaches.

Nevertheless, all 30 papers recognised that increased participation – interchangeably referred to as engagement, involvement, communication and interaction – was an integral part of programme effectiveness.

The following findings present eight main themes resulting from the literature analysis, according to three key areas: *The Individual*; *The Group*; and *Place, Space and Objects* (Figure 2.2). These key areas are followed by methodological and theoretical considerations of the reviewed papers.

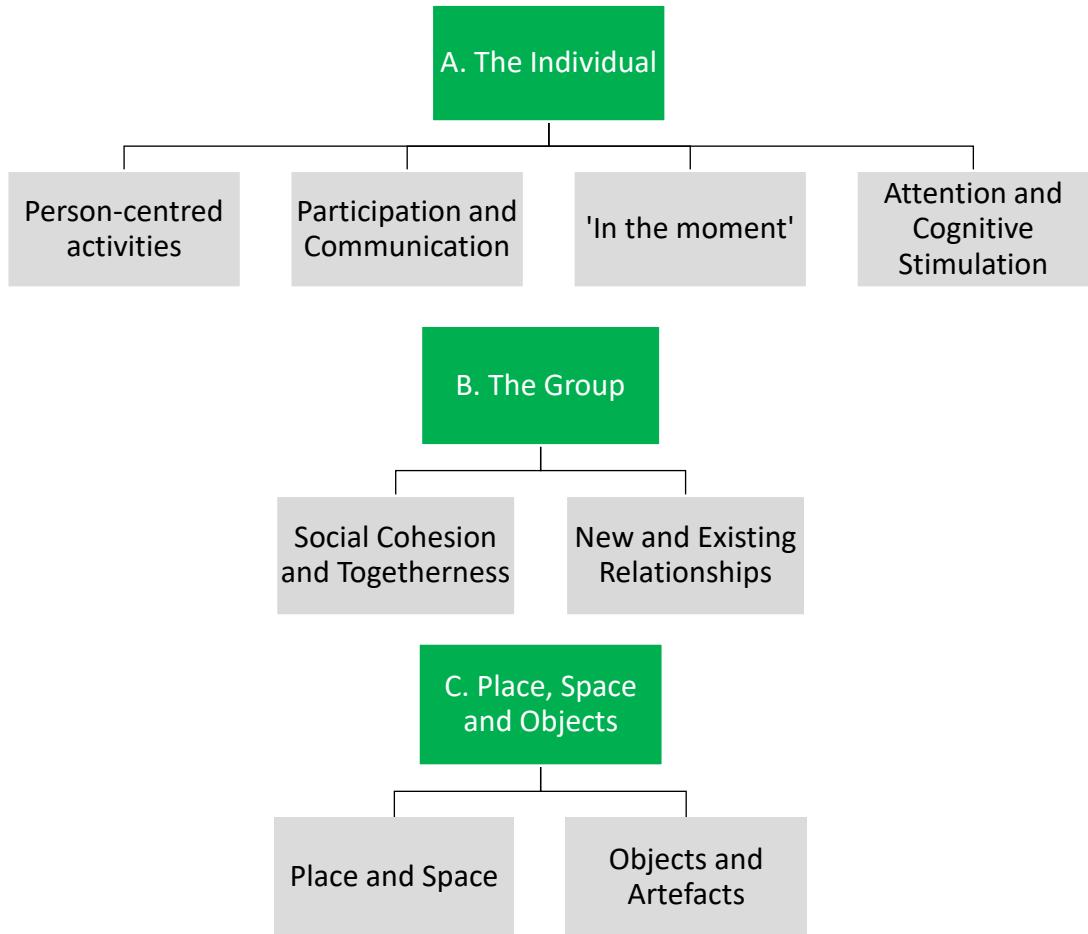


Figure 2.2: Thematic Overview of Findings.

2.3.2 The Individual

2.3.2.1 Person-Centred Activities

Eighteen of the reviewed papers recognised the value of the individual, their personhood and/or using a person-centred approach (Stevens, 2012; Hafford-Letchfield, 2013; Camic et al., 2013; 2014; Petrescu et al., 2014; McCabe et al., 2015; Selberg, 2015; Osman et al., 2016; Swinnen, 2016; Burnside et al., 2017; Unadkat et al., 2017; Harris & Caporella, 2018; Tan, 2018; Evans et al., 2019; Zeilig et al., 2019; Synnes et al., 2020; Tseklevs et al., 2020; Innes et al., 2021). Four papers specifically identified the importance of balancing the needs of the individual with the needs of the group to improve overall participation (Ullán et al., 2013; Belver et al., 2017; Chauhan, 2018; Tseklevs et al., 2020). Some actions taken to encourage person-centeredness included incorporating participants' hobbies into sessions (Camic et al.,

2013; McCabe et al., 2015; Swinnen, 2016; Belver et al., 2017; Chauhan, 2018; Schall et al., 2018; Evans et al., 2019); attending to participants' self-narratives (Synnes et al., 2020); and ensuring the themes, topics and materials were biographically relevant (Hafford-Letchfield, 2013; Osman et al., 2016; Belver et al., 2017; Schall et al., 2018; Innes et al., 2021). This suggests that the broader participatory arts concept, regardless of art form, has the capacity to aid reassertion of one's self-identity independent of dementia diagnosis, reaffirming them as a 'whole' person (Petrescu et al., 2014, p.213; Hafford-Letchfield, 2013, p.20; Burnside et al., 2017, p.36). By encouraging person-centredness, participatory arts activities also subsequently promote a strength-based approach, whereby participants can exhibit what they are still capable of doing and learning, as opposed to skills they are losing as a consequence of dementia (Camic et al., 2013; Ullán et al., 2013; Harris & Caporella, 2014, 2018; Petrescu et al., 2014; McCabe et al., 2015; Swinnen, 2016; Chauhan, 2018; Richards et al., 2018; Tan, 2018).

Notably, Ullán et al. (2013) aligned person-centred participatory arts with Article 27 of the Universal Declaration of Human Rights, which states that people have a right 'to participate in the cultural life of a community' and 'enjoy the arts' (p.443). Where biomedical methods towards health and wellbeing are limited, person-centred participatory arts and culture can contribute to the wellbeing of people with dementia (Chauhan, 2018).

2.3.2.2 Participation and Communication

Participatory arts demonstrated a positive impact on engagement, particularly on the verbal communication of people with dementia (Stevens, 2012; Ullán et al., 2013; Harris & Caporella, 2014, 2018; Petrescu et al., 2014; Selberg, 2015; Swinnen, 2016; Belver et al., 2017; Burnside et al., 2017; Unadkat et al., 2017; Chauhan, 2018; Tan, 2018; Evans et al., 2019; Synnes et al., 2020; Tseklevs et al., 2020). Participants were respectful of others and displayed appropriate turn-taking in group conversations (Swinnen, 2016), in addition to instigating spontaneous conversations without targeted stimulation from others (Ullán et al., 2013; Unadkat et al., 2017; Chauhan, 2018; Tan, 2018). These individual contributions demonstrate the willingness of participants to develop social exchanges and share personal

information with other members (Selberg, 2015; Osman et al., 2016; Chauhan, 2018; Harris & Caporella, 2018; Tan, 2018). Conversely, some papers found no verbal improvements and instead observed difficulties (Selberg, 2015; Windle et al., 2018). This hints at the importance of non-verbal means of communication, which were encouraged and noted throughout the programmes, commonly observed through physical contact or touch, body movement, and facial expressions (Bannan & Montgomery-Smith, 2008; Camic et al., 2013; Ullán et al., 2013; Harris & Caporella, 2014, 2018; McCabe et al., 2015; Unadkat et al., 2017; Chauhan, 2018; Swinnen, 2016; Tan, 2018; Evans et al., 2019; Zeilig et al., 2019; Tsekleves et al., 2020). However, papers did not refer to bodily and sensory engagement as alternative communication, reserving them more as general participation.

Inevitable use of the body and senses was made during creative engagement, including tasks such as sculpting (Chauhan, 2018), dancing (Zeilig et al., 2019) and object-handling (Camic et al., 2019). Reference to 'sensory' or 'multi-sensory' experiences was made in seven recent papers (Johnson et al., 2017; Chauhan, 2018; Schall et al., 2018; Tan, 2018; Camic et al., 2019; Tsekleves et al., 2020; Innes et al., 2021). Most of these papers only referred to the senses tenuously, with movement and embodiment more commonly explored. Zeilig et al. (2019) demonstrated that participants were more expressive and playful in their uses of objects, while participants in other papers enjoyed '*creating with [my] hands*' (Chauhan, 2018, p.11). Furthermore, 'motor gestures' were observed to 'reinforce the emphasis of... spoken words' and improved participants' abilities in call and response activities (Swinnen, 2016, p.1394). This hints at the interplay of verbal and non-verbal engagements and suggests ways of nurturing the senses of people with dementia to aid communication (Camic et al., 2019).

Participants also communicated through emotional expression, with most participants across all papers demonstrating increased enjoyment, pleasure and improved mood during or after participatory arts. This was described by some as '*uplifting*' (Camic et al., 2014, p.164), '*a positive feeling*' (Petrescu et al., 2014, p.210) and a way to "*feel better...brighter... more like your old self*" (Osman et al., 2016, p.1333). Participants were also observed to '*brighten up*' (Innes et al., 2021). Positive

emotions and improved mood were occasionally found to extend into the home environment after attending activities (Belver et al., 2017; Chauhan, 2018; Richards et al., 2018). However, others found that positive affect was limited to sessions: “...as soon as you take them away, it’s gone... it needs to be back in the group” (Evans et al., 2019, p.1188). Whilst evidence of longevity remains inconclusive, experiences during arts participation are positive and increase the recognition of ‘in the moment’ experiences for people with dementia. Furthermore, it can be understood that the wellbeing benefits of participatory arts are strongest when the participant truly enjoys what they are doing whilst taking part, contrasting to the impersonal and detached nature of most biomedical interventions.

2.3.2.3 ‘In the Moment’

Participatory arts are accessible to people with cognitive decline, given that they rely on ‘in the moment’ interactions. This was a common theme across 17 papers and unanimously empowered participants to socially and creatively present themselves in ‘the here and now’ (Bannan & Montgomery-Smith, 2008; Stevens, 2012; Hafford-Letchfield, 2013; Camic et al., 2014; Harris & Caporella, 2014; Petrescu et al., 2014; Flatt et al., 2015; Selberg, 2015; Swinnen, 2016; Belver et al., 2017; Burnside et al., 2017; Johnson et al., 2017; Unadkat et al., 2017; Chauhan, 2018; Windle et al., 2018; Evans et al., 2019; Zeilig et al., 2019; Tseklevs et al., 2020; Innes et al., 2021).

Placing importance on being ‘in the moment’ may explain the observed improvements in communication levels of participants. Specifically, participatory arts removed pressure and reliance on short-term memory recall (Hafford-Letchfield, 2013), instead focusing on improvised, spontaneous conversations and activities using the body, senses, and identity (Petrescu et al., 2014; Burnside et al., 2017; Unadkat et al., 2017; Chauhan, 2018). Nevertheless, participants were given freedom to build upon their long-term memory and contribute aspects of their past experiences to unfolding situations:

‘I don’t know where that came from. I used to sing that to my daughter.’ (Participant; Tseklevs et al., 2020, p.924).

Being 'in the moment' resolved judgment on correctness or biographical accuracy, allowing participants to freely use their imaginations (Tseklevs et al., 2020) and reconnect aspects of their pasts into the present, unfolding moment (Petrescu et al., 2014: 212). Innes et al. (2021) similarly described this as attributing 'meaning to their lives both past and present' (p.13). This temporal consideration leads participants with dementia to not be judged on their cognitive abilities, nor to be ignored for their deep-rooted identities and life experiences. Therefore, a balanced approach to life stories and present moment experiences may be of benefit to people with dementia and offer more meaning to activities.

2.3.2.4 Attention and Cognitive Stimulation

Reviewed papers demonstrated that cognitive decline associated with early to moderate stages of dementia was not deemed an obstacle and did not noticeably interfere with participatory arts engagements (Bannan & Montgomery-Smith, 2008; Ullán et al., 2013; Harris & Caporella, 2014, 2018; Swinnen, 2016). Indeed, papers found improvements in participants' memory, particularly of recent conversations (McCabe et al., 2015), other people at the sessions (Hafford-Letchfield, 2013; Swinnen, 2016), activities with visual cues (Chauhan, 2018) and lines from scripts and songs that did not need to be memorised (Stevens, 2012). Furthermore, 11 papers acknowledged the 'in the moment' emphasis of events as aiding improvements in attention, concentration and focus, particularly in cases where participants had previously been socially disengaged (Stevens, 2012; Camic et al., 2013, 2014; Hafford-Letchfield, 2013; Ullán et al., 2013; Belver et al., 2017; Burnside et al., 2017; Johnson et al., 2017; Chauhan, 2018; Tan, 2018; Evans et al., 2019; Hendriks et al., 2021). Improved attention was also attributed to the stimulation that creative activities offered, including through tactile handling of materials (Chauhan, 2018; Schall et al., 2018; Tan, 2018; Camic et al., 2019); visual cues (Johnson et al., 2017; Evans et al., 2019); and auditory sounds, rhythms and music (Swinnen, 2016; Unadkat et al., 2017; Zeilig et al., 2019). Collectively, the literature can be interpreted as suggesting that better participant attention and focus can, in part, be attributed to immediate sensory stimulation.

Twenty papers discussed evidence relating to the learning of new skills, including new songs (Bannan & Montgomery-Smith, 2008; Camic et al., 2013; McCabe et al., 2015; Unadkat et al., 2017); art-making techniques (Ullán et al., 2013; Camic et al., 2014; Flatt et al., 2015; Selberg, 2015; Belver et al., 2017; Johnson et al., 2017; Chauhan, 2018; Richards et al., 2018; Schall et al., 2018; Tan, 2018); comedy performance skills (Stevens, 2012; Hafford-Letchfield, 2013); poetry methods (Petrescu et al., 2014); Synnes et al., 2020); factual information (Innes et al., 2021); or simply learning from each other (McCabe et al., 2015; Burnside et al., 2017). This demonstrates that new learning was not solely attributed to one art form using one particular technique, but that all types of programmes were capable of encouraging new technical and social learning through different mediums and tasks. Priority was given to a person's willingness to try something new, as opposed to the sophistication of their skill (Unadkat et al., 2017; Tsekleves et al., 2020). Overall, new learning led to improved confidence, which was also displayed in participants' own surprise at their potential to learn (Bannan & Montgomery-Smith, 2008; Camic et al., 2013, 2014; Ullán et al., 2013; Belver et al., 2017; Tan, 2018). This suggests that participatory arts are effective because participants are not being restricted by assumptions and stigma, but can freely explore their abilities and boundaries through non-judgemental stimulation.

2.3.3 The Group

2.3.3.1 Social Cohesion and Togetherness

All 30 papers made a varying level of reference to the underlying social benefits of participatory arts, which were viewed as effective means to reduce social isolation, both for people with dementia and their carers (Camic et al., 2013; Harris & Caporella, 2014; Flatt et al., 2015; Osman et al., 2016; Swinnen, 2016; Tan, 2018). This was particularly in co-creation programmes that heavily relied on collaboration between different group members (Chauhan, 2018; Zeilig et al., 2019; Tsekleves et al., 2020). Participatory arts improved social interactions by creating a social 'safe space' (Zeilig et al., 2019, p.22), 'circle of friends' (Burnside et al., 2017, p.35) and a '*party atmosphere*' (Hafford-Letchfield, 2013, p.19). Indeed, dementia became less pertinent in programmes, instead being replaced with a shared focus on the arts

activities that could be appreciated by all members collectively (Camic et al., 2013; Harris & Caporella, 2014; Osman et al., 2016; Johnson et al., 2017; Unadkat et al., 2017; Zeilig et al., 2019). Activities were valued as 'mediators', 'channels' or 'catalysts' for social relations, demonstrating that different types of arts can elicit the same social benefits when based within group settings (Bannan & Montgomery-Smith, 2008; Hafford-Letchfield, 2013; Belver et al., 2017; Johnson et al., 2017; Harris & Caporella, 2018). Other papers emphasised that pleasure was experienced by being with other people and feeling part of a community (Selberg, 2015; Burnside et al., 2017; Harris & Caporella, 2018). Regardless of what element produces the greatest positive affect for different participants, the evidence suggests that participatory arts elicit enjoyment through the act of being creative and through connecting with other people who are being creative together.

Other group-centric features mentioned in 16 papers were humour and laughter (Stevens, 2012; Hafford-Letchfield, 2013; Ullán et al., 2013; Harris & Caporella, 2014, 2018; McCabe et al., 2015; Selberg, 2015; Belver et al., 2017; Swinnen, 2016; Unadkat et al., 2017; Schall et al., 2018; Chauhan, 2018; Tan, 2018; Camic et al., 2019; Zeilig et al., 2019; Synnes et al., 2020). The use of humour, entangled in social occasions, helped to increase participation and led to lively and relaxed environments where friendships could blossom (Hafford-Letchfield, 2013; Belver et al., 2017; Tan, 2018; Synnes et al., 2020). Laughter was also capable of dissolving dementia-related tensions and was contributory to a non-judgemental shared attitude (Selberg, 2015). Notably, both comedy-centric papers found that performing to create laughter was more beneficial than 'passively induced laughter' (Stevens, 2012, p.61). The role of humour, therefore, seems especially beneficial and integral to performative settings, as well as to everyday human communication.

2.3.3.2 New and Existing Relationships

Sixteen of the reviewed papers explored the benefits of participatory arts in the dyadic relationship between the person with dementia and their family member/informal carer (Bannan & Montgomery-Smith, 2008; Camic et al., 2013, 2014; Hafford-Letchfield, 2013; Ullán et al., 2013; Harris & Caporella, 2014, 2018; McCabe et al., 2015; Osman et al., 2016; Burnside et al., 2017; Unadkat et al., 2017;

Chauhan, 2018; Schall et al., 2018; Evans et al., 2019; Zeilig et al., 2019; Innes et al., 2021). This common theme demonstrates the importance that participatory arts place on familial relationships and inclusivity. The programmes were considered by some researchers as a non-clinical opportunity to reinforce dyads (Camic et al., 2014), who benefited through shared attention and experiences (Johnson et al., 2017). In addition to reinforcing relationships, the novelty of participatory arts activities helped to refresh marital relationships (McCabe et al., 2015; Osman et al., 2016; Innes et al., 2021), since partners were able to learn new things about each other and from each other, regardless of who had dementia (Unadkat et al., 2017). Participating in creative activities can thus help strengthen relationships through dementia, in contrast to the commonly held understanding that familial relationships will be negatively impacted. The enjoyment gained from both members of the dyad suggests that participatory arts activities can provide joint respite (Flatt et al., 2015; McCabe et al., 2015; Burnside et al., 2017) and help to overcome the 'carer and cared-for' dynamic that arises with dementia.

Reviewed papers also acknowledged the importance of building new friendships in participatory arts groups (Hafford-Letchfield, 2013; Ullán et al., 2013; Harris & Caporella, 2014, 2018; Flatt et al., 2015; McCabe et al., 2015; Osman et al., 2016; Swinnen, 2016; Belver et al., 2017; Burnside et al., 2017; Evans et al., 2019; Zeilig et al., 2019; Synnes et al., 2020). People with dementia were consistently observed making connections with others, with some participants defining others as their friends (Harris & Caporella, 2014; Zeilig et al., 2019) and showing physical affection when recognising them at sessions (Swinnen, 2016). Overall, whether friendship was demonstrated physically, emotionally or verbally, it remained a central element of participatory arts. Rather than ruminate on the declining social networks of people with dementia, the reviewed papers suggest that spaces where new friendships can be developed and maintained are important.

2.3.4 Place, Space and Objects

2.3.4.1 Place and Space

All 30 reviewed papers were based in museums, day care centres, theatres or heritage sites, and were conducted in small groups. These community-based

locations were praised by participants, who enjoyed the creative space (Camic et al., 2013; Belver et al., 2017; Burnside et al., 2017; Tan, 2018; Innes et al., 2021) and appreciated the quiet atmosphere (Camic et al., 2014; Selberg, 2015; Schall et al., 2018). Participants also felt connected to the wider community through the semi-public setting of the activity, suggesting that arts activities may benefit from private spaces within larger venues, where there are less distractions but an increased sense of societal contribution (Selberg, 2015; Belver et al., 2017). Participants in some studies continued visiting museums and art galleries independently after sessions, demonstrating continued interest and venue accessibility (Belver et al., 2017). However, some settings lacked accessible amenities for meeting the immediate health needs of participants, which particularly impacted the experiences and perceptions of carers (McCabe et al., 2015; Hendriks et al., 2021).

Only one paper (Innes et al., 2021) had a dedicated section to the role of space, place and temporality that went beyond rudimentary or practical considerations. The paper addressed 'sensory, physical and emotional experiences' that iconic heritage sites offered participants whilst engaging within them, exhibiting that activities connected to a physical environment can '*come alive*' because of their tangibility (p.10). Whilst only coming from one paper, this hints at physical spaces and sensory surroundings having useful roles in creative activity.

2.3.4.2 Objects and Artefacts

Whilst all of the papers were centred on art-making or artefact-based activities, few gave extended consideration to how props and objects shaped activities or engagement. Object-handling activities and sculpture interactions were observed to aid the verbal communication and emotional experiences of participants (Chauhan, 2018; Tseklevs et al., 2020), both through their kinaesthetic and visual stimulation (Camic et al., 2019). Everyday objects, conventional arts materials and museum artefacts were important for creating spontaneous conversations (Tan, 2018), enabling various arts creations (Burnside et al., 2015; Schall et al., 2018) and stimulating participants' imaginations (Tseklevs et al., 2020). Props were occasionally engaged with in 'non-traditional ways, such as a participant gently striking a tambourine against their head' (Zeilig et al., 2019, p.21). Though not

confirmative in the studies, it appears the papers collectively suggest that objects influence how participants engaged with arts, creativity and self-expression.

Objects and participants' own artworks were often a point of conversation and connection. Participants were observed showing interest, praising, encouraging and conversing about other participants' creations (Ullán et al., 2013; Flatt et al., 2015; Burnside et al., 2017; Chauhan, 2018; Tan, 2018; Tsekleves et al., 2020). Drawn from these findings, objects may be argued as having social agency in participatory arts contexts, given that many of the documented interactions may have been lost had the physical object or artwork been removed from the setting. This was particularly true where imaginative co-creation resulted in new or novel objects:

'We've just created about three new instruments, in this table, that I never knew existed. . . how great is that!' (Participant; Tsekleves et al., 2020, p.923).

As hinted at in the literature, objects can create physical contact and social discussion for people with dementia, accompanied by an additional sense of achievement when the object is something novel and participant-made.

2.3.5 Methodological Considerations

The approaches adopted in the reviewed papers can be broadly categorised as 'qualitative' (N = 14), 'mixed' (N = 12) and 'quantitative' (N = 4). Regarding their overarching methodological frameworks, two papers indicated using an intrinsic case study methodology, due to their site-specific exploration of arts programmes (Swinnen, 2016; Zeilig et al., 2019). Others used phenomenological and pragmatic methodologies to investigate participants' lived experiences and the practical implications of participatory arts (Bannan & Montgomery, 2008; Stevens, 2012; Hafford-Letchfield, 2013; Harris & Caporella, 2014, 2018; Chauhan, 2018). Furthermore, three papers employed creative and practice-led research, including gathering data during active art-making (Chauhan, 2018) and using participant-written poetry as data (Swinnen, 2016; Synnes et al., 2020).

Of the fourteen broadly qualitative or multi-method papers reviewed (see Table 2.3), three were explicitly ethnographic (Selberg, 2015; Swinnen, 2016; Belver et al., 2017) while others included elements of participant observations, interviews and

fieldnotes (Stevens, 2012; Chauhan, 2018; Tan, 2018; Synnes et al., 2020; Tseklevs et al., 2020). These methods offered balanced insights into 'in the moment' experiences during activities, and participant reflections following sessions, although their effectiveness was dependent on design and content. For instance, two studies chose reflective phone interviews for participants with dementia, leading to confusion and difficulty answering questions (Stevens, 2012; Burnside et al., 2015). Comparatively, other studies resolved interview issues by conducting in-person, dyadic interviews with the presence of carers (e.g. Unadkat et al., 2017) or 'in the moment' interviews as part of observations (e.g. Chauhan, 2018). This highlights the importance of adapting methods according to the needs of people with dementia.

It was common for qualitative and mixed methods studies to use photographic or video data, recorded during arts sessions (Bannan & Montgomery, 2008; Hafford-Letchfield, 2013; Swinnen, 2016; Belver et al., 2017; Chauhan, 2018; Tan, 2018; Zeilig et al., 2019; Tseklevs et al., 2020). These were able to gather participant responses as they occurred during activities, including 'gaze, gestures/facial expressions, or bodily comportment' (Tan, 2018, p.27). Contrastingly, the four papers using solely quantitative measures focused on pre- and post-intervention evaluations, bypassing 'in the moment' experiences (Johnson et al., 2017; Richards et al., 2018; Camic et al., 2019; Hendriks et al., 2021).

The remaining mixed-method papers were beneficial for capturing diverse data from different respondents (Bannan & Montgomery, 2008; Camic et al., 2013; Hafford-Letchfield, 2013; Ullán et al., 2013; Camic et al., 2014; Harris & Caporella, 2014, 2018; Schall et al., 2018; Windle et al., 2018; Evans et al., 2019; Zeilig et al., 2019; Innes et al., 2021). While most findings were positive, Camic et al. (2014) found mixed results, depending on the type of data analysed. Whilst their quantitative measures detected cognitive deterioration and no significant quality of life changes, qualitative results demonstrated high arts activity engagement levels and an overall positive impact on wellbeing. This indicates the importance of method choice and how mixed approaches can grasp methodological inconsistencies in research.

Lastly, all but one paper (Bannan & Montgomery, 2008) included participants with dementia as direct respondents in their studies, rather than seeking knowledge

indirectly or solely from alternative stakeholders. This suggests a positive progression towards the inclusion of people with dementia in research. However, minimal studies engaged with inclusive, participatory research methods (McCabe et al., 2015; Tseklevs et al., 2020). Most notable was the co-design/co-creation methodology adopted by Tseklevs et al. (2020), which was acknowledged as challenging but nevertheless highlighted the potential for people with dementia to be involved in collaborative research and design. Whilst ideas of social flexibility and collaborative knowledge were said to underpin Camic et al.'s paper (2013), these were not matched with methodological rigour.

2.3.6 Theoretical Underpinnings

Wellbeing was a central theme across most papers, but few authors engaged with wellbeing literature or made a clear statement of their interpretation of this term. Papers variably engaged with Kitwood's dimensions of wellbeing (Osman et al., 2016; Innes et al., 2021), subjective wellbeing (Johnson et al., 2017), wellbeing or 'ill-being' (Tseklevs et al., 2020) and emotional wellbeing (Schall et al., 2018). Innes et al. (2021) made reference to the geographies of wellbeing in their research rationale, but did not delve further into its contribution. Extended consideration, however, was made by Zeilig et al.'s theoretically-driven paper (2019), which conceptualised wellbeing and agency as being relational and ongoing in the context of dementia, rather than a complete state. Beyond these studies, wellbeing remained ill-defined, raising questions about how researchers effectively or consistently measured it.

Papers with clear theoretical frameworks were often embedded by concepts around self and social relations. Hafford-Letchfield (2013) and Swinnen (2016) both referenced Kitwood's person-centred framework, which improved research inclusivity and attention to participants' identities. A clearer explanation of conceptual framework was provided by Harris and Caporella (2014, 2018), who applied the psychological 'intergroup contact theory' alongside 'the benefits of music' framework, to study social dynamics and the accompanying benefits of music. More obscure practice-led or performative theories were adopted by Synnes et al. (2020), who explored 'poetry as a linguistic and ethical practice' and as an indicator of 'narrative citizenship' of people with dementia. Likewise, Swinnen (2016) engaged

with 'oral poetry traditions' that attended to relationships between speakers and listeners in creative activities (p.1381). The papers mentioned thus far illuminate the varied ways that researchers may examine the social and/or creative benefits of participatory arts.

Other papers applied theories at the analysis stage – such as grounded theory (Unadkat et al., 2017; Tan, 2018) – and developed their own conceptual or theoretical models. Those produced included a 'group singing model in dementia for couple dyads' theoretical model (Unadkat et al., 2017) to disseminate the experiences of couples across community singing programmes; a model for the Frye Art Museum's 'here: now' programme, to outline the important antecedents, structures, processes and outcomes linking to its effectiveness (Burnside et al., 2017); and the 'Three S's model' informing the arts practice of a programme about spaces, senses and stories (Innes et al., 2021). These conceptual models relate to the important tenets of creative arts practice and of programme development derived from findings, rather than underpinning the initial research conduct.

2.4 Discussion

Given the recent growth of recognition in arts for people living with dementia, this thematic modified scoping review offered an up-to-date overview of community-based, dementia-friendly, participatory arts peer-reviewed literature. The review aimed to identify the wellbeing benefits and general effectiveness of participatory arts for people living with dementia, including psychological, cognitive, emotional, social and physical components of wellness. While visual and music-based activities remain the most common art types analysed in the literature, other multi-art, literary, drama, dance and comedy-based activities have also shown to be of benefit. Collectively, this suggests that participatory arts can offer comparable benefits to people with dementia, regardless of the specific art form. This is a useful finding, given that researchers often aim to explore the intrinsic value of particular art forms or have studied them separately and comparatively (e.g. Zeilig et al., 2014; Young et al., 2016). While the literature does not specifically allude to this, the review suggests that rather than seeking to compare different arts, the focus should be on

identifying and understanding how the *underlying* processes and mechanisms of participatory arts activities promote wellbeing for people with dementia.

'Person-centred', 'strength-based' and 'in the moment' approaches were alluded to in the literature, which have been shown to attend to the needs of participants and support arts engagement without dementia symptoms inhibiting opportunities (e.g. Burnside et al., 2017). These approaches could, however, be further examined to better ascertain how they are promoted in, and contribute to, participatory arts practices. Indeed, the values of person-centred, strength-based and 'in the moment' approaches can also be promoted in how research is conducted, yet few studies considered the use of co-design, co-creation or participatory approaches (Tseklevs et al., 2020). Whilst the literature is strongly engaging with qualitative and mixed-method approaches – involving participants with dementia in interviews, focus groups and visual data – further communication with people living with dementia could be achieved through adaptive participatory research approaches that complement person-centred, participatory arts practices and give further platforms to participants with dementia.

The review suggests that participatory arts can aid communication for people with dementia, which can be attributed to the use of novel and multisensory forms of stimulation. Few papers overtly addressed, but appeared to hint at, the importance of participatory arts in facilitating non-verbal, alternative forms of communication and expression. This insinuates a connection between objects and the senses, of which Chauhan (2018) makes the most established observations in their discussion on touch. Beyond this, however, multi-sensory enquiry is missing from the evidence base and there are knowledge gaps in understanding how the materials world shapes activities, social relations, and engagements. This review therefore identifies the need for further research to elucidate the value of human-object interactions in participatory arts. Arguments for further examination of human-non-human interactions can also be extended to place and space, which was mostly considered for venue practicalities. Whilst one paper offered insights into place-based factors of the arts (Innes et al., 2021), this remained on the periphery of space by predominantly acknowledging relations between activity and space, but not of

participants' extended socio-spatial relations. Hence, there is a gap in understanding how socio-spatial-material factors shape participation, imagination and behaviour.

The literature has established that being part of a group and building relationships with others is a positive aspect of participatory arts programmes. Indeed, increased social motivation was observed in participants and improvements were made to personal relationships. This alludes to unique benefits of creative engagement within group settings, which can be further explored by considering the group dynamics that develop in long-term participatory arts programmes. Considering individualised experiences, hints were made throughout papers about the roles of individuals within groups, but with more focus on the subjective outcomes of participatory arts than of how individuals contributed to, or were benefited by, the in-depth group dynamics channelled by the arts. Further research could tease out these inter-subjective benefits of participatory art-making, to gain a wider perspective on the social sphere integral to such programmes. This would include how the identities of carers – paid/professional or informal/family – fit into participatory arts settings, which is yet to be given considerable attention.

Lastly, the current literature sparsely engaged with theory or did not make clear indications of theoretical underpinnings. This is, in part, due to the multidisciplinary backgrounds represented in participatory arts literature. Some studies considered wellbeing literature (e.g. Osman et al., 2016; Zeilig et al., 2019) and psychological group theories (Harris & Caporella, 2014), whilst others engaged with practice-led, linguistic and performative concepts (Synnes et al., 2020). With variability and lack of transparency in the reviewed literature, stronger theoretical engagements could contribute novel perspectives to the field. More specifically, conflicts were found in how researchers theorised wellbeing and subsequently how they intended to measure it, with some considering it a process (Zeilig et al., 2019) and others approaching it as an outcome (e.g. Johnson et al., 2017). This is an important issue, given that the literature aims to make an argument for why participatory arts promote wellbeing, but yet it does not consistently specify what wellbeing means.

2.5 Putting Findings into Practice: Concluding Remarks

This thematic modified scoping review has summarised and evaluated the published literature considering the benefits and implications of community-based participatory arts activities for people living with dementia, with some consideration given to carers' experiences. The review was designed with relevance to the current research project and the setting of Theatre by the Lake, with the aim of shaping how this thesis would unfold. Section 2.4's discussion has ruminated on knowledge gaps in this field, including an opportunity to further explore how underlying processes can influence the effectiveness of participatory arts. This could involve further exploring person-centred, strength-based, and 'in the moment' perspectives, expanding on provisional impressions drawn from the analysis of reviewed papers. Furthermore, this thesis acknowledges the gaps in how space, place, objects, and the senses interplay within arts engagement, aiming to make these tenets central areas of enquiry, whilst previous literature only gave them infrequent attention. Furthermore, there is an opening for using inclusive methodologies for people living with dementia and engaging with theoretically-informed research. This thesis aims to address these opportunities by ensuring transparent and complementary uses of theory and method, with an interest in participatory methods, wellbeing conceptualisations, participation and communication. Finally, considerable attention has been given to the social and individual benefits of participatory arts for dementia, but further exploration is required into the inter-subjective roles of individuals within groups, and of the group dynamics on the individual, to highlight the personal and social narratives of living with dementia.

Considering these identified gaps, this thesis sought to:

- 1) Explore the effectiveness of the *Setting the Scene* model's multi-arts approach in assisting wellbeing experiences;
- 2) Examine how to best sustain the attention and engagement of participants during sessions;
- 3) Identify the contributions of material and relational factors of space, place, setting and objects to wellbeing experiences and *Setting the Scene* programme effectiveness; and

- 4) Consider how group relations, family relationships and friendships during sessions contributed to, or were benefited by, arts engagement.

Beyond these empirical objectives, the review findings have influenced this study's priority to adopt an inclusive research design, that collectively recognises the needs of participants and the CASE partner, Theatre by the Lake. This will be reflected in the chosen methodology and the aim to develop user-friendly toolkit deliverables for the theatre. Informed by the findings of this background literature chapter, the remaining chapters of this thesis will lay the theoretical and methodological foundations for the study, followed by the empirical findings that emerged from *Setting the Scene*.

Chapter 3. Relational Wellbeing and More-than-Representational Landscapes: A Theoretical Framework

3.1 Introduction

Since dementia is principally a cognitive condition – mainly affecting memory, attention, problem-solving and language (Alzheimer's Society, 2021b; 2021c) – research has often engaged with seemingly complementary cognitive and psychological approaches to study the condition (Gate et al., 2011; Woods et al., 2012; Gonzalez et al., 2015). This inspired an early prioritisation for investigating the long-term cognitive benefits of arts for dementia (e.g. Särkämö et al., 2014; Young et al., 2016) and may have led research to overlook the importance of process-oriented engagement and socio-natural-material relations in living well with dementia (Banerjee et al., 2006; Beard, 2012; Kontos, 2014; Keady et al., 2020). While there is a significant body of research investigating the human, emotional and social geographies of ageing (e.g. Andrews & Phillips, 2004; Milligan, et al., 2004; Rose & Lonsdale, 2016), only a smaller proportion of these specifically consider dementia (e.g. Blackstock et al., 2006; Brittain et al., 2010; Mossabir, 2018). Influenced by literature on wellbeing and geography, this chapter engages with more-than-representational theories, therapeutic landscapes and relational wellbeing literature, integrating these human geography threads to better ascertain holistic socio-natural-material experiences of dementia (Conradson, 2005). With a section dedicated to each of these three theoretical contributions, this chapter explores the extent to which wellbeing for people living with dementia can be comprehended through performative, creative, relational and affective interactions, as experienced at *Setting the Scene*. I first outline my chosen conceptualisation of wellbeing as being relational, drawing on more-than-representational and assemblage theory concepts, before exploring the tenets of 'more-than' geographies and therapeutic landscapes in further detail. Overall, the intention of this integrated theoretical framework is to attend to the alternative ways that people with dementia may express themselves,

going beyond what language-driven, reflective, or outcome-oriented studies may consider.

3.2 Defining and (Em)Placing Wellbeing with Dementia

3.2.1 Introduction to Wellbeing

Wellbeing is a broad umbrella term that, depending on how it is defined and conceptualised, can impact services, research conduct and the interpretations of people's lived experiences (Devine & Lloyd, 2015). Within the existing literature evaluating the benefits of creative programmes, authors have identified that 'wellbeing' is commonly referenced but is often ill-defined (Leckey, 2011). Defining what is specifically meant by 'wellbeing' has continued to be debated across policy-making and different academic disciplines, particularly over the past two decades, with little consensus. The term is often considered alongside 'health' and 'quality of life', further complicating its specific meaning. As outlined by Andrews, Chen and Myers (2014), we can collectively go as far as to agree 'that 'wellbeing' is fundamentally about 'being-well': content, healthy and in a good place in life'...with links to 'positive mental and physical health and welfare, attained or obtained in some way by fulfilling personal needs' (pp.212-213).

Our understandings of individual and personal wellbeing have historically built upon the philosophies of scholars such as Aristippus and Aristotle: the former treating wellbeing as hedonic and linked with pleasure or happiness, whilst the latter theorised the eudaimonic wellbeing approach entrenched in meaning and purpose (Atkinson, Fuller & Painter, 2016; Dewitte et al., 2021). Since then, new perspectives of wellbeing have continued to be proposed, with particular attention over the past decade (Dodge et al., 2012). Nevertheless, it remains common, even in recent literature, to refer vaguely to wellbeing without providing an in-depth exploration of how it is being conceptualised (e.g. Holst & Edberg, 2011). Transparent wellbeing definitions can facilitate a reader's grasp of the lens through which research is being undertaken, but more importantly can progress the knowledge gained about participants' experiences and their own wellbeing priorities. Such findings can usefully feed back into health care, policy and expanding knowledge of what contributes to wellbeing. In this thesis, my understanding of 'wellbeing' was

intentionally broad and multi-dimensional, inspired and informed by more-than-representational theories and therapeutic landscapes literature, as opposed to alternative psychological or individualistic perspectives as will be explored.

3.2.2 Wellbeing Definitions in Policymaking

Literature on the conceptualisation of wellbeing is often provoked by the outdated but unchanged World Health Organization's [WHO] collective definition of 'health and wellbeing', described as 'a state of complete physical, social and mental wellbeing and not merely the absence of disease or infirmity' (WHO, 1948; *cited in* Williams, 1999; Fleuret & Atkinson, 2007; Ward Thompson, 2016; Mossabir, 2018). While this definition is seemingly all-encompassing – taking wellbeing outside of a biomedical scope and incorporating social and psychological branches – it has been contested by health geographers and dementia researchers who acknowledge the definition's assumption that wellbeing is a goal-oriented state that can be 'complete' or fully achieved (Andrews et al, 2014; Zeilig et al., 2019). Applying this definition verbatim to older adults with dementia would be to disenable them from ever fully achieving wellbeing, given the ongoing physical and cognitive decline associated with their symptoms (e.g. Steptoe, Deaton & Stone, 2015). Research can challenge the WHO's definition of wellbeing by demonstrating that older adults with long-term health conditions may report having good levels of subjective wellbeing (Verropoulou, 2012; Dionigi, 2015). On a larger scale, the implications of the WHO's definition of health may lead to continued negative and inaccurate stereotypes about the capacities of older adults with dementia. Indeed, research considering a social wellbeing framework in public policy confirms that understandings of wellbeing vary across populations, where 'the pursuit of wellbeing by some, results in the denial of the opportunities of wellbeing of others' (Deneulin & McGregor, 2010, p.513). Hence, wellbeing may require reformulation to improve understandings of how it is manifested in particular communities or individuals.

Wellbeing, as portrayed by the United Kingdom's Department of Health [DoH] (2013), is considered as an 'individual's experience of their life; and a comparison of life circumstances with social norms and values', which comprises relational, subjective and objective wellbeing perspectives (p.1). Whilst less biomedical, the

DoH nevertheless measures wellbeing using quantifiable and standardised methods, in addition to advocating a more comparative understanding of wellbeing; these may overlook the complexities of wellbeing in everyday contexts and implicate how research conduct informs UK health policy. To counteract the implications of these previous definitions, it is necessary to move away from goal-oriented, quantified health and towards a more accessible, richer and realistic conceptualisation. It has become increasingly important to redefine understandings of wellbeing for those living with dementia through a lens of emergence, becoming, changeability and 'situatedness', supported by Andrews et al.'s description of 'being-well' (2014). In essence, moving beyond wellbeing as something to be achieved or aimed for can open avenues for considering it instead as a process that is 'being' experienced with more immediacy.

3.2.3 Geographical and Relational Contributions to Wellbeing

Associated with experiential, (post)-phenomenological and more-than-human philosophies, a process-oriented or relational wellbeing encourages 'a view of being human that is always in process' and 'not finished', due to changes that arise from our 'journeys' circumstances' (Dalberg, Todres & Galvin, 2009, p.267). Defining wellbeing as fluid and changeable corresponds with the progressive, always-changing nature of dementia and its impact on individuals' circumstances and personal needs. Viewed as a life-changing diagnosis, dementia is often consecutively described as unpredictable in the short-term, yet inevitable in the long-term (Hall & Sikes, 2020). Hence, the evaluation of wellbeing often requires more regular renegotiation on a day-by-day, moment-by-moment basis, in a bid to live well with dementia. This raises the relevance of emerging everyday experiences and the entanglement of people, place, space and materiality to definitions of wellbeing (Anderson, 2015).

The entanglement of different entities within everyday experiences and relationships can be collectively referred to as an 'assemblage'. Stemming from Deleuzoguattarian concepts, an assemblage is a 'constellation of elements' heterogeneous in nature (Deleuze & Guattari, 1987) and may consist of the 'human and non-human, organic and inorganic, technical and natural' (Anderson & McFarlane, 2011, p.124). Notably,

assemblage is often referred to as a verb – what it does – than as a noun – what it is – but researchers often interchange between these (Anderson & McFarlane, 2011, p.125). Assemblage theory attends to the processes of transition, becoming and disruption between different actants (Dewsbury, 2011), looking outside of mere connection and towards how they dynamically transform one another (Rose, Bingley & Rioseco, 2020). Wellbeing through a lens of assemblage is therefore positioned as more than an independent state, but one that relies on the co-functioning of multiple entities whose roles, relations and influences are ever-changing and developing (Anderson & McFarlane, 2011). This relational dimension of wellbeing has been referred to by others as demonstrating the ‘dynamic’ and ‘anthropological richness’ of human wellness experience, which is often overlooked (Giovanola, 2005, p.251). While assemblage theory has been applied to the ‘always-unfinished’ process of recovering and ‘becoming well’ after an illness or accident (Duff, 2016), so too can this theoretical perspective be applied to the equally dynamic process of ‘being well’ and accepting a life with a degenerative condition like dementia (e.g. Tan, 2020).

Through the process-oriented lens of assemblage theory, dementia experiences can be considered not only as individualised and cognitive, but also as social, emotional/affective and relational (Anderson, 2006; DeLand, 2006). As with assemblages, ‘relationality’ in this sense – and used throughout this thesis – refers not simply to elementary connections between two or more things, but to the transient interplay of ‘socio-natural-material’ features in experiences of wellness (Conradson, 2005, p.339). By approaching wellbeing as both inherently relational and as an experience promoting individuality, the work of Conradson (2005) becomes relevant, within which he encourages consideration of ‘the relational notions of selfhood’ in wellbeing and therapeutic encounters (p.337). This was alternatively described in recent lifeworld literature as people with dementia ‘continuing to participate in the dance of life as oneself’ (Dewitte et al., 2021, p.1).

Conradson’s suggestions contrast with conventional psychological perspectives on selfhood and wellbeing, which tend to concern eudaimonic or hedonic conceptualisations (Huppert, 2009). Such models include the PERMA model of wellbeing (Seligman, 2011), which addresses social factors alongside personal

factors, but pertains more to the individualised product of ‘flourishing’ than to the relational process. Contrastingly, health geographers advocate a wellbeing focus that is more circumstantial, situated and ‘place-sensitive’ (Andrews, 2002), attending not only to interactions but to where and how they emerge (Conradson, 2005). A geographical lens therefore welcomes insight into the facilitation of wellbeing through the social, spatial, relational and creative (Thien, 2005; Atkinson, 2013; Fox, 2013); where the ‘knowing, being and doing’ of wellbeing goes beyond the representational and textual, focusing instead on atmospheres and unfolding events (Anderson & Smith, 2001: p.8). It is hoped that this conceptualisation of wellbeing can aid better understanding of ‘the hidden, multisensory and emotional geographies that are entangled with different environments and practices’ (Barron, 2019, p.5; Skinner et al., 2015, p.787). This relational, situated and process-oriented approach not only has potential to observe the community-based ‘creativity – assemblage’ of participants at the *Setting the Scene* programme (Fox, 2013: p.498), but can also consider the extent to which the programme itself can enable and emplace wellbeing.

A further contribution of process-oriented wellbeing to dementia rhetoric is in its consideration of temporality. Unlike ‘the seamlessness of everyday life and its qualitative character’ as referred to by Dalberg et al. (2009, p.266), dementia experiences can feel more fragmented than seamless, with short-term memory loss potentially impacting the interpretation of one moment to another (Requena-Komuro et al., 2020). The impact of memory loss and altered time awareness can be resolved through a move away from past and future perspectives of wellbeing, to one that focuses on moment-to-moment facilitation (Keady et al., 2020). Wellbeing, however, cannot be entirely immediate, pre-cognitive and pre-personal either, given that emotional and corporeal experiences play intricate roles in worldly interactions and considerations of self: ‘...biography, practice, time, settings and other people, combine to create and sustain the experience of being in the moment... as part of the complex processes through which moments are created, sustained, ended and... re-lived once again’ (Keady et al., 2020, p.25). This description highlights the richness of influences which are comprehended ‘in the moment’ and demonstrates how the

narrative of 'being-well' is built in practice. Considering this, a wholly pre-cognitive approach to dementia could diminish the essentiality of personhood and selfhood, risking the 'total erasure of the human subject' in the construction of wellbeing (Simonsen, 2013, p.12). Instead, wellbeing as an unfolding narrative and a relational construct is beneficial for upholding a sense of self, empowerment and authenticity. This is particularly important for healthy ageing and living with dementia, when people may feel that their sense of self is under threat (e.g. Bryden, 2018). A balanced approach would not only have potential to uphold the empowerment of participants, but could also better attend to the multiplicities of wellbeing where 'subjectivity emerges through relational and circumstantial processes' (Ferretti, 2020, p.8). Hence, a theoretical framework that integrates more-than-representational theories (e.g. Whatmore, 2002; Simonsen, 2013; Ferretti, 2020) with therapeutic landscapes literature (e.g. Gesler, 1992; Williams, 1999; Bates, 2019), can aid the exploration of relational, place-oriented, affectual, and wellbeing experiences. Merging with arguments already presented, the following section will critically explore the relevance of more-than-representational theory to this thesis.

3.3 More-than-Representational-Textual-Human

Much of the arts-based dementia literature published thus far has focused on using either social constructivist ideas (Webb, 2017), phenomenological and pragmatic approaches (Hafford-Letchfield, 2013) or positivist, realist studies (Woods et al., 2012). An alternative theoretical stance can be taken using more-than-representational theory, a revised interpretation of the non-representational theory largely developed by Nigel Thrift (1996; 1997). Broadly, non-representational theory is based on Thrift's reworkings of Deleuze and Guattari (1987), Latour (1996; 2000; 2005), Massumi (1997; 2002) and other prominent philosophers and social theorists (Thrift, 2008). The theory is a practice-based (rather than practice-led) multi-modal ontology, formed as a rejection of social constructivism and integrating different philosophies ranging from post-phenomenology, neovitalist philosophies and poststructuralism (Cadman, 2009; Vannini, 2015). These various philosophical areas and their contemporary revisions lay the foundation for non-representational theory, and, to a varying degree, more-than-representational theory. Although the

more-than-representational approach has since been adopted by numerous geographers (Lorimer, 2005; Griffen, 2007; Carolan, 2008; Barratt, 2012; Waterton, 2014; Barron, 2019; Doughty, Duffy & Harada, 2019; Andrews, 2020), it is most fruitful to consider its intentions in light of the original non-representational tenets. The following exploration presents the main non-representational arguments relevant to this thesis, highlighting the preferred 'more-than-representational' adaptations which will be applied.

3.3.1 Biography, Cognition and the Present Moment

Process-oriented, 'in the moment' philosophies are central to both non-representational and more-than-representational theories, having already been introduced in the earlier exploration of relational wellbeing and dementia. Indeed, the philosophy has also been encapsulated in arts-based research, where Massumi (2011) considers interactive art as 'not so much the aesthetic form in which a work presents itself... but the behaviour the work triggers in the viewer', participant or artist (p.39); a behaviour that is affective and emergent in nature. Whilst sharing in these ideas of affect, emergence and process, more-than-representational revisions diverge from the original non-representational tenets in the prioritizing of the pre-cognitive.

The purist forms of Thrift's non-representational theory hold scepticism over biography, maintaining that it treats life as something to be studied individually 'rather than endlessly redescribed' by the onflow of emerging events (Phillips, 1999, p.74). Non-representational theorists reject methodological individualism in favour of the study of associations between things (Andrews, 2014, p.166). This tenet causes much debate amongst human geographers and is central to the shift towards more-than-representational revisions, which aims towards 'a promising middle ground between the extremes of a wholly precognitive, transhuman affect and the meaning-saturated discursive subject position' (Müller, 2015, p.414). This is reflective of Conradson's proposal of wellbeing (2005) as discussed earlier, which gives balanced consideration to relationalities and selfhoods. In line with Müller's proposed ideas (2015), more-than-representational perspectives can maintain a mutual appreciation for life stories as told through the lens of dementia, whilst also

respecting that a person with dementia is more-than-words, more-than-actions, and continuing to write their personal narrative. This promotes an unfolding biography and open narrative that comprises past events and presently experienced moments (Randall, 2009). Recent more-than-representational proponents, such as Barron (2019), demonstrate this in practice through their work, whereby 'past, present and future temporalities are in an ongoing dialogue, ever-reconfigured by the potentialities flowing in the present' (p.10). Here, individual knowledge and life experiences signify how the everyday onflow plays out and how it is understood by people. More-than-representational approaches therefore reject Thrift's total abandonment of biography, which could undermine the self-narratives, memories, and aspects of past and present identity of people living with dementia (Randall, 2009).

'More-than' viewpoints of selfhood actively refute the negative and damaging dementia discourse that has been previously used around loss of self, being 'vacant' and becoming 'an empty shell' (Dementia Australia, 2018: p.2). Although at the centre of our understanding of dementia is a sense of disruption to memory and biography (Williams, 2000), it is important to acknowledge the capacity of people living with dementia, in the same way that wellbeing was discussed previously (see Section 3.2.3). These ideas can therefore inform the perspective of this thesis, alongside 'in the moment' interactions – before they are interpreted and translated through the use of language – which can support the empowering pursuit for the use of the body and senses to interact with the world (Shusterman, 2000).

3.3.2 The Social Body and More-than-Verbal Communication

Adopting a post-phenomenological 'rejection of the linguistic paradigm' supports more-than-verbal enquiries and helps to reframe our understanding of being a human actor entangled with other things (Boyd, 2017, p.13). Turning again to assemblage theory, recent work by Mazzei and Jackson (2017) illustrates that the multiplicity of 'voice' can be supported through the concept of assemblages.

Touching on the work of Deleuze and Guattari (1987), Bennett (2010) and Barad (2003, 2007), the authors consider communication as more than humanistic and subjective, moving 'to emphasize voice as (re)configured in the intra-actions

between the material and discursive', whereby 'bodies, words, [and] histories' are entangled and bound by human-non-human practices (Mazzei & Jackson, 2017, pp.1091-1092). This more-than-verbal approach to 'voice' as bound by practices offers leeway between purely pre-cognitive and purely reflective perspectives, where different 'dimensions of voice' can be acknowledged for embracing materiality, the body, and the present moment (p.1096). This attention to body and atmosphere has been exemplified in recent dementia and gender research (Campbell, 2019) but otherwise has limited engagement in dementia studies. Nevertheless, I argue that this theoretical positioning lends itself to the study of arts engagements for people with dementia, where more-than-verbal expressions – be it textual discourse or non-verbal activity – require recognition. A blended, more-than-textual approach has empowering potential for exploring cognitive impairment and dementia experiences, particularly for those who may have verbal communication difficulties as part of their dementia (Hubbard et al., 2002). Hence, more-than-representational theory promotes the capturing of varied mediums of 'voice'; where pre-cognitive and unfolding, or post-event and reflective, threads are equally acknowledged.

More-than-representational reconsiderations of the body can be informed by Simonsen's ideas of 'new humanism' (2013) and what she termed 'experienced otherness', in which social and cultural experiences are felt by the body (p.3) and a 'non-cognitive way of knowing is practised' (p.16). As previously expressed by Young (2005), 'the body as lived is always layered with social and historical meaning and is not some primitive matter prior to or underlying economic and political relations or cultural meanings' (p.5). The body is a social body, in a world that experientially differs depending on the place, space and relationality of others in that landscape. Experienced otherness is applicable to those living with dementia, who may feel socially disadvantaged by the assumed and perceived changes to behaviour, mood and cognition from the perspectives of surrounding family and community. This can result in social isolation and stigmatisation, which can become realised through restricted activities, a change in communication, unaccommodating attitudes from others, and an altering sense of socio-cultural belonging and power in the world

(Biggs, Carr & Haapala, 2019). Through this perspective, dementia is not simply an internalised, neurological experience ‘residing in the brain of the person with dementia’ (Kindell et al., 2017, p.396), but is a socially and physically experienced phenomenon (Biggs et al., 2019). Therefore, Simonsen’s experienced otherness implies the importance of encouraging embodied unity and felt community, for which programmes like *Setting the Scene* endeavour to create. Indeed, these theoretical concepts suggest that the people surrounding those with dementia play important roles in ensuring that they do not make them feel estranged or lesser, but are enabled through emotional support and positive affectivities that ‘act on bodies, are produced through bodies and transmitted by bodies’ (Lorimer, 2008, p.2). Through body, affect, and the plurality of communication, insights can be made into how processes are developed in the assemblage of dementia-friendly communities, as well as how wellbeing can be experienced by individuals in relation to others.

3.3.3 Relationality and Materiality

The influential tenets of relationality and materiality in non-representational and more-than-representational theories can help shape the enquiry of human-object interactions and illuminate the role of the body in dementia studies. Indeed, a relational materialist lens has been applied to disability research to better understand how disabled bodies are navigated, but also how bodies are actualised through the biological, social and material (MacPherson, 2010; Kaley, 2017). The same theoretical approaches can therefore illuminate how dementia is navigated.

Interest in these concepts derive from Latour’s Actor-Network Theory: a theory of power that rejects humanism and concentrates on the constantly shifting networks of human and non-human actants (Clegg & Haugaard, 2009). Inspired by Latour (2005), Thrift’s non-representational theory shifts away from subjective embodied experiences and considers how people or bodies are affected by other actants.

Proponents of the alternative more-than-representational stance commonly turn to Whatmore’s ‘more-than-human’ reconceptualization (2006) for a nuanced, critical approach to what the roles and agencies of actants are in these so-called networks or assemblages. Whatmore’s ‘more-than-human’ approach to relationality opens up a processual and mobile view of interaction, observing ‘the co-fabrication of socio-

material worlds' as something iterative and non-hierarchical (p.604). In this way, attention can move away from objects as 'indifferent stuff' (p.602) or entirely meaning-entrenched, to focus on what objects *do* alongside human activity (p.604).

Research with a 'more-than-human' focus has demonstrated that objects can be interpreted and used for different purposes, including having transitional properties for people with dementia and aiding them in coming to terms with dependency on family carers (Stephens, Cheston & Gleeson, 2012). Meaning-entrenched possessions, clothing, or gifts of people with dementia - embodying familiarity, home and a sense of self – can help to illustrate the agency of human interaction with objects, by showing their roles as go-betweens in the relationships of humans (Wallace et al., 2012; Buse & Twigg, 2016; 2018). Notably, a more-than-representational approach to relationality can pave a way to explore objects as holding material memory or being 'markers of memory and identity' (Ratnam, 2018). The anthropological study of cognitive materiality has considered the transformative and affective relationship between people and objects or places, and the ways that these non-human agents can be occupied with memories that can, in turn, affect people (Navaro-Yashin, 2009). Indeed, previous more-than-representational studies have illuminated the manner in which human engagements in particular activities are 'dependent upon entering into symbolic and synergistic relationships with material others' (Barratt, 2012, p.46). This opens up interesting questions about what objects do in an arts-based setting and how they contribute to engagements with participants living with dementia. Relational materialism will subsequently play a major role in this thesis, extending understanding of *Setting the Scene* by considering the variable uses of objects, props and materials throughout sessions to invoke meaning and create focus.

3.3.4 Space, Place and 'Aliveness'

Despite being vaguely defined, 'aliveness' is about awareness and response to a world of people who often 'do not inhabit the midst of life' and are unaware of how 'jam-packed with entities' the world is amongst what we call space (Thrift, 2008, pp.14-17). Rather than refer to this as 'aliveness', it is more fitting in this thesis to align these descriptions with wellbeing or indeed resilience in dementia (Whelan,

Teahan & Casey, 2020), helping to draw together the more-than-representational approach with relational wellbeing and place-oriented ideas. Place constitutes lived space, comprising identifiable, meaning-entrenched, material locations of activity (Agnew, 2011; Dourish, 2006). Space, on the other hand, is more generalisable and can be considered as what a ‘place becomes when the unique gathering of things, meanings, and values are sucked out’ (Gieryn, 2000, p.465). According to Thrift (2008), space has an ambience from being ceaselessly lived in and lived through, regardless of whether it is done consciously – such as climbing a mountain - or through habituated, mundane routine – such as working at an office desk (p.17). Irrespective of the process or occasion, human beings form part of the materialistic and sensory ‘process of encountering and being in the world’ (Griffen, 2007, p.7). Literature on the sensing of place and space often relates back to actor-network theory or relationality, given that some researchers have considered that ‘meaningful senses of space emerge only via movements *between* people and places’ (Davidson & Milligan, 2004, p.524) and that the movement of bodies is ‘potentially generative of different kinds of spaces’ (McCormack, 2008, p.1822). This theoretical tenet therefore considers spaces and places to be as ‘affective’ as objects and artefacts when in interaction with a person, hinting at the contributions of therapeutic landscapes concepts to ‘more-than’ geographies and of the ‘ecological embeddedness of human beings’ (Ash & Simpson, 2016, p.63). This offers a multi-modal approach to exploring the richness of activity and agency at Theatre by the Lake’s *Setting the Scene* and the landscapes within which it is situated. These elements of place and wellbeing require further contemplation within the theoretical framework, achieved through ‘therapeutic landscapes’ and the role of the senses in embodying and experiencing place.

3.4 Therapeutic Landscapes and the Senses

3.4.1 The Evolution of Therapeutic Landscapes

The therapeutic landscapes concept was coined and developed in health geography by Wilbert Gesler (1992), who wanted to expand upon medical geographers’ interests in studying the therapeutic processes within particular locations and settings. Broadly, the concept can be defined as any landscape or place that offers a

therapeutic, healing, or restorative experience for individuals interacting with it or in it. From the outset, Gesler considered therapeutic landscapes to have physical, social, symbolic and material components (Bell et al., 2018) with potential to promote physical, psychological, emotional and spiritual health encounters (Rose, 2012). Yet, much of the initial research was concerned with traditional natural, built, or spiritual sites that were/are believed to possess the power to heal, including Epidavros in Greece (Gesler, 1993); Lourdes in France (Gesler, 1996); the Roman baths in Bath, England (Gesler, 1998); or areas of wilderness such as Denali National Park in Alaska (Palka; in Williams, 1999). The idea that a landscape may intrinsically 'possess' something therapeutic, however, remains contended by many scholars (Williams, 2007; Bell et al., 2015). While landscapes are generally understood as something tangible and physical, their therapeutic qualities are not necessarily inherent but are better understood as resulting from the dynamic, relational processes at play with the entities within and around the landscape (Conradson, 2005; Bates, 2019). The therapeutic landscapes lens regards place as relational, whereby wellbeing can emerge through the connection of environmental, societal, social and individual influences present (Milligan & Bingley, 2007). Other health geographers such as Williams (1999) understand the interactive processes of therapeutic landscapes 'in which space is implicated as human activity' (p.2). This relates to the anthropological work of Ingold (1987), who addresses humans for their intrinsic ecological relations to, and embeddedness within, place. These interactive qualities mean that wellbeing has the potential to 'take place in everyday, ordinary places, whether a residential backyard, a hospital room, or an imagined landscape' (Williams, 2007, p.2). Hence, the relational view of place runs in accordance with the principles of more-than-representational theory, valuing the relationality of 'what happens' between people, places and things. More importantly, considering place for more than its intrinsic properties enables ordinary, everyday geographies to be considered for their roles in wellbeing maintenance (Milligan et al., 2004). A therapeutic landscape is therefore not simply defined by its physical characteristics, but by the activities, interactions and assemblages that exist within it.

3.4.2 Therapeutic Landscapes: An Emotional and Multi-Sensory Perspective

Therapeutic landscapes literature is complementary of assemblage theory and the study of heterogeneous relations (Deleuze & Guattari, 1987), as has been explored thus far in this chapter. More specifically, the relationality within places, or the ‘mixtures of the natural and social and the human and the non-human’, can help to reconceptualise therapeutic landscapes as less detached and physical, and more interactive and experiential (Murdoch, 2006, p.3). This hints at post-phenomenological revisions of intersubjectivity, corporeality and embodied existence, which consider the body as ‘the point where I touch the world, where I intervene, and equally, where the world touches me’ (Russon, 1994, p.295).

Assemblages of health can therefore enrichen the therapeutic landscapes concept, which acknowledges any tangible or symbolic place that involves the promotion, development and maintenance of physical, psychological, social or spiritual wellbeing (Williams, 1999; Rose, 2012; Foley, 2016). This can further recognise wellbeing as something achieved through the embodiment and interactions *within* certain landscapes (Lea, 2008). An all-encompassing view of therapeutic landscapes thereby enables Theatre by the Lake’s physical landscape, social environment and other material or immaterial features to be considered for their collective therapeutic potential, whilst also placing weight on the participants, their embodied experiences of intersubjectivity, and multi-sensory engagements (Jeong, 2017).

With an interest in furthering the acknowledgement of body and senses, therapeutic landscapes researchers have been going beyond the predominantly physical or visual and considering how landscapes are interacted with and embodied (e.g. Doughty, 2013). For Doughty, this involves ‘the lens of the body in movement’, which attends to how the body *senses* and *feels* in practice (p.140). This perspective can be further enriched through emotional geography’s considerations of the inter-dependence of space, place, emotions and the senses. As discussed by Davidson and Milligan (2004), ‘emotions are understandable – ‘sensible’ – only in the context of particular places... likewise, place must be *felt* to make sense’ (p.524; italics in original). This discussion on emotions and embodiment is reminiscent of anthropologist Steven Feld’s work on the senses (1996), where he notes that ‘as place is sensed, senses are placed; as

places make sense, senses make place' (*in* Bates, 2019: 10). Sense of place can therefore be considered as a product of sensorially and emotionally engaging with the world.

Given the underlying connotations of visualism, tangibility and aesthetics in the term 'landscape', some researchers are going so far as to propose an expansion of the term to therapeutic 'sensescapes', to account for the heterogeneity of place (Howes, 2005; Bates et al., 2020). These alternative conceptualisations, which place multiple senses at the forefront of the research, are relevant to the multi-sensory, more-than-representational and relational components of this thesis. The term 'sensescapes' has its strongest ties to the work of Howes (2005), who defines them as 'the idea that the experience of the environment and of the other persons and things that inhabit the environment, is produced by a particular mode of distinguishing, valuing and combining the senses' (p.143). This is compatible with the prior suggestion of the inseparability of senses and emotion from place. Other recent developments in sensescapes research argue for going outside of 'landscape's visible realm' and prioritising non-visual senses of sound, smell and touch to ultimately exaggerate relationality (Bates et al., 2020: p.1). Sensescapes therefore not only consider the sensorial and affective interactions with place, but also overcome the separation of different senses as understood by decompartmentalised terms like soundscapes (Schafer, 1969), smellscapes (e.g. Jackson, 2011) and tastescapes (e.g. Pazo, 2016). Indeed, sensescapes can extend outside of the basic five senses, being inclusive of bodily experiences including balance, proprioception, interoception, movement, as well as affective concepts such as claustrophobia and pain (e.g. Bates, 2019). Given the changes in mobility, balance and bodily awareness that commonly coincide with the progression of dementia symptoms (Kenigsberg et al., 2015), the multi-sensory prominence aptly attends to the many ways that wellbeing (and indeed broader health) can be experienced in particular settings, as well as within and through the body for those living with dementia. However, while 'sensescape' proposals remind health geographers of the importance of renegotiating the perspective of the bodily senses in approaches to place and space, it can be contended that places and spaces are the reason that sensory experiences are possible. Hence, this thesis indorses the

continuation of the ‘therapeutic landscapes’ concept, while gaining influence from sensescapes and post-phenomenological literature. This has the potential to reinstate focus on how senses are informed by physical, social, symbolic and material components of landscapes; in doing so, a more-than-representational lens is supported through balanced attendance to non-human and humanistic enquiry.

A sensorial, movement-based, embodied emphasis in understanding therapeutic landscapes enlivens and binds this project’s integrative theoretical framework, given that therapeutic properties can be understood spatially and sensorially. The attention on body and senses may, however, be deemed particularly phenomenological in nature, privileging the subjective, human experience that more-than-representational theory aims to overcome. How, then, can this understanding of the outside world and therapeutic landscapes be put into practice without falling into the trap of phenomenological enquiry? Whilst coming from a purist perspective on non-representational theory, Candice Boyd’s *Non-Representational Geographies of Therapeutic Art Making* (2017) explains that to access the world through the lens of a performative, affect-based non-representationalist, we must start with ‘the body – a sensing body in *relation*, rather than a perceiving body’ (p.51; italics in original). This treats the body and human as a part of a larger assemblage and therefore confirms ideas previously discussed in earlier sections. Adopting these ideas but with more-than-representational threads, Dewsbury (2003) advises that we must move ‘away from the self and towards the ‘unknown’ ... [while also moving] ... ‘towards the self and one’s own experience of the ‘unknown’ (*in* Boyd, 2017, p.52). Applied to my own understanding of therapeutic landscapes and the study of dementia, a sensorial turn can attend to the significance of self in dementia and the inevitability of the unknowns that accompany the diagnosis. The sensoriality and interrelationality of therapeutic landscapes – encompassing the natural, built, symbolic, belief-based, social, sense-based and relational – can be ultimately viewed through a more-than-representational lens and an ‘in the moment’ knowing. As described by Simonsen (2013), this opens the way for viewing people or ‘body-subjects’ through a critical,

multi-modal lens of intercorporeality; 'as visible-seers, tangible-touchers, audible-listeners' (pp.16-17).

Contemporary therapeutic landscapes studies are vast and varied, having included the impact of woodland on mental health (Milligan & Bingley, 2007); housing for the homeless (Bridgman, 2002); experiences of rural stroke survivors (Meijering et al., 2017); and the painting of re-imagined landscapes for older adults (Rose & Lonsdale, 2016). Specific to dementia research, projects with explicit associations with the therapeutic landscapes concept have included researching the moral therapeutic landscapes of nursing homes for dementia (McLean, 2007); the use of technologies for dementia care (Brittain et al., 2010); the benefit of gardens and outdoor spaces (Marcus & Sachs, 2013); and changing personal-spatial relationships in home environments (Van Steenwinkel et al., 2014). However, few projects have involved the investigation of dementia and community-based participatory arts from a therapeutic landscape perspective. More broadly, there is a large knowledge gap in the application of therapeutic landscapes to arts in general (Bell et al., 2018). The proposed project therefore offers an original perspective on the collective study of dementia and the arts, with an additional focus on multi-sensory, multi-modal and relational elements. Exploring the *Setting the Scene* creative sessions through a therapeutic landscapes lens not only encompasses the arts activities being employed, but additionally the environments in which the activities are conducted; the people that are conducting them; the objects and artefacts that play central roles in the sessions; and the roles participants play with all of these elements considered in relation.

3.5 Concluding Remarks

This chapter has focused on the integration of more-than-representational theory, therapeutic landscapes and a relational wellbeing approach, and how they can collectively inform the study of participatory arts at Theatre by the Lake's *Setting the Scene* programme. Viewed as a whole, this theoretical framework contextualises the exploration of dementia, wellbeing and participatory arts through place, space, embodiment, affect, process and above all, relationality and assemblage. Intending to support people with dementia in research, a more-than-representational lens

goes beyond a conventional, pathological and outcome-oriented approach to give precedence to more-than-verbal and more-than-cognitive interactions. The previously explored more-than-representational tenets set out in this chapter offer an alternative approach to understanding dementia, shifting focus towards 'in the moment' experiences to illuminate how participatory arts promote living well with dementia.

To effectively consider the holistic wellbeing experiences stemming from the programme, an equally holistic framework is required; one that identifies wellbeing as both place-sensitive and relational so as to unveil the spatial, social and material elements of participatory arts. The relational view of wellbeing has shown to be integral to therapeutic landscapes and sensescapes literature, since it gives context to 'what happens' between people, places and objects, and also attends to the affective elements of particular environments and communities. The sensorial emphasis in therapeutic landscapes literature enriches how *Setting the Scene* can be explored, by overcoming visualism and focusing on multi-sensory and embodied qualities with arts.

Conclusively, this theoretical framework supports the exploration of dementia-friendly arts processes and spaces, and how wellbeing can be understood through a lens that looks beyond a reflective and solely cognitive perspective on dementia. A supportive methodology, with similar philosophical ties to process and relationality, is necessary to best support this theoretically informed exploration of dementia and participatory arts. In the following chapter, I outline how this framework can be operationalised through a collaborative, qualitative and multi-methods approach, guided by participatory action research (PAR) and sensory ethnography.

Chapter 4. Dementia, Participatory Action and Participatory Arts: A Collaborative and Sensory Methodology

4.1 Introduction

4.1.1 Chapter Outline

Building on recent work about dementia, wellbeing, and socio-cultural or human geographies, this project explores engagement experiences of participants at Theatre by the Lake's *Setting the Scene* participatory arts sessions. The initial design of this CASE project was proposed by my multidisciplinary supervisory team, with my own contributions made to the theoretical framework, research objectives and methodological design. Seeking to uphold the importance of a strength-based approach to understanding dementia – focusing on what people *can still* do – it was vital to choose a methodology capable of capturing the nuances of this. This chapter presents a rationale for choosing a combined participatory action research [PAR] approach and sensory ethnography methodology, drawing on existing literature. Falling under the transformative-emancipatory paradigm, I address the extent to which combining the main tenets of PAR with sensory ethnography achieves a balance between the practical and theoretical needs of this project, as presented in Chapters 2 and 3. Consideration of the methodology's main characteristics is followed by an overview of the research setting, recruitment strategy, and adoption of sensory ethnographic multi-methods, which are outlined in a chronological four-phase PAR framework that guided the fieldwork procedure. Following this, a step-by-step guide to thematic data analysis is given, as well as issues of quality, validity and ethics in applying PAR and sensory ethnography to dementia-based research. Reflections on the benefits and challenges of this methodological approach are provided in Chapter 9's discussion.

4.1.2 Revisiting Aims and Objectives

This project aimed to explore the wellbeing benefits of engaging in the *Setting the Scene* participatory arts programme for people with dementia and their carers.

Informed by knowledge gaps explored in earlier chapters, the objectives aimed to:

- 1) Explore the effectiveness of the *Setting the Scene* model's multi-arts approach in assisting wellbeing experiences;
- 2) Examine how to best sustain the attention and engagement of participants during sessions;
- 3) Identify the contributions of material and relational factors of space, place, setting and objects to wellbeing experiences and *Setting the Scene* programme effectiveness; and
- 4) Consider how group relations, family relationships and friendships during sessions contributed to, or were benefited by, arts engagement.

Influenced by openings in the existing literature, this study prioritised adopting an inclusive research design, to encourage direct participant involvement throughout the research process, and to develop user-friendly toolkit resources for CASE partner Theatre by the Lake. These overall empirical and practical aims motivated the methodological decisions of this project, as will be laid out in the following sections.

4.2 Methodological Insights from Existing Literature

Explored in Chapter 2, recent research on community-based participatory arts for people living with dementia has involved progressive, wide-ranging methodologies, with researchers promoting visual data (e.g. Tan, 2018), ethnography (e.g. Swinnen, 2016) and creative or practice-based methods (e.g. Chauhan, 2018). Whilst this indicates positive developments in dementia and arts research, there remain inconsistencies in how much research involvement and responsibility participants receive, with few papers adopting participatory or co-design methodologies for research or arts practice (McCabe et al., 2015; Zeilig et al., 2019; Tseklevs et al., 2020). Indeed, the social inclusion and active engagement promoted by participatory arts programmes is not consistently matched by the methodologies employed to evaluate their effectiveness. Subsequently, and inspired by the knowledge gaps, this project adopted a participatory action research [PAR] design, endorsing the tenets of the transformative-emancipatory paradigm; an umbrella term for frameworks recognising social injustice, inequality and marginalised groups, such as those living with dementia (Shannon-Baker, 2016). The following section explores existing

literature that informed these methodological choices, given that discussion on the subject has so far been limited in this thesis.

4.2.1 Transformative Paradigm

Methodologies falling under 'transformative' are numerous and may include participatory appraisal, feminist and activist research, experience-based co-design, co-creation, co-operative inquiry, ethnographic action research, decolonised research and participatory action research (Pain & Francis, 2003; Tacchi et al., 2008; Donetto et al., 2015; Kara, 2015; Swarbrick, 2015; Tseklevs et al., 2020). Collectively, transformative methodologies encourage greater participant involvement and empowerment, by ensuring that the community being researched remains central and informed from initial research stages. Hence, data collection and other project-specific, methodological decisions are chosen in accordance with their usefulness in accentuating participants' perspectives (Mertens, 2012). Whilst sounding pragmatic in nature, transformative research extends beyond pragmatism's attention to 'what works' by prioritising participant voices (Kara, 2015); enabling social change through the building of collaborative relationships (Mertens, 2012); and focusing on being process-oriented over outcome-oriented (Shannon-Baker, 2016). Research aligning with transformative principles can therefore contribute to, and correspond with, the current UK dementia policy, which encourages the active seeking of empowering, decision-making opportunities for people with dementia (Daly, Bunn & Goodman, 2018). By conducting such research *with* participants, not simply *on* or *for* them (Cameron & Gibson, 1992; Humphries & Truman, 2005), more personal insights can be made into the 'more-than' geographical inquiry of arts, space, relations and wellbeing experiences in the context of dementia, which reinforce the theoretical framework. This was the aim of adopting a participatory action research [PAR] design in this project.

4.2.2 Participatory Action Research [PAR]

PAR methodologies conventionally involve 'researchers and participants working together to examine a problematic situation or action to change it for the better' (Kindon et al., 2007, p.1). These processes of shared knowledge production rely on the building of trust and reciprocity with and between participants and researchers.

PAR is therefore useful for contributing to critical, collaborative action (Walker, 1993), such as evaluating or modifying new and existing community services alongside participants. Explained by Kindon, Pain and Kesby (2007), participation can be presented on a continuum from passive participation, to co-research status, and ultimately to self-mobilisation (p.16). Thus, PAR's flexibility towards collaboration can accommodate for people with dementia, whose voices remain inconsistently sought due to the perceived challenges associated with dementia (Hendriks et al., 2013) and the potential adaptations required to access these voices effectively.

In theory, PAR is a complementary choice for investigating participatory arts, given that both share a priority for community, process-oriented learning and alternative methods of communication or self-expression (Pamelia, 2015). Yet, a limited number of studies have adopted PAR for investigating community-based creative activities alongside people with dementia (Dupuis et al., 2012; Morrissey, 2017; Tischler et al., 2019). Outside of arts research, however, PAR studies have demonstrated their worth in improving healthcare services by collaborating with dementia sub-groups (Nomura et al., 2009; Pipon-Young et al., 2012; Goeman et al., 2016; Swarbrick et al., 2019; Dupuis et al., 2021). Though varied in topic and scope, the collective strengths of these dementia-based PAR studies lie in their engagement with broad research questions; wide-ranging multi-methods; diverse research teams; the production of practical output; and their adherence to flexible, project-specific, cyclical phases. Each of these factors have been considered in this study's design.

The cyclical, iterative process of planning, acting/observing, and reflecting involved in PAR (e.g. Harrington et al., 2013) is distinguishable from other methodologies, as illustrated in Figure 4.1, which displays my own interpretations of the methodology.



Figure 4.1: Sample PAR Cycle (Inspired by Tacchi et al., 2008).

Although most empirical research will employ these steps to some degree, the cyclical nature of PAR is unique, given that it acknowledges the successes and limitations of a phenomenon as they take place, rather than withholding findings until a project's close (Wadsworth, 1998). This is particularly key in the 'reflecting' and 'planning' stages of PAR, which often call for specific types of data collection methods in addition to main fieldwork, such as action learning groups, for aiding reflective and actionable group-based conversations on emerging data (Wood, 2019). Applied to the *Setting the Scene* programme, PAR is principally about participation in team building, encouraging all members of a community to inform richer reflection and knowledge transfer (Whitmore & McKee, 2001).

Monitoring research while it unfolds allows researchers to use the processes of everyday life to further promote action and change, highlighting social experiences (Somekh, 2006) and present-moment interactions (Keady et al., 2020). To optimise these principles, this study integrated the PAR framework with sensory ethnography, to complement the embodied and emplaced experiences of participants, and capture the complexities of engagement (Phillipson & Hammond, 2018).

4.2.3 Sensory Ethnography

If ethnography broadly explores social and cultural phenomena, societal structures, and patterns through observation and/or interaction with participants (e.g. Hammersley, 2007; Dewan, 2018), sensory ethnography, then, replicates this by

allocating greater weighting to body, senses, and more-than-human interactions. In essence, sensory ethnography allows for closer, embodied understandings of 'other people's multisensory experiences, knowing, practice, memories and imaginations' (Pink, 2015, p.134). When combined with PAR, ethnography's contemplation of everyday social processes can be observed alongside flexibility, reflexivity and more-than-textual discourse (Somekh, 2006; Mazzei & Jackson, 2017). Although previous research has merged critical ethnographic and PAR approaches within public anthropology (e.g. Hemment, 2007), few have regarded sensory ethnography.

Similar to PAR, attending to sights, smells, tastes, touches and sounds through an ethnographic enquiry involves 'learning through participation and shared experience' (Pink, 2015, p.151). This expands the outlook of research observations and interactions from what participants *say*, to discover what they also *do and feel*. This sensory, theoretical and nuanced turn in ethnography helps to consolidate the project's holistic point of enquiry, with more-than-human threads emplacing human participants within larger assemblages. Yet, the 'human' is also empowered through this methodological approach, since ethnography's sensorial turn can help to overcome the dominance of vision (ocularcentrism) and oral communication (verbalism) in Western cultural research, which can be polarising for participants with different needs (Jay, 1988; Ingold, 2000; Pink, 2015). A multi-sensory acknowledgement can highlight participants' sensory or communicative strengths and subsequently benefit the contributions of people with dementia in research, given the associations between ageing, dementia and sensory impairment (Behrman, Chouliaras & Ebmeier, 2014; Vogelpoel & Jarrold, 2014). Nevertheless, limited studies – comprising predominantly doctoral research – have adopted sensory ethnography in an attempt to be inclusive of people with dementia (Hatton, 2016; Mossabir, 2018; Mullins, 2018; Campbell, 2019; Motta-Ochoa et al., 2021). There remain knowledge gaps in community-based participatory arts research using this approach.

The theoretical underpinnings of sensory ethnography are important to reiterate, given that they influence the undercurrents of how ethnographers approach 'performativity, corporeality, sensuality and mobility' within fieldwork circumstances

(Vannini, 2015, p.318). Overall, sensory ethnography can give further meaning to the overarching PAR framework, by aiding the gathering of ‘in the moment’ data, reconfiguring communication, and examining social processes. Whilst a PAR methodology can capture the philosophies of this project’s theoretical framework, the integration of sensory ethnography offers a means to support a community of people affected by dementia, to share and collaborate through body, voice and creative expression (Phillipson & Hammond, 2018).

4.3 A Participatory and Sensory Multi-Methods Design

4.3.1 A Sensory PAR Approach

Influenced by existing literature and the acknowledged gaps in how dementia and participatory arts are investigated, this project adopted an integrated sensory PAR approach to study Theatre by the Lake’s *Setting the Scene* programme. A visualisation of this project’s adaptation of PAR has been depicted in a cycle matrix (Figure 4.2). As illustrated, qualitative multi-methods were chosen in line with the methodological design and can be considered as either those that aid ‘observing’ – notably participant observation (with field notes and researcher diary entries), visual and audio recordings, and ethnographic interviews – or those associated with ‘reflecting’ – comprising action learning groups and dyadic interviews.

Questionnaires were considered but later removed prior to main fieldwork (see Section 4.4.1 for further information). Indeed, acting and planning remain integral elements of the process, but for illustrative purposes the matrix draws attention to the rationale and suitability of the chosen data collection methods to enrich observations and reflections, as associated with PAR.

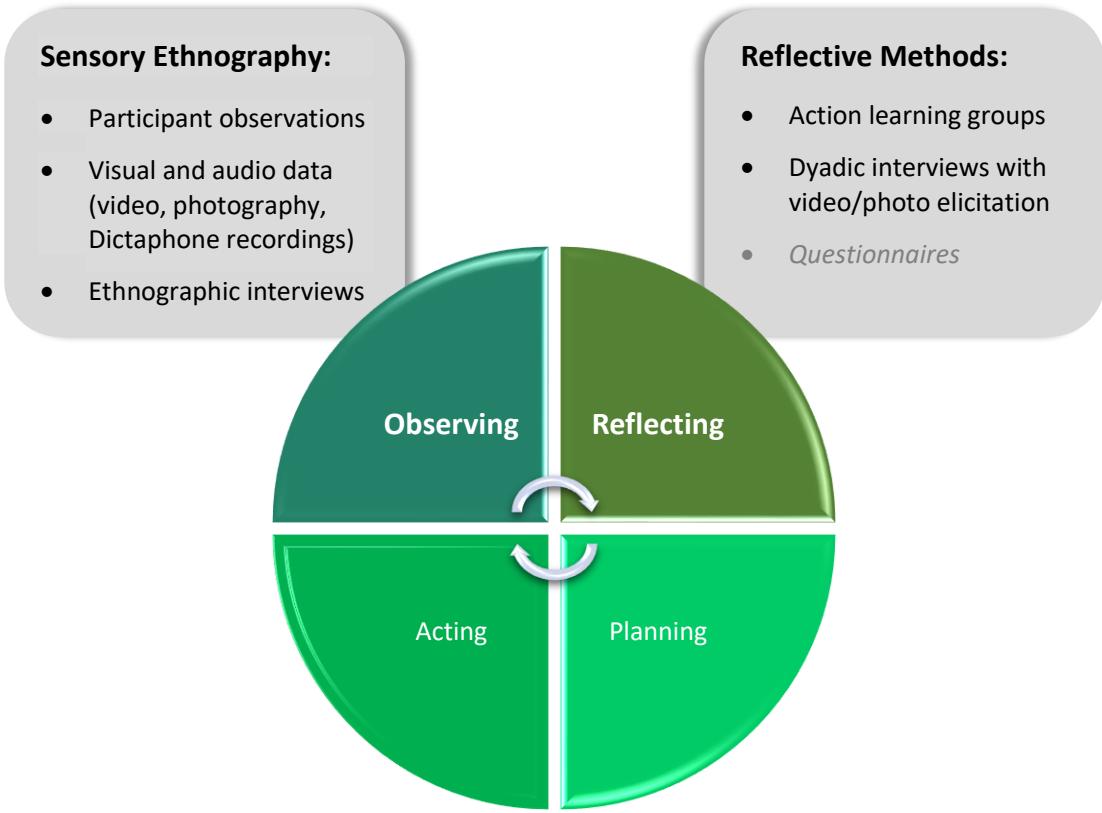


Figure 4.65: Visualisation of this project's PAR cycle and data collection.

The cyclical approach and accompanying methods in Figure 4.2 were implemented in a four-phase framework across the fieldwork. As outlined in Table 4.1 below, the four phases comprised: a brief action and reflection pilot study to test and refine the design alongside participants; two main PAR phases involving acting, observing, reflecting and planning; and a final post-fieldwork analysis stage, which was unfortunately impacted by the COVID-19 pandemic (see Section 4.4.3). Each of the summarised sections of Table 4.1 will be expanded on in further detail in a succeeding section outlining the fieldwork procedure. However, from the initial stages of this CASE project, it was known that Theatre by the Lake, their *Setting the Scene* programme and its members would be the sole research focus. Hence, the setting and recruitment strategies will first be considered before addressing the data collection methods and how they informed each research phase.

Table 4.1: Four-Phase PAR Process

Phase	Intention	Implementation
Phase One: Jul – Sept 2018	Pilot Study: Brief 'action and reflection' phase to test and refine the research design.	<ul style="list-style-type: none"> Four session visits. Two interviews.
Phase Two: Oct 2018 – Jan 2019	Main Fieldwork: Based on traditional PAR cycle.	<ul style="list-style-type: none"> Opening interview with theatre practitioners. Nine session visits. Three dyadic interviews. Closing interview with theatre practitioners. Nine-member action learning group with visual elicitation.
Phase Three: Jan – Jul 2019	Main Fieldwork: Repeat of Phase Two to implement potential changes and complete dyadic interviews.	<ul style="list-style-type: none"> Six session visits. Four dyadic interviews in participants' homes/public spaces. One individual interview with carer in home. Sixteen-member action learning group. Two interviews with facilitators and programme manager.
Phase Four: Jul 2019 – Apr 2020	Post-fieldwork: Analysis and final feedback stage.	<ul style="list-style-type: none"> Occasional informal session visits. Deliberative panel (cancelled due to COVID-19 pandemic).

4.3.2 *Setting the Scene* Programme and Field Sites

Due to the nature of this CASE project, the choice of study site was predetermined by Theatre by the Lake and the circumstances of their participatory arts programme. Arts sessions were primarily located in the Friends Gallery on the first floor of the Theatre by the Lake building in Keswick, Cumbria (Figure 4.3). Essential maintenance work from January to March 2019 led to temporary relocation at Crosthwaite Sunday school, a 5-minute car journey from the Theatre (Figure 4.4).



Figure 4.66: Friends Gallery.



Figure 4.67: Crosthwaite Sunday School.

These two Keswick-based locations became the main field sites for conducting observations and action learning groups, whilst interviews were predominantly undertaken in participants' own homes across North West Cumbria.

Fieldwork had to comply with the *Setting the Scene* seasonal schedule, comprising 40 annual sessions organised into summer, winter and spring blocks. These sessions were conducted weekly on Thursday mornings, from 11:00am to 12:30pm, during which time I based my main observations. Altogether, 19 sessions were observed at these sites, including a four-session pilot study and 15 main fieldwork sessions. The

full pilot study and ten of the main fieldwork sessions were conducted in the Friends Gallery, with the remaining five at Crosthwaite.

4.3.3 Recruitment Strategies

Participants were recruited using opportunity sampling from members already attending the *Setting the Scene* programme. Since turn-out at sessions often reached the programme's maximum capacity of 26 participants on busy days, the project only recruited from existing members and potential new arrivals, giving people the opportunity to self-select or decline participation in the research. There was continued potential for new members to arrive – often as spontaneous drop-ins – given the relatively open format of the programme. Hence, recruitment was a conscious rolling process beginning during Phase One's pilot study and extending into Phase Three. Notably, a large proportion of attendees came as a group from 'Amy's Care', a Cumbrian day care organisation who began partnering with Theatre by the Lake during the initial stages of *Setting the Scene*'s development. While this added unavoidable recruitment bias, it offered a stable participant group for the research and overall programme.

Early rapport with Theatre by the Lake and *Setting the Scene* members was built during the first year of my CASE studentship in 2017, during which I conducted a Master of Research degree and developed the doctoral project's proposal. Regular visits to sessions began during this same period, where I maintained full transparency about my research role. When the fieldwork was ready to commence in 2018, a formal address of the research project took place at the beginning of two *Setting the Scene* sessions, approximately 2-4 weeks before the recruitment and consent procedure occurred for Phase One's pilot study; this timescale was also repeated for the main fieldwork in Phase Two. Repetition was to ensure that all regular members and their carers were informed before being invited to participate. On these occasions, I explained the research project to the group with accompanying information sheets (see Appendix 2), addressing its aims, the benefits for Theatre by the Lake, and the potential involvement of members.

The informed written consent procedures took place at the beginning of *Setting the Scene* sessions, including July 2018 for the pilot phase and October 2018 for the main

fieldwork. All members living with dementia who required assistance could be paired with a family member, paid/professional carer, facilitator or researcher to help fill out information on forms (see Appendix 3). On both occasions, all of the present members and their carers gave consent to participate. For members arriving late near the end of Phase Three, I informed them of the research, used labels such as 'carer1' or 'participant1' where involvements were audio-recorded, and took precautions to direct unmanned camcorders away from them. If the latter was not possible, their faces and personal identifiers were pixelated in final visual files. A similar approach would have been taken for those declining to participate in earlier stages, but this did not occur.

After receiving informed written consent and demographic information, separate photo and video release forms (see Appendix 4) were completed at a later stage to enable the use of visual imagery in the research and other academic or public contexts. Lastly, additional recruitment and informed consent was required during the dyadic interview stage at the end of Phase Three, from family and spousal participants who had not attended *Setting the Scene* sessions due to their family members attending Amy's Care group.

4.3.4 Participants

30 participants consented to the research, including 14 people with dementia and 16 family/professional carers, all of whom are hereafter referred to by pseudonyms (see Tables 4.2, 4.3 and 4.4). Pseudonyms were chosen to give further protection to participants, given that a high number of personal identifiers were already being gathered in the project's visual data. Pseudonyms also provided a practical solution to seven of the participants who shared the same, or similar, names. Although real first names and name labels were used throughout *Setting the Scene* sessions, these were subsequently pixelated in images and removed from text. An exception was made for the facilitators, who agreed to have their real names used to acknowledge their roles in the theatre's programme (see Section 4.7). All of the participants with dementia were either regular members or had attended multiple sessions of *Setting the Scene*. Comparatively, only eight of the overall carers were regular, given that a small cohort of professional carers had variable working hours and subsequent

inconsistent attendance. Moreover, four of the family carers were only recruited for dyadic interviews at the end of the fieldwork and did not attend sessions alongside their family member, due to Amy's Care membership. The table shares information on the number of observed sessions a participant was involved in, helping to identify the regular participants and carers.

Table 4.2: Details about Participants Living with Dementia

Pseudonym	Age	Gender	Pilot (P), Main (M), Both (B)	Sessions attended	Amy's Care	Living situation	Past occupation	Hobbies/Interests
Molly	71-80	F	B	17	N	With spouse and extended family	Clerical work	Dog walking, day trips, singing, dancing, the outdoors.
Isaac	81-90	M	B	17	N	With spouse	Engineer	Walking, painting/drawing, gardening, travelling, adventure sports, Amy's Care.
Carol	71-80	F	B	17	N	Living independently	Designer	Walking, art-making, reading/writing, maths, bus trips, singing, dancing, Theatre/Cinema, study groups, volunteering, museums, Amy's Care.
Eric	81-90	M	B	14	Y	With partner	Business/Management, Entrepreneur	Classical music, Water Polo (semi-professional and national level), non-fiction reading, Amy's Care.
Howard	81-90	M	B	13	Y	With spouse	Office worker	Coffee evenings, Amy's Care, spending time with family and friends.
Todd	81-90	M	B	13	Y	With spouse	Farming and craftsmanship	Craftmanship (hand-making raw horn walking sticks), walking, the outdoors.
Stanley	71-80	M	M	13	Y	With spouse	Joiner and Businessman	Gardening, building/craftsmanship jobs (designing and self-building narrowboat).
Emily	71-80	F	B	12	Y	With spouse	-	Walking, caravanning, travelling, church activities.
Harry	81-90	M	M	11	N	With spouse before specialist care	Farming and served in Army	Day centres activities, local village community café, sports (hockey), jigsaws, gardening, walking.
Joe	81-90	M	B	8	Y	With spouse	Manual labour and farming	Bowls, caravanning, gardening, Amy's Care.
Peter	81-90	M	M	7	Y	With spouse	Manual labour and farming	Jigsaws, dominoes, television, gardening.

Sam	71-80	M	M	6	Y	With spouse	Surveyor (and served in RAF?)	Walking, meeting family and friends, craftsmanship (designing and self-building narrowboat).
Noleen	81-90	F	M	5	N	With spouse	Civil Servant	Church activities, singing, sudoku puzzles, bird watching.
Clint	61-70	M	B	4	N	Residential/specialist care	-	Sports, armchair aerobics, libraries, social groups, swimming, Singing for the Brain.

Table 4.3: Details about Facilitators

Pseudonym	Age	Gender	Occupation and role	Hobbies and interests
Jenn	25-34	F	Co-Facilitator (founding member)/Freelance Creative Practitioner	Yoga, competitive fell running and running club member, cycling, outdoor pursuits, cooking/baking, art groups.
Rachel	25-34	F	Co-Facilitator/Theatre by the Lake Sales Manager	Wild swimming, fell walking, theatre, reading/writing.

Table 4.4: Details about Carers

Pseudonym	Age	Gender	Pilot (P), Main (M) or both (B)	Sessions attended	Care relationship	Amy's Care	Hobbies and interests
Ray	85-94	M	B	17	Spouse/informal carer	N	Walking, singing, dancing, local day trips, 'handy man' jobs around the house.
Jake	45-54	M	B	16	Professional carer	N	Walking, cycling, canoeing, painting with clients, museum trips, historical landmarks.
Anthony	55-64	M	B	13	Professional carer	Y	Poetry, dancing, art-making and art galleries, day trips, museum visits, games/quizzes, gardening, café visits, Amy's Care activities.

Laura	45-54	F	B	12	Professional carer	Y	Walking, cycling, singing in choirs, cooking/ baking, spending time with family.
Patricia	65-74	F	M	10	Spouse/Informal carer	N	Women's Institute member, reading groups, Parish Council member and member of Village Hall Committee, Keep Fit classes, craft groups.
Ben	85-94	M	B	6	Spouse/Informal carer	N	Walking, reading/writing, giving community seminars, <i>Setting the Scene</i> sessions.
Liz	45-54	F	M	5	Daughter/Informal carer	N	Dance classes, classical music, theatre, reading, cooking, spending time with friends and family, church activities.
Janet	45-54	F	M	3	Professional carer	Y	Singing in choirs, dancing, cycling, walking, jogging.
Natasha	25-34	F	M	3	Professional carer	N	Swimming, armchair aerobics with clients, shopping, bowling, lunch clubs, art clubs.
Cassie	45-54	F	M	3	Professional carer	N	-
Phil	45-54	M	M	2	Amy's Care manager	Y	-
Wendy	35-44	F	B	1	Professional carer	Y	Socialising, walking, drawing.
Agnes	65-74	F	M	0	Spouse/Informal carer	N	-
Deborah	75-84	F	M	0	Spouse/Partner	N/A	Circle dancing, gardening, village activities, socialising with close family and friends.
Peggy	75-84	F	M	0	Spouse/Partner	N/A	-
Olive	75-84	F	M	0	Spouse/Partner	N/A	Bridge, Art Society, Theatre, lunch clubs, painting.

4.4 Fieldwork Procedure: PAR Phases in Process

The overall *Setting the Scene* fieldwork process commenced in July 2018 and ran over a 12-month period, principally comprising data collections during participatory arts sessions and dyadic interviews in multiple locations. The first two months were dedicated to a pilot study, while the remainder comprised main fieldwork.

Altogether, nineteen sessions were observed and recorded between July 2018 and March 2019, until data saturation was achieved, in addition to two action learning groups, nine participant interviews, and four facilitator interviews. Considering the time constraints on the fieldwork sessions, participants' health care needs, and the COVID-19 pandemic in the latter stages of the project, full involvement in all stages of the research could not be effectively maintained; hence, I retained a flexible approach to participants' positions (Kindon et al., 2007). Rather than prioritise co-researcher status, the sensory PAR methodology sought alternative ways of capturing participant voices through rich data. Using the loose framework in Table 4.1, I relied on an 'in the moment' approach during fieldwork based on emerging findings, to help make informed decisions about when and how to conduct different forms of data collection within each phase. Insight on this began during Phase One's pilot study.

4.4.1 Phase One: Pilot Study

This stage covered a 7-week period comprising four session visits and two individual-based interviews. Action learning groups and dyadic interviews were not trialled due to limited participant availability. A smaller cohort of nine people with dementia, four professional carers and two family/spousal carers participated in trialling materials and fieldwork methods (Table 4.5). This phase was a fundamental part of the overall PAR procedure, creating the opportunity for participants and facilitators to contribute to the research design from the early stages. The data collected during this period was merged with the overall fieldwork data, hence it is important to consider Phase One alongside the succeeding research phases, rather than as an entirely separate pilot study.

Table 4.5: Phase One Timeline and Implementation

Phase One: Implementation Focus:	
All Weeks	<ul style="list-style-type: none"> Participant observations and fieldnotes.
Week 1	<ul style="list-style-type: none"> Information sheets and consent procedure. Tripod video recording with Sony Handycam camcorder.
Week 2	<ul style="list-style-type: none"> DEM-QoL and AC-QoL questionnaires. DSLR camera photography.
Week 3	<ul style="list-style-type: none"> Tripod/hand-held video recording with Sony HXR-NX100 camcorder.
Week 4	<ul style="list-style-type: none"> Tripod video recording with Sony HXR-NX100 camcorder. Dictaphone recordings.
Weeks 6-7	<ul style="list-style-type: none"> 1 hour interview with Carol in Keswick Museum. 1.5-hour interview with Ben in his home.

Throughout all of the pilot sessions, the chosen data collection methods were shown to complement each other in practice and participants shared positive feedback about their uses. Whilst the consent procedure ran smoothly, some participants without family support had difficulty recalling contact details, while others could not accurately specify their dementia diagnosis on demographic forms. Challenging questions were subsequently removed and an increased correspondence with Amy's Care on client details was required in succeeding phases.

Phase One resulted in the removal of the DEM-QoL questionnaire for people living with dementia (Mulhern et al., 2013) and the AC-QoL questionnaire for carers (Elwick et al., 2010). Although sitting outside of the overall methodological vision of this study, questionnaires were initially chosen in accordance with Theatre by the Lake's request for self-reported survey data. However, the small sample size was deemed insufficient for continuing the tools into the main study and discordance was observed while some participants were being assisted by carers to answer questions. Lack of agreement on responses put into question the validity of answers

and risked participant trust, which PAR aimed to uphold (Pain et al., 2007). Overall, it was deemed more effective to use 'in the moment' qualitative and visual methods.

Beyond this change, Phase One's emerging findings validated the methodological choices for the project, helping to inform their future implementation and resolve technical issues prior to the main fieldwork. The higher-quality, wide-framed Sony HXR NX-100 was chosen to capture primary unmanned visual data of the session space, with back-up support from a second unmanned Sony device. A high-quality Dictaphone was also employed to be later transcribed, replacing the poor camcorder audio feedback. Alongside a handheld DSLR camera, this variety was deemed effective in capturing objective and subjectively informed visual data to supplement participant observations.

Whilst participant observations were successful, 'in the moment' interviews were challenging to initiate, with some participants being distracted from their art-based interactions, contrary to advice in previous research (Camic et al., 2014). This method was therefore used selectively during Phases Two and Three.

Outside of sessions, early benefits of formal interview methods were observed with two participants. Firstly, interviews enabled carer Ben to share his perspective on *Setting the Scene*, reveal his life story and share important personal artefacts relating to his wife in the comfort of his home. Conversely, Carol's interview in a public space led to confusion, given that the familiar Keswick Museum location, chosen by the participant, was associated with other creative and voluntary experiences unrelated to *Setting the Scene*. Answers were initially muddled but became more focused during video elicitation sections, hinting at its potential for offering purposeful stimulation. Hence, Theatre by the Lake and participants' homes were prioritised for future interviews, alongside elicitation methods.

4.4.2 Phases Two and Three: Main Fieldwork

Phases Two and Three of the project were the main fieldwork stages, spanning October 2018 to July 2019, and coinciding with *Setting the Scene* seasonal blocks. This period offered enough time to fully immerse in the sessions and become familiarised with the programme, staff and participants. By splitting the main

fieldwork into two phases, the application of the PAR cycle could be aided; in this case, Phase Three could implement potential feedback received during Phase Two's observations and reflections. Table 4.6 below exhibits the timeline for the data collection procedures of Phases Two and Three, which will now be outlined in further detail according to 'observing' and 'reflecting'.

Table 4.6: Phase Two and Three Timeline and Implementation

Fieldwork Date	Data Collection and Implementation
Phase Two: Oct 2018 – Jan 2019	
Oct 2018: Planning	20-minute opening interview with theatre practitioners.
Oct 2018 – Jan 2019: Acting and observing	Nine ethnographic session visits , each comprising: <ul style="list-style-type: none"> • 1.5 hours of video/audio recordings. • 10-30 photographs. • Jottings and 'in the moment' interviews. • Post-session diary entries + facilitator de-briefings.
Nov 2018 – Dec 2018: Reflecting	Three dyadic interviews (two at the theatre, one in participants' home, 20-80 minutes each).
Dec 2018: Reflecting and planning	90-minute closing interview/mini action learning meeting with theatre practitioners.
Jan 2019: Reflecting and planning	1-hour, nine-member action learning group with visual elicitation.
Phase Three: Jan – Jul 2019	
Jan – Mar 2019: Acting and observing	Six ethnographic session visits comprising same data collection procedure as Phase Two.
Apr – Jul 2019: Reflecting	Four dyadic interviews in participants' homes and one in a public café (60-120 minutes each) and one 80-minute individual home interview with a carer.
Apr 2019: Reflecting and planning	Two interviews with facilitators and programme manager (60-80 minutes each).
May 2019: Reflecting and planning	1-hour, sixteen-member action learning group with visual elicitation.

4.4.2.1 'Observing': Sensory Ethnographic Methods

Participant Observation

A fundamental part of most ethnographic research, participant observation offered a flexible, reflexive and iterative method of active observation that greater attended to participants' points of view, researcher interpretations, thick description of events, and 'in the moment' experiences (Geertz, 1973; Atkinson & Hammersley, 1998; Thrift, 2008). Researchers often intuitively move between 'participant' and 'observer' roles, based on the context of their research, which enables flexible involvement in both data collection and participatory group activities (Preissle & Grant, 2004). By adopting participant observation in this project, experiences during *Setting the Scene* sessions could be both personally felt and recorded. Given the unpredictable nature of participant attendance, group size, researcher seating arrangements and activity types week by week, some aspects of sessions were highly observatory with my presence on the periphery (Figure 4.5), while others were more participative with less notetaking (Figure 4.6).



Figure 4.5: Observational.

Figure 4.6: Participative.

In Phase Two, six sessions were based in the Friends Gallery and three in Crosthwaite Sunday School, while Phase Three consisted of four Friends Gallery sessions and two at Crosthwaite. For each session, observations of people with dementia, carers, and facilitators began from the moment of arrival at the location until the room was emptied and tidied up. Particular attention was paid to mood, behaviour, multi-sensory participation, social interactions, engagement with objects/props, place-

based experiences, ideas around wellbeing potential, and other stand-out moments. Jottings were chosen as an efficient way of note-taking in the moment, capturing brief snapshots of unfolding events and my own multisensory and emplaced involvements (Emerson, Fretz & Shaw, 2011; Pink, 2015; Lönngren, 2021). Fieldnote jottings were written in anticipation of development into richer diary entries – either audio-recorded, typed or handwritten – immediately after each participatory arts session, while experiences remained fresh. These post-session write-ups were conducted in an available office space within Theatre by the Lake; hence audio diaries became an efficient way to promptly record data whilst based in a busy environment. These audio entries also took note of the unplanned and informal ‘de-briefing’ conversations that naturally occurred between the facilitators and I at the end of sessions, which were useful for PAR reflecting. Participant observations and fieldnotes were further supplemented and verified by audio/visual recordings of the same session contents but from different perspectives, to be explored further below.

Ethnographic, ‘In the Moment’ Interviews

Ethnographic encounters, or ‘in the moment’ interviews, are characteristically unstructured, impulse conversations that are otherwise challenging to arrange in advance (Skinner, 2013, p.29). Adopting this informal interview method enabled viable encounters to be established more naturalistically by participants, carers, or facilitators during sessions, rather than being initiated by the researcher alone. Focus was placed on conversation topics based on ‘what happens’ in the present moment (e.g. Dowlen, 2019); this included asking participants about what they were doing, thinking or feeling about activities. This method was, however, carefully used after the pilot study’s indications and was mostly entangled with other participant observation experiences recorded in jottings, fieldnotes, and audio data where possible. Occasional opportunities arose at the beginning and end of sessions where more substantial, one-to-one encounters could take place with available participants, but this varied week by week.

Visual Recordings: Video and Photography

Video, photographic and audio data are commonly advocated in contemporary ethnographic fieldwork, with influences from visual and sensory researchers

including Sarah Pink (2012; 2015; 2020). Visual recordings are not only useful for supplementing observations, but for capturing some aspect of how 'our social, material and sensory worlds' are encountered and embodied through non-visual senses, which is difficult to capture discursively (Pink, 2020: 6; Garrett, 2010).

Indeed, visual data can support more-than-representational and assemblage theories by capturing real-time encounters in their complexity (Hellman & Lind, 2017). At *Setting the Scene*, visual data from various devices captured a corporeal, multi-sensory richness that text alone lacked, demonstrating real-time interactions between participants; individual participant engagements with different facets of arts; and the spatial or material features aiding arts facilitation and participation.

Prior to the beginning of each participatory session, unmanned camcorders were set up on tripods at adjacent corners of the room, maintaining little or no interference throughout sessions to retain a perspective other than my own as researcher (Asan & Montague, 2014). A benefit of this was that a more complete frame of the *Setting the Scene* landscape could be recorded, capturing significant interactions that may have been overlooked during more selective, subjective participant observations (Wilkinson, 2002). This is relevant to *Setting the Scene*, where potential sessions of up to 26 people could become busy, loud, and distracting.

A handheld DSLR camera was worn throughout sessions for sporadic photography and shorter videos constituting noteworthy or personal moments. Although having greater bias, this 'observer-as-participant' visual data offered a supplementary, informed glimpse into interactions from within, unlike unmanned footage taken from the perimeter. Researcher photography was commonly taken during activity engagements, apprehending 'empirical hauntings' that are an important part of a researcher's ethnographic knowledge in process, not merely a visual depiction or claim of authenticity (Boyd, 2017, p.87). Photography from sessions aimed to enrich written dialogue and my own sensory, affective experiences.

An exception was during a 'Beauty and the Beast' intergenerational session that invited a classroom of children to the session, thereby limiting my data collection to selective fieldworks, for ethical reasons. Overall, the nineteen observed sessions accumulated 30+ hours of footage and 400+ photographs. The uses of the visual data

were threefold – for analytic purposes, for supplementing spoken and written word, and as data collection tools in reflective activities.

4.4.2.2 'Reflecting': Methods for Collaboration and Reflection

Dyadic and Formal Interviews

Dyadic interviews involve conversations with two participants, often between a family/professional carer and a person with dementia. They have been used in past dementia research to assist 'in overcoming dementia-specific communication issues' and foster a more supportive atmosphere than individual interviews (Morgan et al., 2013, p.1279). In this study, dyadic interviews were organised near the end of the timelines of Phases Two and Three, fitting with the 'reflecting' stages. These were typically conducted in participants' homes, with occasional interviews based in Theatre by the Lake and a local café (Table 4.6). Using a semi-structured interviewing approach, their content focused on three broad areas that were difficult to gather during participatory arts sessions: a) a general biographical overview of participants' life stories, relationships and interests; b) the perspectives of the carer and their experience of dementia; and c) participant perspectives and opinions of *Setting the Scene* participatory arts activities, with support from visual elicitation techniques.

Video and photo elicitation offered context-heavy, multi-sensory information to participants, to guide deeper conversation with less pressure on accurate memory recall (Henry & Fetter, 2012). Visual elicitation methods were incorporated into dyadic interviews (and action learning groups), for which I chose participant-specific content for each interview to stimulate personable discussions. Elicitation methods also supported participants to provide their own running commentary on footage being viewed, thereby bringing an 'in the moment' focus into reflective tasks to make them more approachable. This was normally introduced midway through interviews, when participants and partners/carers were settled and had shared in-depth biographical information. On one occasion during Phase Three, carer Patricia was interviewed on an individual level without elicitation, due to personal circumstances.

Shorter formal interviews, also engaging with visual elicitation, were conducted at the beginning and end of research phases with the facilitators and programme manager/CASE supervisor. Though initially unplanned, these helped to better grasp arts practices and intentions from facilitator perspectives, as well as to assist smaller reflective or planning conversations regarding emerging data and session designs.

Action Learning Groups

A key element of PAR studies, action learning groups can contribute towards reflective inquiry and collaborative learning (Marquardt, 2011). When designed effectively, they aid in fulfilling PAR's shared knowledge production and can be flexibly applied in dementia research using a supportive, strength-based approach towards making conversation more manageable.

Two action learning meetings were conducted at the end of Phases Two and Three, and were supplemented by the smaller reflective interviews with facilitators as part of the integral monitoring of the PAR methodology. Whilst Phase Two's action meeting was intended for December 2018, it was postponed until January 2019 due to limited theatre time and space during the Christmas pantomime season. This indicates the realities of conducting research with an organisation for whom other activities and priorities influence when people and spaces are available.

Phase Two's action group comprised myself as coordinator, the CASE supervisor, both facilitators, three participants with dementia (Carol, Isaac and Harry), one spousal carer (Patricia) and one professional carer (Jake). Phase Three's group was a larger base of Amy's Care members and staff, in addition to Ray, Molly and Ben. Each action learning group was a planned meeting after a specified participatory arts session, where lunch was provided and conversations were shared in the familiar programme venue. Although each meeting engaged with a different sub-group of participants, all members received at least one opportunity to participate in an action learning meeting during the fieldwork.

The key purpose of action learning groups was to discuss positive aspects of the sessions, suggest areas of interest or improvement, and form an actionable plan for future session designs. To encourage discussion on these topics, meetings were

based on emerging questions from the data, including those from my own ethnographic reflections, facilitator concerns, or hints from participants in the data. This content was enhanced by a PowerPoint presentation shown during meetings, consisting of visual footage and preliminary raw data from interviews and observations. As with dyadic interviews, utilising visual elicitation methods during action learning meetings usefully supplemented feedback and conversation in dementia groups. Feedback from the meetings was mainly positive and reflected satisfaction with the programme, with only minor comments about new table set-ups, experimenting with musical instruments, and preference for personal session themes. Whilst not leading to any major areas of improvement, the meetings offered opportunities and insights into participant views (see Section 9.4).

4.4.3 Phase Four: Post-Fieldwork

This phase of the research primarily involved the process of data analysis (see Section 4.5) but also intended to include a deliberative panel in March-April 2020 and a closing exhibition at Theatre by the Lake in Autumn 2020. Unfortunately, neither activity could proceed due to the national lockdown measures associated with the COVID-19 pandemic. The aim of the deliberative panel was to present preliminary data analysis to stakeholders and those involved in the PAR project, to consider their thoughts on the emerging findings and gain their input on contents that could be presented in a Theatre by the Lake transferrable toolkit. Whilst the action learning groups during Phases Two and Three offered opportunities for participants to give ongoing feedback on data collection, Phase Four was a significant stage in following through with the principles of PAR methodologies, where fieldwork had been completed and the data was more sophisticated. Whilst virtual alternatives were considered, Theatre by the Lake staff had been furloughed and participants lacked the necessary technological infrastructure in their homes. I offer further reflections on these missed collaboration opportunities in Chapter 9.

4.5 Data Analysis Approach

In choosing a suitable analytical approach, consideration was given to the multi-method perspective, participant sample, reflexivity, and the multi-disciplinary, collaborative nature of this CASE project. Given the disparate forms of qualitative and visual methods, an iterative thematic approach was deemed most effective at systematically analysing all forms of data and improving cohesion between them (Vaismoradi et al., 2016). Thematic analysis has been previously adopted in empirical dementia studies to better explore participants' experiences (e.g. Osman et al., 2016; Windle et al., 2020) or as a method to review broader dementia literature (e.g. Dowlen et al., 2018; Ward et al., 2020). It can attend 'within and across data' to the 'experiential' aspects of what participants 'think, feel and do' (Clarke & Braun, 2017, p.297). Subsequently, thematic analysis complements a more-than-representational stance by supporting both semantic (surface level) and latent (interpretative) coding processes, and establishing balanced inductive and deductive coding practices through data, theory and experience (Boyatzis, 1998; Braun & Clarke, 2006). This offers a greater opportunity for successful axial coding and the linkage of disparate forms of data (Allen, 2017). Since this project engages with visual data and acknowledges the common verbal communication impairments accompanying dementia, 'language heavy' approaches such as discourse analysis (Johnstone, 2018) and framework analysis (Gale et al., 2013) were discounted. While other analytical methods were considered for visual data – such as using a five-step qualitative method introduced by DeCuir-Gunby, Marshall and McCulloch (2012) – most methods shared steps or leant themselves to a thematic approach.

The thematic analysis was conducted in iterative steps influenced by Braun and Clarke (2006) and was achieved using ATLAS.ti Version 8 computer analysis software that supported visual data (Smit, 2002).

4.5.1 Data Familiarisation and Textual Data

This initial stage of data analysis was built into the PAR approach, given that interviews, action learning groups and elicitation methods required researcher immersion and data familiarisation throughout the PAR phases, to inform knowledge production. Furthermore, fieldnotes intentionally included researcher reflections

week by week in addition to observed accounts, which maintained awareness of theme emergence and flagged areas of importance in the project's development.

All data were then re-engaged with immediately prior to the coding process, starting with textual and audio data. Interviews, *Setting the Scene* session audio recordings, action learning groups, and research fieldnotes were transcribed verbatim using Microsoft Word, initiating the process of familiarisation. While transcribing, I made occasional memos accompanying data to signpost my early interpretations.

4.5.2 Coding

All of the data was coded using ATLAS.ti software, beginning first with textual transcripts (interviews, followed by session recordings and fieldnotes) before repeating the process for visual data (see Section 4.5.2.1). Initial semantic codes were inductively generated, in addition to latent codes that were occasionally informed by previously written memos. Maintaining separation between each interview transcript in initial stages ensured that codes emerged intuitively, resulting in a large coding bank that required gradual reviewing before and during the coding of session recordings and fieldnotes (see Appendix 6). This process was repeated and a final coding review completed before moving into visual data. As with transcript memos, a separate document was used during the coding process to log stand-out thoughts on patterns or ideas of theme emergence.

4.5.2.1 Visual Data Familiarisation and Coding Process

Previous studies have adopted thematic analysis for visual data, describing it as a polytextual approach with dependence on other forms of data to fully comprehend its content (e.g. Gleeson, 2012; Edmondson, 2013). Visual data analysis was therefore a distinct stage of familiarisation and coding that followed the completion of textual transcripts. Video and photographic data were too large in number to watch and analyse in full, leading to a specially designed systematic selection process before analysis. This process began with re-watching extracts of data, paying careful attention to items used in video elicitation. Coded transcripts were also cross-checked for flagged practical codes – such as where I coded 'video recording' or 'elicitation' – to highlight ambiguous text that depended on the contextualisation of visual content. Becoming familiar with unmanned camcorder footage was important,

since subtler events were captured that were not always picked up in researcher observations. In addition to elicitation and contextual factors, visual data were also selected for coding based on the following criteria: positive and negative participant experiences; demonstrating different art forms and modalities; displaying individualised and/or communal activity; changing behaviour and/or relationships of participants and partners/carers; and poignant moments from researcher, facilitator, or participant viewpoints.

A Microsoft Excel spreadsheet was created to log the visual data chosen for analysis, including reasons for choice and any anecdotal notes of initial interpretations (see Appendix 6). Since *Setting the Scene* sessions had been audio-recorded, transcribed and therefore coded in the textual data process already underway, the visual data coding process built upon the codes already generated and aimed to fill gaps. Focus was on cross-checking and deepening interpretations of events, as well as coding non-verbal gestures, expressions, movement and additional interactions.

4.5.3 Theme Searching and Reviewing

'Searching' and 'reviewing' are often considered as separate analytical stages (Braun & Clarke, 2014) but remain part of an iterative process of theme development. Upon completion of all textual and visual coding, theme development involved further cross-analysis and refinement of codes across all data. This was partially influenced by the emerging ideas within Word and Excel documents, but the process also acknowledged coding deviations or inconsistencies. Through a repeated process involving the grouping and networking of codes, 42 sub-themes were generated.

4.5.4 Defining and Naming Themes

There were initial difficulties in further refining the 42 sub-themes into overarching themes. This was primarily due to the complexity of the codes within sub-themes, the different sources they were derived from, and the potential for some codes to be placed under multiple themes. To aid theme refinement, it was helpful to consider how the sub-themes would tell a narrative as expressed through the empirical thesis chapters. Subsequently, four final themes were defined (Table 4.7). A visual example of theme development – focusing on the 'Multi-Sensory Therapeutic Landscapes' theme – is displayed in Appendix 6, offering further transparency to the analysis.

Table 4.7: List of Themes and Sub-Themes

Themes	Sub-Themes
The Setting the Scene Model	Setting the Scene model features; Role of facilitators; In-the-moment; Theatre-based activity; Visual arts and craft activity; Dance and movement; Music-based activity; Games; Performances.
Attention, Communication and Participation in the Arts	Materiality; The Senses; Humour and laughter; Verbal communication; Non-verbal communication; Types of participation; Dementia symptoms/behaviour; Positive emotions and responses; Negative emotions and responses; Body and embodiment; Physical health; Storytelling/creative writing.
Individuality and Relationality	Family relationships; Intergenerational; Personal changes; Identity and individuality; Life stories; Individual skills; Emotional and self-expression; Friendships; Professional carers; Roles, experiences and responsiveness of carers; Health and care.
Multi-Sensory Therapeutic Landscapes	The natural landscape; The built landscape; The social landscape; Temporality; Living well with dementia; Creative wellbeing; Mental health.

4.6 Quality, Reliability and Validity

Establishing quality within ethnographic, qualitative or multi-methods research is often more complex than in (post)positivist quantitative data, which typically relies on standardised, control measures to maintain validity, reliability, objectivity and generalisability (Flick, 2008). The credibility of context-specific, smaller-scale ethnographic research is achieved through transparency of methods, thick description, participant feedback and researcher immersion in the fieldwork setting (LeCompte & Goetz, 1982; Mays & Pope, 1995). While the study findings do not aim towards generalisability or objectivity, the thesis intends to deliver transparency and potential transferability (Cope, 2014). Considering these requirements in further detail, the following section explores the strengths and limitations of the multi-methods design adopted in this project, and also explores the decision-making behind optimising authenticity and integrity of the findings.

4.6.1 A Multi-Methods Design: Triangulation and Validation

Whilst some discussion on the effectiveness of methodology and methods will be provided in Chapter 9, it is also necessary to discuss the broader multi-methods design – chosen in line with the principles of PAR and the needs of participants living with dementia – and how multi-methods' strengths and limitations impact research quality.

The multi-methods design endeavoured to provide wider data sources that would have greater potential to accentuate participants' diverse voices and research contributions (Mertens, 2012). A strength of this was in the ability to optimise each individual's contribution to the research project, by focusing on the methods that best reflected their own communicative strengths. However, this inevitably meant that some methods – particularly interviews and action learning groups – were less insightful for some participants than others, particularly when researching dementia experiences that involve communication difficulties (Henry & Fetter, 2012). In projects with a person-centred focus, additional time investments are required to trial methods for different participants, and to build professional yet insightful relationships with each person, to know how best to proceed with, and personalise, their involvements.

Following the influence of recent participatory arts research (e.g. Chauhan, 2018; Tan, 2018; Tseklevs et al., 2020), visual methods were chosen as an important element of the multi-methods design, providing a means of capturing participants' more-than-verbal emergent experiences during art-making and socialising (Shannon-Baker, 2016); engagements that could not be effectively gathered by using solely auditory or observatory data collection methods. Indeed, the visual dimension also had practical benefits, given that it enabled the *Setting the Scene* programme's multi-activity nature to be better captured through different data collection methods, be it a multi-sensory embodied dance activity, the audio of a storytelling segment, or the capture of visual art-making. Collectively, the visual, sensory and textual data sources making up the multi-methods design of this project provided a comprehensive understanding of *Setting the Scene* and its participants, capturing experiences through different channels and activities (Carter et al., 2014).

The leading strength of using a multi-methods design was that the shortcomings of one method could be counterbalanced by the strengths of another (Shenton, 2004). Although the choice of a multi-methods design was primarily based on the appropriateness to the research scope and the accessibility to people living with dementia, it subsequently led to increased validity through triangulation. To exemplify this, the use of multi-sensory and richly descriptive visual data enabled written and felt researcher fieldnotes to be better supported with visual evidence. On the contrary, unmanned visual data recorded during *Setting the Scene* sessions was also reliant on 'in the moment' textual data and audio recordings, which offered more focused content that could not be captured on the camcorder data. While each medium recorded the same unfolding *Setting the Scene* sessions, any interpretations remained ambiguous without the context gained from other sources. Outside of the sessions, data triangulation was extended to the action learning groups and interviews, given that their contents were mostly guided by the gathered video and photographic data (Henry & Fetters, 2012), as well as the emerging fieldnotes and participant observations. Together, all of these data sources had dependency on each other to provide conversation stimulus, an in-the-moment focus, and an enhancement to the emerging knowledge sought for an effective PAR study.

Further research validation was possible through interviews and action learning groups outside of *Setting the Scene* sessions, which gave balanced acknowledgement to the viewpoints of the researcher and the researched. This ensured that participants could express their thoughts in a supportive manner without requirements to read challenging research material. With a varied participant sample, feedback from discussions could aid in scrutinising my own observations as researcher and contribute to a greater data source triangulation by considering different interpretations (Carter et al., 2014). The central feature of participatory research approaches – to seek and uphold the voices of participants – therefore had strategic secondary benefits for improving the validity and reliability of findings.

In addition to the data collection methods, the chosen thematic analysis approach fed into data triangulation, given that it integrated all forms of disparate data and incorporated the findings into overarching themes. While the presence of outliers

was minimal, individual differences were important to recognise given the project's small sample size. For instance, Clint had Down's Syndrome, Emily progressed into advanced stages of dementia, Harry had adverse negative responses to certain stimuli, and Carol stood out for her flamboyancy and uninhibited nature. Nevertheless, while contributing to 'further analytic thinking', all participants – outliers or otherwise – offered an individuality that benefited data transparency and participant subjectivities in dementia contexts (Bazeley, 2009, p.12).

Whilst multi-methods have been considered for their wide-ranging benefits in the current study – in terms of research scope, participant suitability, and triangulation – a prominent drawback is in the management of large and disparate data sources, during and after fieldwork. Firstly, gathering multiple data sources simultaneously requires advanced planning and ongoing multi-tasking, which can risk a lack of researcher attention in any single data collection source whilst in the midst of fieldwork. It is, however, important to recognise that this drawback is predominantly resolved by the richness and detail of data evidence captured through these multi-method experiences (Hellman & Lind, 2017; Pink, 2020). Secondly, in the case of this project, greater time was required to negotiate the uses of video and photographic data, given that large quantities were gathered but only small selections could subsequently be analysed. Whilst the integrating nature of thematic analysis eased the challenge of working with complex qualitative and visual data, an extended stage of familiarisation was also required to work with the data confidently. Nevertheless, the in-depth insight gained during this extended process eventually led to greater validation and reliability of the overall findings (Yin, 2003).

4.6.2 Researcher Reflexivity and Scrutiny

While fieldnotes were primarily designed to capture 'in the moment' impressions of sessions, they also contained thoughts on the benefits and shortcomings of the data collection methods being used. By building on notes from previous sessions, I could better attend to emerging themes and maintain awareness of my own continuing actions. Moreover, the smaller participant sample strengthened the ability to examine how accurate, authentic and valid the research process was in capturing behaviours and individualities. I was able to develop better relationships with

participants as the research progressed – both through observations and discussions – that fed into a constructive, continual assessment of my research conduct. This reflective and reflexive content created a critical impression of what I was gathering and the method used to gather it. This content was also used to frame peer scrutiny, where topics emerging in the fieldwork informed meetings with supervisors and Theatre by the Lake staff. Thus, conversations could be constructive, where multiple voices and different perspectives could contribute to refining my research approach.

4.7 Ethical Considerations

Prior to fieldwork, the project received initial approval in 2018 from the Lancaster University Faculty of Health and Medicine Ethical Review Board (see Appendix 5). Further ethical amendments were approved for the addition of pilot research, photo and video release forms, and data storage over the COVID-19 pandemic. Numerous ethical issues were considered in advance of fieldwork that are common in PAR, ethnography, or dementia research (Lofman, Pelkonen & Pietila, 2004). These issues included receiving informed consent; using visual data; confidentiality and anonymity; the role of the researcher; and research ownership.

Due to the potential of complications during the consent procedure for people with dementia, it was important to safeguard their interests alongside other potential participants. During my doctoral studies, I received training and certification on the Mental Capacity Act, to become better informed on ethical conduct for people living with dementia. According to the British Psychological Society's 'Code of Human Research Ethics' (2014), people living with dementia – depending on their symptoms – are often considered as having decreased capacity. This can, at times, lead to consent being given or confirmed by another person who is 'well-placed to appreciate the participant's reaction' (p.17). This is more applicable to those with moderate symptoms, while this study was focused on earlier dementia stages.

Whilst I endeavoured to establish as much independence as possible for participants during the consent procedure, proxy consent and confirmation from family was required in isolated cases. To verify consent throughout fieldwork, participants were also frequently asked for confirmation before photographs or interviews, to ensure that they were aware of the research and were comfortable being recorded.

Anonymity issues can often arise from visual and audio recordings of participants, which contain stronger personal identifiers than other data. Economic and Social Research Council guidelines state that photographic and video-based ethical issues are specific to the research context and preferences of individual participants (Wiles et al., 2008). It is also important to consider visual data not only for participant consent and approval, but for 'the potential harm that the materials might cause' to the people and relevant organisations (Pink, 2020: 64). These ethical issues became more transparent as the research project progressed, leading to the development of a separate photo and video release form in line with the Data Protection Act (Parry & Mauthner, 2004). All participants were given an option to accept or decline the use of their images and videos in research publications and outputs. In this project, all participants agreed to have their images used, with one participant (Noleen) declining the use of video and her daughter (Liz) asking to avoid use of her images in online or public settings. Any new *Setting the Scene* members who joined too late in the research to participate were kept out of camera frames during recording or were pixelated in chosen visual data. As previously mentioned, verbal consent was commonly sought prior to taking photographs during fieldwork, where possible.

My positionality as researcher needed to be ethically determined, given that ethnographically informed PAR requires close proximity to participants (Dawson, 2010). As discussed in Section 4.4.2.1, the aim of adopting an 'observer-as-participant' position had the benefits of retaining researcher status whilst participating in the field site alongside participants (Hammersley & Atkinson, 2007, p.82). This eliminated many potential ethical issues by maintaining transparency of my role. However, attention needed to be given to the possibility of ethical issues persisting after fieldwork completion. Discussed by Kara (2015), transformative methodologies like PAR can call into question the expectations of participants to continue their newly formed relationships with researchers. A departure plan was therefore created, to maintain *Setting the Scene* visits on an informal, less regular basis and to present a final exhibition to showcase participants' achievements. Both strategies were impacted by the COVID-19 pandemic, leading to a more abrupt discontinuation of contact than initially hoped.

Lastly, owing to its collaborative ‘participatory nature and democratic approach’, it is important to consider research ownership in action research projects (Lofman et al., 2004, p.338). Whilst understandings were met between Lancaster University and Theatre by the Lake from the outset, questions were raised during fieldwork by the programme facilitators regarding their personal roles and acknowledgements in *Setting the Scene*. This was due to their designing and development of the programme, but an ambiguity regarding the intellectual property and their research involvement.² This highlighted ownership issues internal to the *Setting the Scene* programme rather than between Lancaster University and Theatre by the Lake. Nevertheless, it was agreed between facilitators to use their real names in this thesis, to offer some acknowledgement of their contributions to *Setting the Scene*.

4.8 Summary

This chapter has outlined how the integration of participatory action research (PAR) and sensory ethnography can offer an iterative and collaborative process to the study of multi-sensory, ‘in the moment’, wellbeing engagements during participatory arts, while living with dementia. With a drive to better support the participation of people with dementia in research processes, the chosen ethnographic, sensory and visual methods were adopted to capture the multiplicity of communication and the importance of accessibility. This chapter primarily outlines the practicalities of the chosen methodology and offers an in-depth overview of the data collection methods, PAR phases, and analysis approach. It also aims to complement Chapter 3’s more-than-representational theoretical contribution, by attending to assemblages of wellbeing through the capturing of embodied, creative, socio-cultural and more-than-human interactions. While not without its challenges in its application to dementia research, a sensory PAR approach encourages inclusive and strength-based research participation for all associated participants. The following four chapters of this thesis now demonstrate the empirical findings that emerged through the process of sensory PAR fieldwork at *Setting the Scene*.

² As a Freelance Creative Practitioner, Jenn has since worked across multiple Cumbrian sites, programming other activities comparable to *Setting the Scene* (e.g. Tullie House, 2021). These are acknowledged as her own creative work with no associations with Theatre by the Lake, contrasting with how ownership has been acknowledged in this CASE project.

Chapter 5: The Impact of *Setting the Scene*'s Multi-Art, Multi-Modal and Thematic Design on Participant Engagement

5.1 Introduction

Influenced by therapeutic landscapes, more-than-representational literature and relational wellbeing, the following empirical chapters draw on discursive, visual and sensory findings from this study's fieldwork, to better understand how participatory arts can impact the wellbeing of participants. Notably, *Setting the Scene* facilitators did not distinguish between carers and people with dementia during sessions, leading this thesis to explore their engagements collectively; however, clear labelling of participant roles has been used throughout for the purposes of the research. The narrative of these empirical chapters reflects how data emerged during the fieldwork period: firstly, the immediacy of the art activities and creative approaches used; secondly, how participants communicated and responded to the arts activities; and thirdly, other human and non-human features that facilitated arts engagement, wellbeing, communication, and relationality at sessions.

Chapter 5 begins by exploring the impact of the *Setting the Scene* programme design, specifically considering the three core multi-art, multi-modal and thematic components of the model. It became apparent during fieldwork that the sessions fused different arts-based activities together, meaning that to explore the contributions of singular art forms would be challenging and counterproductive. The programme is subsequently addressed through a holistic perspective, considering the interconnectedness of the art forms and how they were comprehended through 'in the moment' participant experiences. Secondly, the thematic design of sessions is explored through fieldwork examples, to determine how contextual, meaning-entrenched topics may promote a more person-centred focus. Thirdly, this chapter examines how the multi-modal set-up of sessions – comprising a mix of individualised, paired or communal group activity formats – fostered different engagement types and drew on participants' wide-ranging strengths. After broadly outlining these *Setting the Scene* features, I draw on three participant vignettes to

demonstrate how the programme's components differentially facilitated wellbeing and participation over the course of session attendance. Through the voices of people with dementia, carers and facilitators, the chapter ultimately explores the extent to which *Setting the Scene* promotes wellness and togetherness through creative means, and how the underlying processes of participatory arts can influence selfhood, belonging and achievement whilst living with dementia.

5.2 Behind the Scenes of *Setting the Scene*

Before exploring participant experiences, it is important to consider the design and intentions of Theatre by the Lake's *Setting the Scene* programme. This model of participatory arts was principally focused on the participants and their interests, to ensure that the activities were approachable and meaningful. The programme could be broken down into three core components of design – multi-art, multi-modal, and thematic – which influenced how the facilitators organised the sessions in advance. Nevertheless, session plans remained open and flexible, embodying an overarching 'in the moment' approach and 'no right or wrong' attitude to creativity:

'A lot of what we do... it's not 'doing to', it's 'doing with'... we create an equal playing field and [listen to] some of the things, you know, words or expressions that come out, if you really listen to people... and then it's our job to create something with that material.'

Jenn, interview, 11th October 2018

This collaborative and non-judgemental approach – achieved through active listening and improvisation – was important for encouraging participation without feelings of alienation, apprehension, or incompetence. This was acknowledged by participants during action learning meetings, who attributed their positive experiences at sessions to the efforts of facilitators Jenn and Rachel. From the outset, then, it is important to be mindful of the 'in the moment' roles played by facilitators during participatory arts, in addition to their 'behind the scenes' decision-making in the run-up to sessions (Scholar et al., 2021). To gain greater insight into how the facilitation

and design of the programme played out during sessions, the following section will unpack the *Setting the Scene* model according to its three core components.

5.2.1 A Multi-Arts Participatory Programme

Setting the Scene sessions were characteristically ‘multi-arts’ in nature, commonly comprising drama, music, dance, movement, storytelling and creative writing, with threads of game-playing, comedy and conversation tying them together. These multi-arts activities were incorporated into weekly themed sessions – such as ‘The Sound of Music’ or ‘The World of Work’ – forming familiar or relatable contents for participants (see Section 5.2.2). Whilst each weekly session covered a different amalgamation of activities, a consistent feature throughout was a welcome of refreshments and conversation, to ease participants into the environment as they arrived (see Figure 5.1).



Figure 5.1: Refreshments and conversation upon arrival.

Similarly, each session endeavoured to close with a ‘sing-along’ activity, where elements of music, dance and sound were incorporated. Beyond these staple activities, however, the scope of sessions was broad and rich, using multi-art and multi-sensory elements to complement and enliven the story or theme of the particular session. This can be demonstrated in fieldnotes from a ‘Country and Western’ themed day:

The session plan for today shows multiple activities that may make an appearance during the course of the session: a greetings game with 'howdy' and 'yee-haw' exclamations, accompanied by non-verbal hat-tipping and thigh-slapping; a movement-based storytelling game, where participants will be asked to write a satirical, 'misfortunate incident' on paper and throw it into the spittoon; a Country and Western song-writing game, made up of the previous spittoon entries; a line dancing activity guided by the facilitators; a storytelling activity inspired by 'Wanted' posters set out on the table and encouraging the sharing of participants' imaginary crimes; and a sing-along finisher of John Denver's 'Annie's Song' and 'Take Me Home, Country Roads'.

Fieldnotes from 'Country and Western' session, 7th February 2019

The above session plan summary (see Appendix 1) illustrates how different mediums, senses and art forms were merged within a sample session and could not be effectively considered in isolation. In this case, verbal communication was complemented with non-verbal exchanges; movement informed elements of storytelling; storytelling activities were linked with drama and table props; and comedy and creative writing generated meaningful content for music and singing activities. Whilst being multi-arts in nature, the 'Country and Western' session plan nevertheless leaned towards story-based and verbal content to draw the activities together. Although on a surface level this may contradict concerns about the verbal communication challenges of people living with dementia (Hubbard et al., 2002), the 'in the moment' nature and content of sessions allowed for a greater level of discourse between participants and facilitators. While reviewing a conversation-based activity about inventions, which took place during a 'Chitty Chitty Bang Bang' session, the facilitators and I discussed ways of maintaining the focus of participants to achieve more effective storytelling:

Jenn: ...the first one was about inventions, and I felt like I didn't want to put everybody on the spot, so then I offered it out. But I find that hard to facilitate because... people won't come forward, generally-

Rachel: -no, no-

Jenn: -so then you do prompt and you say 'oh what do /you think about this?'...
But it sometimes feels like it's quite disjointed and a bit haphazard, whereas
when you go around the circle... I think people keep their focus /more?

Facilitators 1 and 2, interview, 6th December 2018

By engaging with storytelling and verbal activities within sessions, facilitators demonstrated that they did not assume skill loss from their participants with dementia. Instead, the group of diverse participants were treated equally through a strength-based lens, where both people with dementia and their carers were invited to contribute. This was made possible by the 'in the moment' approach applied during *Setting the Scene* and the sensitivity of facilitators to this; they intuitively monitored the affect or atmosphere of the room and subsequently gauged how to best proceed with activities as they unfolded. This was further exemplified by activities inspired by theatrical productions – such as those produced for the 'Jeeves and Wooster' week – that reflected theatre's culture of improvisation. *Setting the Scene* exemplified ways of interpreting theatre through props and multi-arts:

For today's Jeeves and Wooster theme, a name game was developed based on the theatre production, covering the surface of the table in sheets of coloured paper that had printed first and last names on them, all deriving from the original production. These were face down on the table, with labelled numbers on show. Participants had to roll coloured dice on the table that corresponded with the numbered and coloured pages. When a number was drawn, the page was flipped around for everyone. The aim of the game was for everyone to be given a quirky character name that they could then choose a costume or prop for. This was well organised, unique and accessible, given that everyone was able to take a turn.

Fieldnote extract, 'Jeeves and Wooster' session, 15th November 2018



Figure 5.2: Visual sequence of 'Jeeves and Wooster' character name game.

In the above fieldnotes and visual sequence of Figure 5.2, the unfolding events of the activity took form in multiple ways: through the connections made between participants as they passed dice to each other and watched one another around the table; the touch of the dice in their hands; the proprioception and sense of movement when throwing the dice; the visual and aural information while the dice rolled along the table and landed on particular numbers; the touch and sound of the pieces of paper being turned; the names being read out loud; the repetition of the words around the room and the affective laughter spreading; and finally, the freedom and combined senses of sight, sound, touch and smell when choosing which costume items would inform their character name. Within this one unconventional creative activity, elements of storytelling and verbal communication were informed by the accessible language of touch, the pre-determined words and names lining the table, and shared laughter, demonstrating that verbal content can be grasped in multi-faceted ways without the need to speak. Whilst forms of communication will be explored in-depth in Chapter 6, it is useful to note in the early stages that there was active verability and storytelling in *Setting the Scene*'s overall multi-arts scope.

While some activities embraced a dominant art form – such as music during sing-along activities or conversation during the storytelling activities – the programme as a whole utilised a multitude of creative mediums that were informed by participants' interests and individualities over time, rather than intended from the outset:

'...it just very naturally developed into this kind of multi-arts dimension... We decided on a framework of doing some bits of movement and singing, but it was... geared more to theatre at the start. But it soon then morphed... I think a lot of it is the way I like to work as well, adapting to the people that you're working with, so... we weren't too prescriptive about what we wanted to do...'

Jenn, interview, 18th April 2019

Setting the Scene's 'multi-art dimension' was informed by the engagements of participants in the 'here and now', but also sought to accommodate and adapt to the unique skills, interests and life experiences of participants within its design. This highlights the importance of being person-centred in the facilitation and designing of art approaches for people living with dementia, in addition to being attentive to the information shared by participants, whether stimulated or spontaneous. The programme's person-centredness was discussed by carer Ben, who continued attending sessions as a lone carer after his wife passed away:

'The thought that goes into it and the things that are produced, are all based on the idea of... seeking for a different aspect... reaching a different part of a diverse variety of people in a group... at different stages of their lives and different levels of experience.'

Ben [carer], action learning group, 10th May 2019

As highlighted by Ben, *Setting the Scene* aimed to connect with people who have varied life experiences and stages of dementia, finding commonalities within a 'diverse' group of differences. With this person-centredness in mind, my observations suggest that whilst being categorised as multi-arts, the programme is

not designed to be art-centric or outcome-oriented, but rather to promote wellness and positive affect as felt *through* the arts:

'...really the activities are secondary. It's who's in the room, it's how they're feeling, it's the atmosphere you're creating, it's... just that feeling of wellbeing and making sure that everybody is feeling... welcomed and safe... enjoying themselves and having a nice time.' **Jenn, interview, 18th April 2019**

Jenn's interpretation of wellbeing as a '*feeling*' again reflects the 'in the moment' approach integral to the programme and the reliance of participatory arts on the social behaviours and engagements of participants. This suggests that facilitators perceived the wellness of their participants through the programme's atmosphere, which was the result of utilising the arts for positive social and relational experiences. Hence, *Setting the Scene* aspired to be felt and experienced as a space of wellness, connectedness and enjoyment, indicating an understanding of relational wellbeing in arts practice (Slaby, 2019). This was creatively constructed not only by the variability afforded by the multi-arts approach, but by the overarching themes that informed each *Setting the Scene* session.

5.2.2 Thematic and Topical Components

According to facilitator Rachel, the planning of sessions was often informed by chosen topics or themes, rather than choosing themes according to the art form:

'A lot of them have shared things from when they were younger and we often try and pick themes... that make people talk about their school days... their wedding days... things that they'll actually have quite a lot in common with, and it'll have been at a similar time.' **Rachel, interview, 6th December 2018**

When discussing *Setting the Scene*, facilitators and participants often reflected on the thematic components of sessions more than on the activity or art form utilised. Sam demonstrated this during an art-making activity when I asked him whether he enjoyed his time at *Setting the Scene*:

Sam: Yes, yes. We've... been here once or, or twice before, haven't we? [turns to Joe while saying this].

Joe: Well I've been-

Sam: -/all on different themes.

'Beauty and the Beast', 29th November 2018

Similarly, insights were made by talking to carers about stand-out session features:

*'It's lovely to come through the door and think 'what's the theme for today?'
Sometimes it's obvious, sometimes it's not...'*

Ben, interview, 13th September 2018

The aspect of *Setting the Scene* that Sam recalled from previous weeks was the theme, whilst Ben suggested that session themes were the first things to be encountered when entering the space, rather than the art forms to be engaged with. This is because a theme – though often abstract in concept – can be made tangible and visceral through the immediate interaction with the facilitators, objects, props, costumes and any music or themed dialogue used by the facilitators to greet participants (Figure 5.3):

Jenn: /Hello! /Welcome to the /rodeo! [Background music continues to play as participants arrive from Amy's Care].

Female participant: Woo hoo!

'Country and Western' session, 7th February 2019



Figure 5.3: Participants in fedora hats arriving at 'Country and Western' day.

As displayed in Figure 5.3 and the accompanying text, the multi-sensory, material, meaning-saturated and affective contents of the programme 'set the scene' for participants' arrivals and contributed to their 'in the moment' responses throughout sessions (Müller, 2015).

All *Setting the Scene* sessions observed during fieldwork began with personal, inviting conversations linking to the session theme, initiated by the facilitators and including participants looking at objects around the table. As with other members, Ben often commented on costumes worn by both facilitators, guessing which era they were from (Figure 5.4).



Figure 5.4: Participants discussing facilitator dresses during 'Weddings' session.

The corporeal nature of objects made the session theme visible and tangible, in turn impacting how individuals with dementia and their carers connected, reflected and recalled session contents, as demonstrated by Ben and Sam. Whilst session themes could influence individual experiences of *Setting the Scene*, they also connected participants to the wider community. Themes could be inspired by Theatre by the Lake's productions, including Beauty and the Beast (Figure 5.5), broad topics like 'school', 'marriage' and 'careers' (Figure 5.6), or themes on local 'Cumbrian' culture.



Figure 5.5: [Left] 'Beauty and the Beast' collated artwork.

Figure 5.6: [Right] 'World of Work' theme.

Linking sessions to the wider Theatre by the Lake and Keswick communities gave participants a greater sense of belonging, purpose and inclusion as a member of the theatre, particularly for those who had a long-standing connection to the venue prior to their dementia diagnosis, such as for Harry and his wife Patricia:

Patricia: Because we come to the theatre, quite a lot. Yes, yes, we are Friends of the theatre, so we do come a lot.

Harry: Yes, yes.

Harry and Patricia, interview, 6th December 2018

Whilst occasionally comprising themes influenced by Cumbria or Theatre by the Lake's productions, most thematic choices were person-centred, based on participants' personal interests or on topics that most participants commonly shared a link to. Broader themes, such as 'The Sound of Music', were adapted to be inclusive of all participants in attendance. During this themed session, participants were invited to draw their favourite things, while the song by the same name from the production was played in the background:

Participants were given options for the mediums they used to reimagine their favourite things. Eric used a ballpoint or ink pen, others used chalk, and Ray used glitter items to create an abstract piece... What I thought was striking was that Eric got involved this time. In previous art-making, he would sit back and pick up a book from the table, almost like a distraction mechanism... He drew a boat, and whilst simple and minimalist, was well drawn and had an accompanying story about his own boat when he lived in Australia. This shows how the theme can make a difference to how people engage in the activity.

'The Sound of Music' session, 11th October 2018

Eric's 'in the moment' art-making (Figure 5.7) contrasted to his usual avoidance of visual arts. Likewise, Harry took the initiative to draw his passion for hockey, capturing the motion of scoring (Figure 5.8). This person-centred interpretation of a theme within a group setting offered multiple benefits, by offering participants something they were personally interested in; giving people an opportunity to learn more about others in the group; and feeding into the facilitators' intimate understandings of participants to inspire future content.



Figure 5.7: Participants drawing their favourite things.

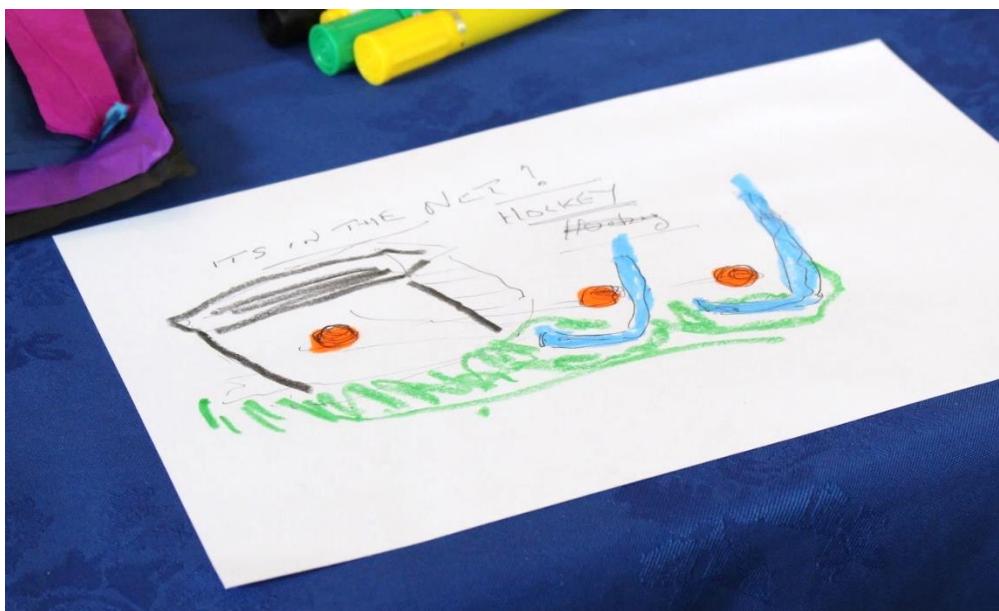


Figure 5.8: Harry's 'It's in the Net!' Hockey artwork.

Another person-centred and improvisational example took place during a 'Beauty and the Beast' intergenerational session, where a group of schoolchildren joined in. A name game, designed to introduce oneself to the rest of the group, offered insights into people's personal interests and their attitudes to self. These were documented in real-time fieldnotes during the session:

Peter, the newest member, needed encouragement from a carer – ‘My name is Peter... and I like driving’ (referring to driving diggers).

Sam: ‘I am an accident – pass it on to someone else’.

Joe: ‘My name’s Joe and I used to like half past 4’ (referring to hometime from work).

Eric: ‘My name is Eric and I like to play water polo’.

Ray: ‘My names Ray and I like singing and dancing’...

‘Beauty and the Beast’ session, 29th November 2018

These opportunities for person-centred interaction were able to inform how the facilitators personalised future sessions and subsequently how responsive participants became over time. An overarching person-centred approach required openness and freedom to allow participants to engage with whichever features of a theme or activity most appealed to them. While both the art form and thematic content had an influence over this, the mode or format of the activities was the third important component of the *Setting the Scene* design.

5.2.3 The Multi-Modality of Sessions

When describing the sessions as multi-modal, I refer to the format of the activities that comprised varying levels of individual, paired, smaller group-based, and larger communal activity designs. Since the central premise of participatory arts is to connect the creative with the social in a group-based setting, it could be presumed that a session would be wholly communal. Yet, *Setting the Scene* encompassed a mix of group-led or performative activities as well as more personal, individual opportunities for participants, situating the programme with a balance between individual and relational wellbeing potentials. With this in mind, ‘participatory’ elements could be social, creative, or both.

Activities with a group focus tended to have greater elements of verbal communication – including storytelling and games - and frequently involved following instructions – including music or dance (Figure 5.9).



Figure 5.9: Group/communal dance activity.

Individualised, paired, or smaller group activities tended to be arts and crafts-based (Figures 5.10 and 5.11), with some occasional creative writing opportunities.



Figure 5.10: An individual or paired art-making activity.



Figure 5.11: Recreating interpretations of Van Gogh's 'Starry Night'.

There was, however, no prescriptive 'rule of thumb' between art form and mode, given that activities were formatted differently throughout the programme. An example was in how art-making and crafts were differentially adapted across sessions, including individuals drawing artwork inspired by Van Gogh's 'Starry Night' (Figure 5.11); pairs working together on technicolour dream coats (Figure 5.12); and larger groups making 3D collages (Figure 5.13).



Figure 5.12: Paired dreamcoat-making. **Figure 5.13:** 3D collage group work.

Smaller artworks were also occasionally collated to create one larger piece, combining individual contributions to a wider communal outcome. This was well-defined during 'The Romans and Hadrian's Wall' session, whereby sections of 'wall' created by small groups were interlinked to form one collated linear wall piece that the facilitators paraded around the room in an improvised performance to end the session (Figure 5.14):

Jenn: Shall we do a little parade with it?

Liz: That looks perfect, see the part you drew? It links in with that one really well.

Noleen: Aw good, good.

'The Romans And Hadrian's Wall' session, 14th March 2019



Figure 5.14: Parading Hadrian's Wall

The sharing and 'performance' of the artwork, comprising the recognisable creations of individuals, created an opportunity to praise others, boost their sense of accomplishment and reaffirm their membership in the *Setting the Scene* community. This contributed to positive interactions, exemplified by daughter Liz's praise of her mother Noleen's input to the activity.

It could be said that all participants were performing at some level in the social landscape of *Setting the Scene*, but more conventional performative or expressive elements were made possible through different art forms. These included

spontaneous individual performances – be it singing a harmony in a room of melodies or changing one's accent to assume a new character during storytelling – or something prearranged and group-based – such as turn-taking drama activities. An activity embodying both improvisation and turn-taking was included in 'Country and Western' week, where participants were each invited to theatrically greet one another (Figure 5.15).



Figure 5.15: Stanley's [far right with raised arm] positive response.

Whilst some participants required more guidance than others, members like Stanley roused the room with their own enthusiasm and interpretations of tasks:

Rachel: *What I want you to do is very simple. We're going to turn to the person next to us, and we're going to say 'howdy how' [laughs].*

[Some group laughter].

Rachel: *And they're going to go, 'yee ha' ...*

Stanley: *[Loud enthusiastic call with raised arm; see Figure 5.15] /Howdy /how!*

[Loud cheers, laughter and applause from the group].

Jenn: *Stanley has already been in the local saloon, having a few jars I /think- [group laughter].*

'Country and Western' session, 7th February 2019

Stanley's affective and enthusiastic engagement – through vocal tone, volume and body movement – demonstrated the benefits of uninhibited participants, who have potential to boost and encourage others' interactions during communal set-ups. There were few strictly conventional performance-based activities in the programme, other than occasional line dancing with participants split between the 'dancers' and the 'audience' depending on their preference of involvement. Nevertheless, elements of performance were engaged with throughout variable modes, blended into storytelling and art-making activities to promote participant voices and identities amongst the group.

Conducting the activities in different modes contributed to session variability and offered content to participants with different personality types; those who may enjoy performance and those who prefer quieter, personal time. This will be further demonstrated in the vignettes considered later in this chapter, where engagement levels are shown to vary across or within sessions depending on different design, activity or modal factors. Nevertheless, this idea was communicated by Harry during an action learning meeting, while discussing how to encourage participation:

'I think most people take part if they want to.'

Harry, action learning group, 10th January 2019

The multi-modal design presented the opportunity for participants to engage so far as they felt able to or wanted to, as expressed by Harry, given that the activity design and content varied. This established the opportunity for participants to occasionally respond in unpredictable ways and accept challenges:

'I think it's a balance isn't it?... between making sure that they don't feel stressed by activities, but then I think it differs /so much day on day with each person, that some weeks somebody's perfectly happy to do something that is actually quite brave in terms of being in front of the rest of the group... and then other days they're not. And, you know, there have been people who have

surprised us in sessions and... got up and done things we wouldn't expect...'

Rachel, interview, 6th December 2018

Rachel explained that participation in arts activities can be variable and unpredictable. Therefore, offering a wide range of activity or stimulation types to a diverse group of people creates opportunities for learning new skills, attempting different tasks, and attaining a sense of pride and achievement through accepting challenges less available during individual, passive or repetitive activities. As reflected on by two separate spousal carers:

'This is the best about it. It's all activity, it's making you think, and do something... keeps your mind busy.'

Ray [carer], interview, 4th December 2018

'...it's not just about occupying the mind, it's occupying the hands isn't it?'

Patricia [carer], interview, 23rd April 2019

Both Ray and Patricia touched on the importance of integrating cognitive and physical stimulation, which *Setting the Scene* activities offer to participants. Indeed, this is a reminder of the effectiveness of changeability and multi-modality in encouraging different forms of stimulation and being well:

Ray: *I mean, in the Lake [Theatre by the Lake], everything changes. The girls [the facilitators] find something else to do with something else-*

Molly: -hm hmm-

Ray: *-it's not constant the same thing, same thing...*

Ray and Molly, interview, 4th December 2018

For couple Ray and Molly, the variability of *Setting the Scene* sessions offered them both stimulation and an opportunity to do something enjoyable together, therefore being inclusive of both their needs. Whilst activities were changeable, *Setting the*

Scene sessions retained a broadly familiar structure and sense of continuity week by week, without the pressure of large performances or final products:

'...it's nice to have that sense of continuity so that when people return after a block they seem to very easily settle back in to... the routine of it all.'

Jenn, interview, 11th October 2018

Although the programme ran for 40 weeks of the year and was broken into seasonal blocks, it adopted a familiar, processual set-up style that accommodated for new members arriving mid-block or those who could not attend regularly. This suggests the significance of varying activity contents, modes, and themes, but with a sense of familiarity and safety coinciding within the regular community space.

The multi-faceted approach was not only intrinsically valuable in terms of the arts activities themselves but had instrumental value in realising particular themes and formats that related to or reflected the identities of the attending participants. To better exemplify and integrate the *Setting the Scene* design and components discussed thus far, I draw on three participant vignettes in the remainder of this chapter. Each participant vignette offers a different glimpse at the effectiveness of the multi-art, multi-modal, and thematic qualities of *Setting the Scene*, and the potential for wellbeing experiences within the context of arts engagement.

5.3 Vignette One: Isaac

In this vignette, I consider how an amateur painter with dementia, called Isaac, engaged with different art forms and activity modes during sessions. Whilst illustrating his enduring visual art skills, this vignette also highlights the ways that people with dementia challenge themselves, aided through creative and multi-sensory stimulation.

Isaac was an 81-year-old resident of Keswick, living at home alongside his wife. He had been a regular member of Theatre by the Lake's *Setting the Scene* for over three years, since receiving a vascular dementia diagnosis. Living with moderate stages of dementia, Isaac experienced decreased verbal communication (aphasia), slowness of thought and mobility challenges, alongside partial vision loss that impacted his balance and everyday tasks. He attended sessions with his personal carer Jake, which gave Isaac's wife respite time. Isaac and Jake met at Amy's Care, where Jake worked before becoming self-employed to offer one-to-one care to local older adults. Isaac's weekly activities were therefore split between Amy's Care and time with Jake. Describing Isaac as introverted and reserved, Jake's knowledge and understanding of Isaac was exemplified during *Setting the Scene* sessions, where the group learned about Isaac's talent for painting and drawing landscapes of his garden and the overlooking peaks. Enjoying adventure sports in his younger years, Isaac more recently showed difficulties with balance and movement, but nevertheless continued to show a preference for non-verbal, movement-based and hands-on activities at *Setting the Scene*. With decreased communication, Isaac's involvement in the research revolved around his non-verbal participation, with Jake taking a lead role in interviews and conversations.

Isaac's interest in visual art-making and his attentiveness to natural landscapes were well matched by Theatre by the Lake's physical location and the artistic content of the *Setting the Scene* programme. Yet, I was also aware that his introverted personality and dementia symptoms may not have always been best supported by

the large, social and often verbal nature of *Setting the Scene*. These factors were raised between Jake, Isaac, and I while discussing their joint session experiences, during which Isaac had some difficulty following the conversation:

Jake: Yeah, he does find it difficult to, get the, the right words-

Isaac: -I'm, I'm, I'm not following-

Jake: No? I'm just saying that you sometimes find it difficult to get the right words to express how you feel.

Isaac: Yeah.

Isaac and Jake, interview, 22nd November 2018

Isaac demonstrated confusion for prolonged periods during the interview, remaining distracted and using short remarks. Conversations felt more focused when Isaac was asked about his favourite activities, where he was most positive and responded with 'yes' and 'that's right' when visual art activities were mentioned and 'occasionally yes, or, or more, yes' to his enjoyment of singing and music listening activities. The opportunity to be individually stimulated was reflected on by Jake, who stated that '*I think it's more practical things*' that interested Isaac, rather than conversation-based or drama tasks. Subsequently, Jake often spoke on Isaac's behalf or supported him to respond on his own terms by using his knowledge of Isaac's life experiences and family relationships. This was beneficial for Isaac if he was invited to answer a question during group sessions, such as being asked about holidaying:

Jenn: ...would you use a holiday to do some of your painting Isaac? Or would you, would you leave that?

Isaac: Oh no I would leave, I would, eh...

Jake: Isaac has been on painting holidays where you just paint.

Rachel: Ah!

Carol: He's an artist, a painter.

Jenn: And would you recommend them Isaac?... Painting holidays?

Isaac: Oh occasionally yes...

Jake: In Scotland-

Isaac: -in Scotland yes.

'Ride Out' session, 23rd August 2018

Whilst not being his preferred type of activity, Isaac showed that conversation was more achievable when its focus was personalised and based around his own interests of painting and landscapes; a hobby which is more solitary. Throughout the fieldwork, the size of *Setting the Scene* began to increase, which was noticed by Jake who said '*it was a lot smaller... and now there's over a dozen people usually.*' His comments reflected the popularity of the group but also suggested his awareness of the potential impact of the increasing size for more reserved members like Isaac. However, Jake spoke positively of the variety of activities made available to participants throughout sessions. He discussed with Isaac, '*you always take your time to start off something don't you? You always think about it for a while before you start*', which Isaac agreed with. This was illustrated in visual data of an individualised art-making of 'my favourite things', where Isaac was seen to require more time than most other participants to start actively participating, though he eventually exhibited extended focus and gaze on his artwork-in-the-making (Figures 5.16 and 5.17).



Figure 5.16: Isaac passively looking at page at the beginning of the arts activity.



Figure 5.17: Isaac participating approximately 5 minutes after Figure 5.16.

This footage was watched and discussed during an action learning meeting involving Jake and Isaac:

Jake: *Most people seem to join in... even if they need a bit of encouragement or... direction... most people do join in. You [towards Isaac] join in with activities.*

Isaac: Yeah.

Extract, action learning group, 10th January 2019

Offering a more individualised activity to focus on – with the aid and reassurance of Jake – enabled Isaac to express his long-term interests of painting the Cumbrian landscapes from his back garden, as mentioned in his interview (Figure 5.18):

Jake: *He likes scenery-*

Isaac: *-hmm?*

Jake: *-don't you?... He likes looking at the scenery.*

Isaac: *Oh, that as well, yes [laughs].*

Isaac and Jake, interview, 22nd November 2018



Figure 5.18: Isaac's landscape artwork featuring mountains and flowers.

Having been registered as partially sighted, Isaac's attentiveness to a long-term hobby of artwork could be interpreted as a form of resilience during an activity that relies heavily on visual information and colour. With one-to-one support, Isaac's finished artwork may not have contained the same level of technical detail as his works prior to dementia, but the art-making was important for its processual nature. His artwork was created with an 'attention to detail' focus and a symbolic, personal relationality between Isaac and the natural surroundings that captured his attention. Despite his deteriorating vision, Isaac did not display a defeatist attitude during art-making, instead exhibiting a strength-based mindset in which his health and dementia symptoms were not deemed obstacles (Whelan et al., 2020).

In circumstances of visual art-making in small group set-ups, Isaac displayed more reluctance to take part and showed signs of self-consciousness, particularly when paired with louder, more extrovert participants such as Carol. Working on a 3D collage together, Carol and Isaac had a muddled interaction:

Carol: Do you want to put, oh-

Isaac: -sorry?

Carol: Where would you like that to go?

Isaac: I can see that. Oh no no, no, not me.

Carol: Would you like them near to you? /Ooh! Do you like playing games?

'The Romans and Hadrian's Wall' session, 14th March 2019

Occasions such as the above demonstrate how the benefits and engagements Isaac had previously experienced when working on a more personalised art-based task were not as effective in group settings, or when paired with participants with differing personality types. This highlights the significance of not only the art form being engaged with, but additionally the social space, relationships, and ultimately the activity modality. In such situations, carers and facilitators intuitively rearranged groupings to ensure that participants, such as Isaac, had improved comfort and opportunity to engage:

Rachel: *Would you like your own bit Carol?*

Jake: *Yes [laughs].*

Rachel: *Would you like your own paper Carol?*

Carol: *No no, he-*

Rachel: *-I know you, you like your art.*

Carol: *He wants to do it with a wall.*

Rachel: *Yeah but I can get you your own piece of paper and you and Todd can be a team then.*

‘The Romans and Hadrian’s Wall’ session, 14th March 2019

The above extract illustrates the importance of facilitators’ sensitivity to how participants best engage with an activity or topic. Multi-arts (but equally multi-modal) activities at *Setting the Scene* therefore offer a range of opportunities that can meet the needs of those that are stimulated by group interaction – like Carol – but also those who find group interactions more challenging – like Isaac. Given that Isaac’s dementia symptoms manifested as delays to processing, movement and verbal expression, his wellbeing experiences could be better fulfilled by removing social or artistic pressures and adjusting activities to ensure speed, movement and conversation were not at their forefront. Giving participants time to verbally respond was often more difficult during group-centric activities, where a greater sense of

urgency was occasionally created by other participants, even with the reassurance of facilitators. During a verbal activity, participants Eric and Harry became impatient with a participant whose needs were different to their own:

Harry: /Boo [laughs; directed to Emily].

Carer: Howdy how? [to Emily].

[**Eric** laughs]

Jenn: /Yee ha.

Eric: Say something.

Jenn: That's it Emily, oh we got a /smile, we got a /smile.

'Country and Western' session, 7th February 2019

In contrast to the pressure often arising from communal conversations, Isaac benefitted from more practical and personal activities that offered a sense of social togetherness by being able to watch others participating around him, as well as having occasional interactions if the opportunity arose.

Meaningful moments of visible change often took longer for Isaac to build towards, although invitations to partake in more challenging activities were made available. Isaac could become hesitant in conversational tasks, leading to props or attention being passed on, like in a 'Chitty Chitty Bang Bang' session activity (see Figure 5.19).



Figure 5.19: A prop being passed between Isaac.

While Jake connected these responses to Isaac's introverted personality, Isaac's appearance of introversion may also have been indicative of the limitation of his dementia, which included aphasia. Over time attending *Setting the Scene*, I observed Isaac showing greater levels of openness in sessions with group and performative elements, including small verbal contributions. Most notable was Isaac's spontaneous agreement to participate in line dancing when invited by facilitators and fellow members during a session of fewer participants (Figure 5.20):

Jenn: Isaac? Would you like to come up? Or are you going to observe?...

Isaac: Hmm.

Carol: Isaac?

Jake: Are you going to have a little dance Isaac?

Isaac: [Pauses to think]. Go on, I'll go.

Jenn: Oh fantastic-

Rachel: -wonderful.

Jenn: Okay so shall we go through it again? Quickly? And it doesn't matter if you don't follow it at all.

Isaac: Alright, where are we going?

Jenn: Do you want to come-

Rachel: -there's a space... here. **'Ride Out' session, 22nd November 2018**



Figure 5.20: Visual sequence of Isaac's line dancing participation.

This participation from Isaac held significance beyond activity preference and art form, given that he was engaging in a performative, standing activity without requiring use of his walking stick. When arriving at sessions each week, Isaac's walking would be slow and considered, such as when he arrived at this particular session earlier that morning (Figure 5.21). To observe Isaac's active participation in a challenging line dancing performance was a surprising and heart-warming moment for myself as a researcher, the facilitators, and particularly for his carer Jake, who watched on intently with a joyous expression, recording parts on his phone to later show Isaac's wife (Figure 5.22). This revealed one of the first moments Isaac moved

from the shared circular space created around the table, to 'stage' and audience space within the Friends Gallery. During an interview after the session, Jake expressed his satisfaction with seeing Isaac's dancing:

Researcher: *Especially today, when you got involved in the line dancing-*

Jake: *-yeah that was good-*

Researcher: *-that was great.*

Isaac: *Under the?*

Jake: *Dancing... the line dancing?*

Isaac: *Oh the line dancing, yes.*

Jake: *Where you were doing the lasso.*

Isaac: *Yes... something like that...*

Jake: *You did /good /dancing today. Your line dancing was good-*

Isaac: *-did I?*

Researcher: */Yeah.*

Jake: *Yeah, I've got photographs to prove it [laughs].*

Isaac and Jake, interview, 22nd

November 2018

Jake exhibited pride in seeing Isaac trying a new activity, to such an extent that he felt inclined to capture the moment on his own camera, to share the achievement and fulfilment with Isaac's family. Isaac's dance movements were slower than the one other



Figure 5.21: Isaac arriving with his walking stick.



Figure 5.22: Jake's expressive response to watching Isaac dancing.

participant taking part and he was visibly displaying more difficulty moving his feet in specific directions, falling behind on speed of movement. Yet, as with the experience of art-making, Isaac's dancing was an 'in the moment' process of taking part, in an environment that was free from judgement. Over time, Isaac came to accept the safe space of *Setting the Scene* and participated in activities irrespective of his physical and cognitive limitations. During the line dancing activity, Isaac did not display visible signs of frustration or disinterest but continued following instructions and watching for the movements of those dancing on either side of him. He was attended to more personally by facilitator Rachel throughout the activity, following her verbal and physical directions. Although I viewed Isaac's dance engagement as possessing 'in the moment' value, his behaviour was notably more open and positive following the activity. He became more talkative, expressing himself with a chirpy 'olé' when the dance music ended; this exclamation would come to be a common, subtle response after music and dance activities from Isaac.

While Isaac was considered a quieter member of the group by Jake and the facilitators, he often expressed himself during seated or table-based dance activities in subtle, unique ways that differed from the movements suggested by facilitators. Illustrated during a 'hula' dance activity, Isaac imitated the sounds of the marimba music being played, tapping his fingers and hands along the table while other participants followed wave movements guided by Rachel (Figure 5.23).



Figure 5.23: Isaac imitating marimba sounds on the table.

Subtle and sometimes unnoticed, Isaac's considered contributions often followed the sounds of the music being played, attending to his aural strengths and adaptability, as opposed to attempting to follow distinctive movements with impaired vision. Carol expressed her awareness of his dance interpretations when he received praise and acknowledgement from Jenn on a separate occasion:

Jenn: And I must say, as much as we said Isaac would be at the bar, having a drink and not dancing, I did see some eh [moves hands]-

Carol: -no he does that-

Jenn: -definitely singing to that one and tinkling away on your fingers.

Isaac: Well... that's nice. [Group laughter].

'Country and Western' session, 7th February 2019

Both physically and verbally, Isaac became active in trying new activities, moving beyond the presumed limitations of his dementia, encouraged by the non-judgemental environment engendered by the facilitators and extended by other participants. Considering Isaac's experiences throughout *Setting the Scene* – but particularly accounting for the previously discussed art-making and dancing activities – he illustrated how participatory arts were defined by their opportunity, adaptability and variety, rather than an obligation to participate. For Isaac, the multimodality of *Setting the Scene* offered him a chance for concentrated creativity in art-making; subtle interpretive movement during dance activities without being centre of attention or feeling judged; and the invitation to perform in front of others where he felt comfortable to do so. Isaac exemplified that self-development and resilience through multi-art creativity meant he could contribute to a sense of 'being-well' with dementia while fulfilling his personal, creative needs (Andrews et al., 2014); during this, his symptoms could sit on the side lines.

5.4 Vignette Two: Peter

Vignette Two presents alternative insights into dementia and the body by focusing on Peter, who was one of few participants that wandered during sessions. Compared with Vignette One, Peter illustrates other design aspects of the *Setting the Scene* programme that stimulated physically active participants and helped to settle wandering behaviours.

Peter was in his early to mid-80s and lived with his wife in the Wigton area of North Cumbria. He began attending *Setting the Scene* sessions as a new member of Amy's Care in November 2018. Due to his wife's poor health at the time of interviewing, we were unable to organise time outside of the sessions to learn more about Peter's life story and past experiences. However, from getting to know Peter at sessions, he became known for his gentle and warm character, typically greeting others with bright eyes, a large grin and hearty laugh. Whilst having excellent mobility, Peter's experience of dementia was demonstrated in his wandering behaviour and separation anxiety when apart from his wife. Such experiences were pertinent during his first session at *Setting the Scene*, which was a busy, noisy and one-off intergenerational day with local school children. Peter's working background was in farming and manual labour, with experience of working with large machinery. He spent limited time doing arts-based or musical activities throughout his childhood and early adult life. On his information form at the beginning of the research, he and Amy's Care staff wrote that his hobbies included dominoes, jigsaws, watching television and gardening.

Upon arriving at *Setting the Scene* for the first time, Peter showed levels of agitation and confusion about the new and unfamiliar space, paired with nervous smiles and laughter:

[Peter starts to stand up and leave the room while Rachel is speaking to the room from a different table. Carer Phil from Amy's Care is based at Peter's table and begins to help him].

Phil: -Peter, we're staying here for a bit-

Peter: -what?-

Phil: -we're staying for a bit, the kids are going to be doing a little play for us...

Peter: Aww right [laughs and sits down in his seat again].

'Beauty and the Beast' session, 29th November 2018

Peter continued to display some anxiety and disorientation throughout future sessions, occasionally getting up from his seat to approach Amy's Care staff member, Anthony, who was a familiar face to Peter. Figure 5.24 illustrates a moment where Anthony spoke to wandering Peter about being apart from his wife, offering him words of comfort and actions of care.



Figure 5.24: An interaction between Peter and Anthony.

On a positive note, his connection from others in moments of uncertainty resulted in positive affect and reassurance from carers, which gave Peter momentary relief. These moments of wandering tended to occur during large group discussions or instances of transition from one activity to another, both of which lacked the

necessary stimulation to engage Peter, whose bodily activity and occupation of the hands were an integral part of his life story and rural working identity.

Over time attending *Setting the Scene*, Peter's wandering and anxiety began to be outweighed by more positive interactions and involvements in the group sessions, typically involving non-verbal art forms and smaller group formats. Within a single session – based on 'The Romans and Hadrian's Wall' – Peter began with wandering behaviour but followed this with attentive collage-making in a small group with Anthony's guidance (Figure 5.25).



Figure 5.25: Visual sequence of Peter's participation during small group collage work.

Following up the art-making activity with more wandering, Peter ended the session with active and central participation in dancing and singing activities (Figure 5.26).



Figure 5.26: Peter dancing with Jenn.

Although he did not have an artistic background, Peter expressed his attentiveness and care to the placement of small materials while creating collage art, continuing to physically engage with the activity while I overlooked his table. Receiving positive feedback from an Amy's Care staff member for his piece of work, Peter responded with sustained eye contact, conversational replies, and laughter.

Furthermore, Peter's performative involvement in the dancing activity was based in the centre of the room with assistance from the lead instructor of the activity, Jenn. As demonstrated from the video still image (Figure 5.26) Peter was positively and emotionally expressive whilst dancing, engaging verbally and non-verbally with other participants and facilitators in contrast to his earlier displays of anxiety and restlessness. Through his movement, Peter demonstrated strong mobility skills, good bodily awareness and extended attention to the activity while following instructions, receiving continued positive encouragement throughout:

Jenn: And the other arm. That's it /Noleen. And then we're going to do our toe taps. That's it Peter, you alright?

Peter: Yes, yes.

Jenn: And we'll do it again [2 second pause]. And down again. [Routine is repeated]. Then your side... flick your wrist if you like. That's it, and the other side. /That's it /Peter, /woo!

'The Romans and Hadrian's Wall' session, 14th March 2019

Peter's fluctuating engagement throughout one sample session demonstrates the ways that different activity styles and art forms can sustain the interest of a particular participant in variable ways. Typically showing less attention during verbal, conversational, listening activities in communal settings, Peter showed his strongest concentration when engaging with his body and hands. Most of his positive contributions at *Setting the Scene* took place when he was given more dedicated attention and social stimulation from another person, whether it be a carer, facilitator or other participant; this is similar to Isaac's experiences of art-making and dancing, where one-to-one support informed some of his positive experiences. Yet, participants like Peter – who were more prone to becoming restless or confused when lacking stimulation – were observed to benefit from the personal and direct nature of dyadic and small group work, in addition to the movement and action-based group activity that required embodiment, touch and rhythm. For Peter, the role of individual-based and group-based activities offered different benefits to those that Isaac experienced. Individual or paired activities were a comfort zone for Isaac, encouraging more movement and involvement. Contrastingly, these smaller activities offered more stimulation, attention, and personal dedication for Peter, temporarily reducing his wandering behaviours. Nevertheless, group activities of dancing for both Isaac and Peter created an opportunity to challenge their bodies, either by progressing through limited mobility for Isaac, or by focusing Peter's energy on creative movement rather than on a sense of disorientation. With his separation anxiety and wandering being interlinked, Peter's overall increased engagement in participatory arts helped to reduce experiences of distress and thereby promote wellbeing. These varied vignettes indicate the reasons for including different activities in the group that engage people in contrasting ways, attending to individualities as well as relationships with others.

Peter became more comfortable as his time at *Setting the Scene* and Amy's Care progressed, sharing some playful actions and words with others. During 'Country and Western' week, when participants were asked to say a statement in a South Western US accent, Peter declined to participate in what he was invited to attempt, but he did so with a humorous, improvised remark to create laughter in the group:

Jenn: *Anyone else? Todd? Or Peter? Would you like to have a go?*

[Todd shakes head].

Peter: *No you're alright [laughs].*

Jenn: *No you're alright [laughs]. [Some group laughter]*

Peter: *My teeth might fall out [laughs].*

Jenn: *[Loud laughter and begins to talk while still laughing]. Peter said his teeth might fall out. That's the best excuse if there ever was one Peter.*

'Country and Western' session, 7th February 2019

Making light of his false teeth exemplified the broader relaxed attitude exhibited by Peter, contrasting to his occasional separation anxiety experiences. His participation, whilst not the intended response, exemplified alternative ways of participating without being entirely passive. Therefore, whilst typically showing better engagement during non-verbal activities, Peter offered glimpses of conversation and wittiness throughout sessions, with socially engaging body language and non-verbal interactions with others. Peter's example illustrates the important roles of both embodied and social stimulations threaded throughout the different art forms and modalities at *Setting the Scene*. Using body and hands, Peter could maintain elements of his sense of self and manual career through the intrinsic worth of the arts, whilst his social engagements were instrumentally facilitated by the arts as a way of combating disorientation and displacement (Örluv, 2010).

5.5 Vignette Three: Carol

The final vignette considers Carol, the only member to attend sessions independently without family or care aid. This vignette exemplifies the ways that *Setting the Scene*'s multi-modality afforded meaningful social connection with others, whilst also supporting independence.

Carol was a 79-year-old woman living independently in Keswick. She was born in Carlisle, before moving with her family and siblings to Africa, where she spent her early childhood. Returning to study in a boarding school in Cumbria, she became interested in the arts and pursued a career leading her to London, but was compelled to travel back again to The Lake District, where she then worked in theatre as a set designer. Carol was an exuberant and flamboyant character, well known around the town of Keswick for her association with Theatre by the Lake, Keswick Museum, as well as her creative endeavours and attendance at community events. Carol joined *Setting the Scene* sessions alone and had a reputation for being theatrical and lacking inhibitions in her participation. With a long list of interests, she portrayed an enthusiasm to participate and express herself in any of the many creative activities conducted at sessions. She had an interest in words and making connections with others, often writing ideas and dialogue down on paper during sessions. During her interview, she hinted at having been diagnosed with other mental health conditions in the past but denied having dementia. She wore the same outfit to most sessions and was known for hoarding, hence her home was unavailable for an interview. Although her dementia symptoms were mild, she sometimes demonstrated swift mood changes, frustration and mild memory loss, though often remembering specific *Setting the Scene* past events.

There were specific moments during sessions when particular people were given opportunities to spontaneously showcase their skills or get involved in something more performative than usual. While the previous vignettes have demonstrated brief glimpses of this, these types of activities were most often taken up by Carol. Displaying a fearless desire to express herself through any available creative

medium, Carol differed from most other participants, who demonstrated some level of inhibition in relation to particular art forms or activities. Carol benefited from her physical agility and independence, given that all the activities were accessible to her in some form. She was often seen spontaneously getting out of her seat in response to background music, dancing on her feet even when she was the only one in the room doing so; often, it was not a direct part of the activity set out by facilitators but something she felt compelled to do 'in the moment' (Figures 5.27 and 5.28).



Figure 5.27: Carol's energy.



Figure 5.28: Jenn following Carol's lead.

Carol's 'outside-of-the-box' thinking emerged from moment to moment, but showed its distinct strength in the making of connections between words and/or actions. Such a moment took place during a session of smaller turnout, where Carol began to perform an impression of a submarine to accompany the song 'Yellow Submarine' by The Beatles (Figure 5.29). She unintentionally performed for the group, moving around the table multiple times, bending her back and pointing her hands in front of her body, guided by the music.



Figure 5.29: Carol's submarine impression.

These moments were described by carer Ray as 'entertaining' with reference to Carol as an entertainer. This might be expected from Carol, given her personality and the knowledge that she was the only active member of *Setting the Scene* to have had a full-time job in the arts sector. Yet, Carol was open during her interview about self-consciousness and discomfort at being the centre of attention, with reference to my camcorder video clips:

Carol: /Oh /gosh! [reacting to her dancing on camera; laughs].

Researcher: Yes, here you are [laughs].

Carol.: Oh /no oh /no I'm dancing! [Laughs].

Researcher: And it looks like you're really enjoying it?

Carol: Yes well then I realise you were... [laughs] and then I hid around the corner.

Researcher: You hid? You hid around the corner. Do you think, do you feel like you're being watched?

Carol: Well... I always have tried to hide but then sometimes you find you're... /there and then somebody's trying to hide behind /you. Which is what's always happening, there are different ones that, one in the front, one in the... [looking at the video clip].

Extract, video elicitation interview, 8th September 2018

Carol demonstrated elements of self-awareness and awareness of other people in the group, admitting to sometimes feeling watched or conscious when she is in a performative zone. Yet, ultimately, she finds that she is '*there*' and exposed, following her instinctive movements to music before realising she is capturing the attention of others. Threading elements of the performing arts into the participatory arts sessions, whether intentionally or spontaneously, placed further emphasis on the process-oriented nature of 'live' and 'unplanned' performance. Carol offered a reminder that the unfolding actions of participants rarely left a lasting, materialistic product, but rather created an affective product amongst other members, leading to praise, accomplishment and a shared expression of creative wellbeing.

Setting the Scene's group-based, participatory arts set-up was able to satisfy both the creative and the social needs of Carol, one of few people with dementia who spoke about the importance of connecting with others and valuing the communal activities. Although portraying herself as self-motivated and independent, Carol often expressed gratitude and value for the social group. Her yearning to be close to others was expressed in storytelling activities, where she was reduced to tears on multiple occasions while talking about the importance of family, friends, and sense of belonging. One such incident took place during the last day of fieldwork, when Carol was asked to answer the question 'what is the essential ingredient to a good party?' during a balloon game:

Carol: Eh... ha [laughs]. Well... when you're with all, everybody, and we all gel, together, and even though your family isn't nearby [begins to cry], you gel with... who you connect with.

Jenn: /Yeah.... So good connections with people, having honest friendships...

'Love and Marriage' session, 28th March 2019

Moreover, Carol would frequently display a sense of togetherness while in the middle of group artwork, upholding a 'we' over 'I' attitude and valuing the contributions of others. Having worked on an art piece with Todd using glitter baubles and tissue paper (see Figure 5.30), Carol presented it to the rest of the group briefly at the end of the activity:

Jenn: Right Carol.? You'll have to be careful-

Carol: -this was a joint effort... we keep losing the balls don't we?

Jenn: Yeah. [Positive responses from group to the artwork]

Rachel: Oh wow.

Jenn: It's gorgeous, /come on Todd, were you the instigator of this wonderful creation? Was it all your-

Patricia: -a lot of work's gone into that.

Carol: Yeah, a joint effort.

'Joseph and his Technicolour Dream Coat' session, 10th January 2019



Figure 5.30: Todd (left in circle) and Carol working on art together.

The emphasis on '*joint effort*' was extended by other participants, including when Sam felt like the room of people were '*rocking and rolling*' after singing 'I've Got a Lovely Bunch of Coconuts', in addition to when Joe simply stated after a group song, '*didn't we do well?*'. Indeed, other participants beyond Carol have displayed an understanding of group or community identity. However, Carol was also the most vocal of participants about gaining benefits from the social side of sessions:

Researcher: *So is that something you like about the Setting the Scene activities, that you get to meet new people?*

Carol: *Well... yes... but I meet people all the way around [the table] but then I'm connecting everybody up, which some people find very /aggravating, because I can't help doing, the connections, which don't mean anything to people who are factual... when we're trying to do, whatever, and then somebody else is getting sad, then there's people all around that can help.*

Extract, video elicitation interview, 8th September 2019

Carol expressed empathy and understanding that the affective presence of other people at *Setting the Scene* could transform sadness into something more joyful. Moreover, she designated herself as something other than 'factual', referencing her tendency to make fictional connections between the things people speak about at sessions. This intent listening to others in the group led to the creation of visual stories or word art on spare pieces of Carol's paper while other activities were ongoing, from which she selected words spoken by others (Figure 5.31).



Figure 5.31: Carol's word art comprising words mentioned in a session.

This behaviour, which Theatre by the Lake staff said was replicated outside of sessions (i.e., in her paperwork and letters), was considered acceptable in the creative, non-judgemental space integral to *Setting the Scene*. This was not only a demonstration of the everyday creativity of Carol, but also of her creative interpretation of other members' contributions, leading to personal, processual word art that presented Carol's wish to connect with others.

Carol offered a reminder that while participants like Isaac and Peter may have experienced moments of reservation and withdrawal in large group settings, other members appreciate this feature of *Setting the Scene* for its contribution to their social wellbeing and sense of belonging to a community. Though admitting to feelings of self-consciousness, Carol's free spirit and creative onflow was an expression of her defiance to letting dementia affect her independence:

'I want to be freer... you /feel like you're going to be put in a home, that's what I felt like, so then I get stroppy. But I assert my independence because you are sort of put on a... streamlined attitude. Sorry, I don't mean to be rude, but it just alarms me because... [2 second pause] I love... to be /free [voice becomes shaky as she begins to get emotional /tearful].'

Carol, action learning group, 10th January 2019

The '*streamlined attitude*' mentioned by Carol is indicative of the feeling of being defined by one's dementia symptoms and the fear of having her individuality overlooked, which she felt she reasserted during the arts. Ultimately, the multiplicity of *Setting the Scene* – the multi-arts approach, the multi-modality set-up and the presence of a diverse group of participants week by week – offered Carol social, creative and physical freedom to be who she wanted to be, do what she wanted to do and to continue living well with dementia. Subsequently, *Setting the Scene* enabled a feeling of independence central to Carol's sense of control, self-identity, and wellbeing.

5.6 Vignette Insights

The experiences of Isaac, Peter, and Carol at *Setting the Scene* sessions suggest that the heterogeneity of participants requires an equally heterogeneous programme, that attends to differences in a bid to create a unifying and safe space. Whilst the three vignettes highlight personal characteristics that can influence arts engagement, they also stress the impact of different sets of symptoms experienced by individuals living with dementia, and of other physical and mental health conditions that co-exist. For Isaac, dancing alongside others while seated quietly at the programme's table gave him a chance for self-expression, movement, and musicality, whilst taking pressure off his vision. More performative forms of dance – demonstrated by all three vignettes – held different purposes and outcomes for participants. Isaac's participation in line dancing challenged his body's mobility and physical wellbeing, by dancing with partial sight and without his walking stick. Peter and Carol – both of whom were more mobile and physically active than Isaac –

benefited from the psychological and social benefits of dance. Peter's active and jovial interpretation of an Italian-inspired dance was an accomplishment which overcame his wandering behaviours and anxieties, whilst Carol's spontaneous and impulse dance 'performances' exhibited her individuality and were received by others as entertainment.

Lively, movement-based, corporeal activities contrasted to the content of gentler, visual art-making activities, but which could also be geared to the different needs of participants. The artistic backgrounds of both Isaac and Carol could be facilitated and maintained at *Setting the Scene*, while Peter's history of manual labour impacted the usefulness of keeping both his hands and his mind busy. Yet, each member showed a different aspect of art-making which improved their involvement in the programme. For Isaac, individual tasks were less verbal and time-pressured, enabling him to revisit his relationship with painting the Cumbrian landscapes as featured through Theatre by the Lake's windows (see chapter 7). Peter's engagement with collage-making was initiated and sustained by teamwork alongside his carer, illustrating the overlaps between social and creative support, which similarly took place for Isaac with his carer Jake. Alternatively, Carol integrated her independent art-making throughout sessions to capture a desired connectedness to others, using her own paper to generate word art and illustrations that portrayed unfolding conversations.

Participants like Isaac and Peter – who were both apprehensive about verbal or conversation-based activities – still presented moments of openness, contribution and humour when the social space felt supportive and safe. Other more extravert or dominant personalities, including Carol, may have found conversation-based activities natural and intriguing, aiding new friendships within a local social network. During the fieldwork, Carol was able to encapsulate, through words, her empathy, experience of affect, and sense of belonging from being with other people as part of the programme. However, she also mentioned the occasional self-consciousness and sense of exposure felt by being watched. This highlights that even the most confident and dominant participants may experience insecurity, irrespective of how long they have been attending sessions. Unlike Carol, both Isaac and Peter were less attentive and focused during larger social or verbal activities. While some communal

activities were difficult for these participants to follow, there were subtle benefits of more concentrated, one-to-one social activity that indicated positive impacts on actions, behaviours and changing moods during and after participation. These moments often led to greater openness to accepting new challenges, such as dancing in front of others. Whilst not expressed through words, Isaac's and Peter's embodied, haptic, and non-verbal communications presented insights into the social and communal benefits of participatory engagement for people with dementia, who may otherwise be anxious about being a part of new or existing social groups. Hence, the wider social setting of participatory arts, alongside contributions from facilitators and carers, created a safe environment for participants to try new things and take up old hobbies regardless of their dementia.

Whilst the chosen vignettes break down smaller aspects of the broader multi-faceted *Setting the Scene* approach, each participant illustrated divergence in the aspects of the programme that struck a chord with them or that challenged them. Yet, they were all able to practise their strengths, attempt new challenges, and participate alongside their carers on an '*equal playing field*', where dementia was not the central focus in the room. Not all art forms were approached equally by participants, but the 'multi' considerations of the programme ensured that different options were available, so that both creative interests and social wellbeing could be potentialized in the group setting. Activity multi-modality enabled participants with diverse life experiences and dementia symptoms to find benefits in activities on different days or at different times throughout sessions; all the while, taking place in one, shared, creative setting.

5.7 Concluding Thoughts

This chapter has demonstrated the impact of the *Setting the Scene* design on participants' creative, social and wellbeing experiences. At the beginning of this chapter, I outlined the roles of multi-arts, multi-modality, and the thematic contents of the participatory arts programme, before detailing in-depth vignettes of how these components related to one another in practice. Each of the art forms and activities designed were purposely employed with a holistic approach, offering potential for physical, psychological, emotional, and social wellbeing. Although the

programme had a multi-arts focus, the effectiveness of its design was most attributable to its overarching person-centred and ‘in the moment’ focus, in addition to the multi-modal and thematic components that aided flexibility and heterogeneity. As demonstrated in Section 5.2.2, themes brought meaning and life to the arts, attracting those with and without artistic backgrounds, and connecting strangers by a common, relatable topic.

The programme, rather than being art-centric, utilised a range of art forms to enable active, creative and social contributions from participants. The actions of the facilitators were important for putting the programme’s design components into practice and encouraging participants to respond in ways that were personal yet comfortable (Innes et al., 2021; Scholar et al., 2021). The programme’s multiplicity – be it the type of art form, mode, or the varying topical content – was necessary for enabling the attainment of participants’ needs, accommodating their personalities, and encouraging the creative endeavours of a diverse group of people with different skills, alluded to by the three vignettes. The vignettes began to tease out the different ways that people engaged within the same programme and they indicated the multiplicity of self-expression beyond the verbal, attending to multi-sensory and embodied experiences of wellbeing and personhood. The programme encouraged the continuation of participants’ self-narratives by inviting their skills and interests to be expressed in alternative ways; whether they were a graphic designer, part-time fine artist, or handy man. *Setting the Scene*’s multi-faceted approach facilitated different forms of engagement from people with dementia who had varying physical, cognitive, and sensory abilities, which may not have been as effective in singular arts activities or entirely non-artistic communal activity. The programme’s design ultimately pursued living well with dementia by attending to the heterogeneity of participants’ interests and identities, establishing a complementary heterogenous, person-centred and strength-based pathway towards wellbeing through creativity.

Chapter 6: ‘In the Moment’ Arts Participation and Communication: Voice, Face, Body, Material

6.1 Introduction

While Chapter Five introduced *what* the *Setting the Scene* programme entailed and hinted at individual responses and wellbeing experiences, Chapter 6 further addresses *how* different forms of participation emerged during arts engagements. The chapter opens by addressing how arts participation, communication and engagement can be defined with an ‘in the moment’ focus. Specifically, communication is considered for its ‘plurality’, comprising the verbal, non-verbal, passive and active. The remaining chapter is divided into three main sections, the first of which explores conversation-based activities for assisting creative ideas, sharing life stories, and aiding selfhood. This area of participation is followed by consideration of humour and laughter as communicative tools, which are currently understudied in dementia research (Stevens, 2012; Hafford-Letchfield, 2013). Beyond verbal means, participants’ bodies and senses are addressed as alternative channels of communication in participatory arts, and objects and materiality are studied for their agency and purpose in these types of non-verbal interactions. With the heterogeneity of both the programme content and the attending participants, this chapter presents further vignettes and exemplar events in each of its main sections to exemplify the multiplicity of communication and self-expression. Overall, this chapter illustrates how the participation, communication, leadership and wellbeing of people with dementia can be empowered through ‘in the moment’, person-centred, more-than-verbal and human-object perspectives. The findings allude to a reconceptualization of communication and engagement, as attended to and understood during dementia-friendly participatory arts activities.

6.2 ‘In the Moment’ Participation: ‘A Play Without a Script’

The main principle behind participatory arts is to encourage active participation from and between participants using creative means (Stickley et al., 2018). Participation,

however, is a broad term that may involve varied forms of communication, attention and engagement. Before addressing the experiences of individual participants in the programme, it is necessary to outline how participation can be defined in light of this project's findings.

As suggested in Chapter 5, arts-based participation in the *Setting the Scene* programme emerged through 'in the moment' occurrences. Carer Ben touched on this through the analogy of theatre:

'It's /aptly named in many ways, Setting the Scene, because that's what they /do. They leave it to the actors to ad-lib with a little prompting, so it's almost like eh... a play without a script...'

Ben [carer], interview, 13th September 2018

To regard participants as 'actors' – taking part in spontaneous 'ad-lib' performances aided by prompts – placed power in the hands of participants through their improvisations. In this light, the programme aimed to be person-centred not only by offering opportunities for individual participants to express themselves, but also by drawing their participation into the ongoing, shared, creative process. This suggests that person-centredness – whilst often thought of as something that intrinsically attends to individualised needs – has application to group settings, where the onflow of an individual's 'in the moment' participation can influence how a group activity proceeds (Andrews, 2014). The agency of participants was deliberated on by facilitators when discussing decision-making during sessions:

'...you provide a brief stimulus, and it could go in any direction but it's about accepting whatever happens... we've made up songs, or poems, and they might start off about one thing... they might include other themes, but you include them because it's all part of the process... it's not about getting the poem right, or to get the song to fit every single bit of rhyme... if we go off in a slightly different tangent then that's okay because often that's the way that people's minds work.'

Jenn, interview, 11th October 2018

This extract offers insight into how participation unfolded at the programme, with prominence given to the unpredictability of participant responses and openness to these contributions. Evidently, the ‘in the moment’ approach to both facilitation and participation is understood to support a creative-based communication between all members present at sessions, which was not conditional on the content being conveyed but rather by the process underpinning it. The excerpts from Ben and Jenn hint at ‘accepting what happens’ within creative settings. Whilst this points to a broader aspect of the social landscape of the programme (see Chapter 7), it also suggests that how participants communicated their creativity was enabled by being ‘in the moment’.

The encouragement of participation was not only facilitated by people and verbal prompts but was also through the integration of novel objects that were open to interpretation. This was shown when an unfamiliar balance board object (a piece of exercise equipment owned by Jenn) was included amongst props in a ‘Ride Out’ session, which was based around the topic of transportation and travel (Figure 6.1).



Figure 6.1: Isaac (far left) holding a novel object open to interpretation.

This object, passed around the group, enticed different creative interpretations from participants, including as a car tyre, steering wheel, bicycle wheel, spaceship, and swaying boat (Figure 6.2). Each answer was unique to the individual and was stimulated by the creative freedom afforded by the object’s novelty.



Figure 6.2: Carol sways the object to the song 'Rock the Boat'.

The way that this exercise board embodied open-mindedness and imagination made an impression on Ray and Molly, as discussed during their interview:

Ray: *It makes you think, what it is and what you could make it into... that was just a piece of wood, and then somebody says 'oh it's a... a wheel on a car' [laughs] or eh... it's a wheel... on the bottom, a car wheel... or a steering wheel.*

Researcher: *Yes, you can-*

Molly: *-that was like, just... something that somebody just thought up well... I think that's /good. You know? [Laughs].*

Ray and Molly, interview, 4th December 2018

The above excerpt was taken from an elicitation interview stimulated by video recordings, and demonstrated how both partners had appreciation for, and understood the importance of, using novel objects to communicate participants' imaginative ideas.

Though attention has been given to the ways that 'unscripted' or material-inspired verbal communication was facilitated by people and objects at sessions, other non-verbal movements or objects incorporated into sessions further illuminated the

plurality of communication. This was displayed by Carol (Figure 6.3) during a closing sing-along activity:

Carol was very expressive and participative, seeming to enjoy the song that she had the opportunity to choose. During an instrumental part of the soundtrack, after having actively sung up until this point, Carol picked up a floral prop and started to improvise in a playful manner to the music, moving it in front of the faces and above the heads of participants seated nearby...

Fieldnote extract, 'Jeeves and Wooster' session, 15th November 2018



Figure 6.3: Visual sequence of Carol using a flower bouquet prop.

Being 'in the moment', Carol embodied partial responsibility over what was to happen next, both by choosing the song to sing and by non-verbally communicating with other members in the group during the song's instrumental. While the rest of the group waited passively for the instrumental to pass, their attention turned to Carol for entertainment. This improvisation reaffirms the multi-arts nature of the programme, where an activity founded on sound and lyrics can be paired with movement, rhythm, and props. Moreover, this sample event helps to amplify the scope of active and passive forms of communication in participatory arts contexts. Considering Carol's expressed desire to connect with others (see Chapter 5), her participation through using props revealed attempts to communicate with other participants non-verbally, visually and haptically. Although it did not instigate active responsiveness on this occasion, it remains a useful insight into how the multi-arts programme facilitated Carol's own ability to interact with the group and the plurality of her modes of communication. This example lays the foundation for the all-encompassing approach to defining participation that has been adopted in this thesis - how, beyond the use of words, other valid forms of communication for expressing self and connecting with others includes the participation of bodies, faces, and inanimate objects in our immediate environment.

Indeed, the effectiveness of participatory arts is reliant on what qualifies for 'participation'. Revealed at *Setting the Scene*, participation and engagement could manifest as active, passive, verbal, non-verbal, or holistically more-than-verbal, depending on the individuals and activities concerned. As Rachel commented:

'Initially you think a successful activity is where everybody's participating and making, doing... but actually I've reassessed what a successful activity looks like... and for me it is if you gauge in the room that everybody is enjoying themselves...'

Rachel, interview, 6th December 2018

Rachel's personal viewpoint as facilitator suggests that participation is not always obvious and conventionally active, but may also entail a subtle smile, moment of eye contact, opportunities of physical affection, or may relate to the atmosphere in the

room denoting positive or negative affect. This was indicated throughout different sessions, such as during a ballet-inspired dance activity, when Howard sat smiling and laughing while others around the room participated actively with their bodies (Figure 6.4). This view of participation will inform the remainder of the chapter.



Figure 6.4: Ballet-inspired dance activity with varied forms of participation.

Overall, participation has been exemplified for its 'in the moment' qualities: its emergence through both verbal stimulation and materiality; the role of bodily and multi-sensory engagement; being active or passive through verbal, non-verbal, or more-than-verbal communicative means; and the affective or emotional qualities of the group. Considering all that has been presented to define participation thus far, a 'more than' lens can best address the complexities and nuances compounded in what communication and engagement entail for people with dementia in creative settings. Contemplating *Setting the Scene* through the lens of assemblage (Bennett, 2010; Mazzei & Jackson, 2017; Tan, 2020), this chapter studies the relations of human and non-human entities for how they contribute to arts-based participation.

6.3 Verbal Participation: Conversation Starters and Life Stories

Setting the Scene sessions were often threaded with verbal and textual content which held different purposes. While not overtly challenging participants to verbally communicate, the sessions offered an invitation to 'share, create and connect' using

creative ideas in a conversational environment (Theatre by the Lake, 2020). While conversation-based participation was often centred on something topical, game-based or imaginative, verbal participation could also be informed by participants' life stories. These types of interactions were observably more engaging when participants could relate to each other. During a 'World of Work' session, the sharing of carer Ray's past professions instigated further contribution from Harry and Sam:

Ray: *And then I went into the Forces.*

Jenn: *Wow.*

Harry: [Turns closely to Ray sitting next to him]. *And then you went where?...*

Ray: *Into the army-*

Harry: *-oh the, the army... So did I [laughs heartily; some group laughter in response].*

Jenn: *Anybody else been in the army then?*

Harry: *\Me [puts on a muffled tone of voice and points his thumb up].*

Jenn: *Yeah?...*

Ray: [Copies Harry and puts his thumb up].

Sam: *I was in the RAF.*

'World of Work' session, 14th February 2019

Although reflective and memory-based in nature, discussing past experiences – especially those that had ties to personal identity or major life events – was accessible to some participants, who displayed improved communication and comradeship with others based on their commonalities. For Ray and Harry, this even extended to how they communicated through non-verbal hand signals in response to questions prompted by Jenn (see Figure 6.5).



Figure 6.5: Visual Sequence exhibiting Ray and Harry's interactions.

The sharing of life histories and the spontaneous contributions made by others suggested that verbal expression was not only a way of expressing 'in the moment' or imaginative ideas, but also aided connection with others through personal and shared biographical narratives, with applied relevance to the arts activities.

For other participants, verbal dialogue and reflective thinking was challenging, and therefore the most poignant uses of verbal communication were those utilised to overcome the challenges accompanying participants' dementia symptoms. To keep to the present moment, it was common for participants to answer simple questions about their interests. Emily, who had the most advanced dementia in the group, was encouraged to participate in a person-centred conversation about her summer holiday preferences. This took place after catching a colourful beach ball as part of a game activity:

Jenn: Do you... like /ice cream Emily?

Emily: What?

Jenn: Do you like ice cream?

Emily: I like ice cream.

Jenn: She likes ice cream.

Emily: Yes.

Jenn: /Strawberry or chocolate, or vanilla?

Emily: Hmm... strawberry.

Both Facilitators [Synchronised response]: /Strawberry /ice cream...

Anthony: /Hmm.

Emily: That might keep me going for a bit [looks at Anthony and touches his shoulder]...

‘Summer Holidays’ session, 23rd August 2018

Prior to the above excerpt, Emily had shown limited participation in storytelling activities that involved imaginative, rather than physical, objects and concepts. Yet, in the beach ball activity, Emily engaged with touch and taste, placing less pressure on memory recall. This suggested the importance of using basic personal prompts to promote the participation of people living with dementia. In addition to verbal contributions, Emily became visually and aurally interactive, demonstrated by making stronger eye contact with participants around the table, sustaining focus on particular members, and responding to verbal prompts. From Emily’s grasp on the beach ball to affectionate touching of Anthony’s arm, the activity facilitated her ability to engage and connect in the group beyond inanimate objects (Figure 6.6).



Figure 6.6: Visual sequence of Emily and Anthony.

Although her contributions were brief, Emily's more-than-verbal interactions demonstrated that people with more pronounced dementia can still contribute to meaningful conversation when given person-centred stimulation and freedom to connect with others using alternative senses.

Whilst verbal communication was often easier for participants with early-stage dementia, their extended focus could be difficult to maintain. Although storytelling was intended to be imaginative and improvisational – rather than comprising oral histories or self-reflections – participants often dwelled on aspects of self-identity or recent personal experiences. Stanley illustrated this in a storytelling activity, during which participants were asked to develop a narrative and characters inspired by '*Chitty Chitty Bang Bang*'. Encouraged by other members to contribute his ideas about a character name, Stanley began to share a recent hospital visit:

Stanley: *I... just relate something that happened yesterday.*

Carol: *Okay...*

Stanley: *I lay in hospital, on a bed, for about 10 hours, never saw anybody, and I says 'what's going on in here?' Everybody were going for a cup of tea and a sandwich and stuff like that, and we were sat, laid... on the bed, nobody come to see us. And I thought 'oh God this is handy this' [sighs]. Talk about-*

Joe: *-that's normal in the bed.*

Stanley: *I know.*

Howard: Eh.

Stanley: Flipping hopeless it were.

Howard: [Sighs]

Patricia: Professor Hopeless?

Rachel: So Professor Hopeless?

[‘Professor Hopeless’ repeated out loud by other members]...

Jenn: Okay...

Stanley: Right, Professor Hopeless, put that down, yeah.

‘Chitty Chitty Bang Bang’ session, 6th December 2018

Setting the Scene offered a space for Stanley to freely share thoughts about a recent, difficult hospital visit, while other members – Joe and Howard – responded empathetically. With the attentiveness of a carer – Patricia – Stanley’s mention of ‘hopeless’ was introduced into the story’s narrative, informing the character name he had initially been asked to develop. Stanley’s character name was influenced by his own personal experience and the interpretations of other members who actively listened to his dialogue. This observation was suggestive of ‘relational self’ and how individual-group relations existed within arts participation (Conradson, 2005).

The recent experiences of Joe also fed into storytelling activities during the same session; these were triggered by feelings of disorientation associated with his dementia and a change to his morning travel route to Theatre by the Lake. Although distinct from the ongoing imaginative conversation about inventions, Joe and other members ruminated innovatively about how his disorientation could be resolved as part of the activity:

Joe: I’m still lost from getting here this morning...

Jenn: You mentioned... you felt a bit lost this morning. What about something like an inbuilt navigation system? [suggested as Joe’s useful invention].

Joe: You could alter that so that something lost would be everything was lost.

[Some group laughter]

Jenn: If... you could design something that eh... I don't know, like a-

Rachel: -like a personal sat nav?

Jenn: -like a /chip-

Rachel: -in your glasses.

Joe: A chip off the old block.

Carol: /Yeah.

Jenn: An implant or something and, and then you could never get lost.

Harry: Oh yes, aye.

‘Chitty Chitty Bang Bang’ session, 6th December 2018

Through humour and creative thinking, the group interpreted the psychological and emotional challenges communicated by Joe in a way that could be shared and explored. Joe’s attention was sustained, his verbal dialogue attended to, and he listened to other contributions that offered a different perspective to his dementia.

For Stanley and Joe – participants with varied past and immediate health concerns distracting them from the present moment – participatory arts were able to take the everyday, mundane and distressing elements of health, and recommunicate them in an unfolding creative way. With varied dementia experiences spanning disorientation, limited verbal communication and reduced attention, the perceived challenges of Emily, Stanley and Joe could be approached and improved through the creative wellbeing potential of participatory arts and the group-based interactions centred around speech (Mossabir, 2018). For other participants, such as Sam, verbal-based participatory arts could fulfil his natural storytelling abilities, for which there were no other outlets available outside of his home. The following vignette considers the centrality of verbal expression in Sam’s innovation, emotional expression, and day-to-day interactions.

6.3.1 Vignette Four: Sam's Storytelling

Originally from Nottingham, Sam was now living in the outskirts of Carlisle with early-stage dementia, and supported by his wife Deborah. Having been married for 60 years, Deborah described Sam as empathetic, reserved, yet strong-willed, hinting that he may have undiagnosed autism. His paperwork simply stated that his hobbies included walking and socialising with family and friends; yet, in reality, creativity had informed much of his life accomplishments. Sam had previously worked as an ordnance surveyor, requiring technical drawing skills and attention to detail. He applied these skills to his hobby of painting, which involved being '*very careful*' to conduct research into local landmarks before painting them. Other interests included designing and building his own narrowboat, and drawing the renovation plans for his family home. Describing himself as having a logical problem-solving mindset, his behaviours began to change on the build-up to his dementia diagnosis, including using toothpaste to fill in holes in the radiators and having challenges with basic object identification. His symptoms also affected his painting, leading him to repeatedly repaint sections. While his technical skills were affected, Sam maintained a strong vocabulary for storytelling and philosophising. Sam's multi-faceted creativity, reflective nature and reliance on complex verbal expression all contributed to his perceived self-identity, wellbeing and participation at *Setting the Scene*.

Sam began attending *Setting the Scene* sessions a few weeks after the fieldwork had begun, during a 'Jeeves and Wooster' session. Although initially quiet, he promptly began to share his verbal articulacy and creative ideas in different activities, particularly in relation to stories and material objects. During a character development game on his first session, Sam offered an imaginative commentary of what he might find while reaching into a bag to pick out a prop, intonating his voice as he moved: '*Something... /horrendous or, just /ghastly?*'. This contrasted to other participants who quietly reached into the bag without outwardly expressing their ideas. Following his choice and inspection of an object – a war helmet – Sam placed it on his head and, being too large, covered his ability to see. With his sight

compromised, Sam reached his hands in front of his body in a comedic, entertaining manner, turning towards the rest of the table and pretending to find his way through the air, prompting laughter (Figure 6.7). Sam accompanied his actions with words:

Sam: [Pretends to feel around the air]. *It's very, very hard for to me find my way around.*

[Some group laughter]

Sam: [Directed to Patricia]. *About 18 sizes over.*

Patricia: *Yes [laughs].*

Sam: *I could make something of it.*

'Jeeves and Wooster' session, 15th November 2018

Sam's spontaneous and theatrical response to the helmet displayed how the meaning of his words and his subsequent meaningful interactions with others had been enlivened by the non-human actants involved in activities. Alongside his verbal communication skills, Sam was stimulated by objects and other people, extending communication to his body. In doing so, Sam's actions were directed towards the rest of the group sitting around the table, creating a sense of connection and inclusion of others through non-verbal participation.



Figure 6.7: Visual sequence of Sam and the war helmet.

Sam demonstrated a similar consideration for other members during smaller group activities, verbally reassuring fellow members to participate. During an art-making activity where small groups were each asked to create a collage of a 'beast', I observed Sam encouraging new participant Peter to contribute his own ideas:

'Just express yourself, you know, with your own artistic way.'

Sam, 'Beauty and the Beast' session, 29th November 2018

Sam continued to encourage his group through descriptions of their 'beast' as '*the ugliest thing in the world*' and suggesting they '*try to use as much as we can*' of the arts materials provided. Whilst working in a team, Sam did not push his own ideas upon the group but instead remained considerate of others, showing that beyond the responsibilities of facilitators or carers, participants can use encouraging words to facilitate each other. This was particularly pertinent for Sam, who was accustomed to working on solitary creative projects in his past, much like Isaac in Chapter 5.

Whilst drawing on his verbal skills for commentating on the non-verbal activity, Sam showed that his verbal participation could support and value participants' individual contributions, offering an opportunity to develop relational wellbeing.

Nevertheless, Sam's participation during sessions was not always outward and active. The following 'in the moment' verbal exchange took place during an art-making activity designed for individuals or small groups, where Isaac, Peter and Sam formed a group led by carer Jake. However, Jenn noticed Sam's lack of physical participation in the activity and decided to approach him:

Jenn: *Are you okay?*

Sam: *I'm having a bit of a... imagining something.*

Jenn: *Shall, shall we come and help you?*

Sam: *We have one, one here, a fella here.*

Jenn: *Would you like me to give you a hand?*

Sam: [Turns to make eye contact with Jake].

Jake: *It's up to you Sam.*

Sam: *Well in my mind he knows, he's got nice colours.*

Jake: *It's alright, isn't it? We're doing alright.*

Sam: *So, we're okay.*

Jenn: *You're okay, sure?*

Sam: *Yes.*

'Joseph and his Technicolour Dreamcoat' session, 10th January 2019

While Sam sat quietly observing others, his narrative suggested that he still felt part of a team, trusting and complimenting the leadership of Jake. Although he was not exhibiting physical art-making, Sam explained that he was rather '*imagining something*' to himself; engaging in private, intimate and intangible creative ideas that were being stimulated by watching others. This imaginative tendency was also displayed during a separate session when asked to think of something 'beautiful' or 'positive', to which he replied '*having a nice dream*'. Whilst Sam's creative imaginings could not be verified, his discursive reference to them offered a reminder that creative *activity* principally begins with a person's visualisations and thoughts (Lea, 2008; Rose & Lonsdale, 2016), and that these enduring strengths in people with dementia can also evoke positive, wellbeing experiences. Indeed, creativity is not entirely defined by what you *do*, but initially what you *feel* and *think*, encompassing both the tangible and intangible. Sam extended this idea during an interview, while discussing his childhood and education. He stated '*curiosity... it's the biggest powerful urge that you'll ever know of.*' In a similar vein, the 'urge' or affective quality of creativity is not always measurable, observable, or indeed acted upon, but nevertheless plays an important role in the motives shaping other active forms of participation in creative settings like *Setting the Scene*.

The theme of the tangible and intangible relates to other involvements from Sam, particularly during imaginative storytelling. Such activities offered an opportunity for

Sam to share his own narrative ideas with others, while engaging with strongly visceral and sensory notions:

Jenn: /Sam? If you could invent any machine... what would you invent?

Sam: [Nods thoughtfully]. Eh, a machine for making gold bullion [group laughter]... in huge quantities [group laughter continues].

Patricia: Enough for /all of us.

Sam: That's it. And then have a bath every, you know, every two or three hours with all the shackles.

Jenn: /Aww, Sam, that's a /fantastic idea.

Sam: And then, and then your life's works finished then.

Jenn: /Yes. [Group laughter].

Sam: You can graze around your meadows.

'Chitty Chitty Bang Bang' session, 6th December 2018

Being quick-witted and spontaneous, Sam used descriptive language to create a humoured visualisation that the group could grasp, based on concepts that had not been hinted at so far during the session. Graphically describing bathing in gold and grazing '*around your meadows*', Sam touched on ideas that he aligned with contentment, riches and an interpretation of wellbeing, including both natural and anthropogenic/material themes. Furthermore, he used his body and animated facial expressions to communicate his enthusiasm with the rest of the group (Figure 6.8). Overall, Sam's contribution revealed his inventiveness without requiring conceptual or material stimulation.



Figure 6.8: Sam [far left] using words, gestures and expression.

Later in the session, Sam was prompted by Jenn to think playfully about the sounds associated with his earlier imagined gold bullion machine (Figures 6.9 and 6.10):

Jenn: *What sort of noise would that machine make?*

Anthony: *That would make a good noise wouldn't it?...*

Sam: *Yes well, you'd have to invent a sort of golden... golden, alloy. [Responses of 'ooh' and 'ah' from the group]. That, that makes the sound of, eh... /presumably something like gold plates being dropped onto the floor... And very fat people picking them up... and then tucking them under their arm...*

[Loud group laughter].

Sam: *So they can take them. [Group laughter continues].*

Sam: *[Speaks louder above the laughter] You know, at /night time, when they're all asleep. They're all under these...*

Rachel: *[Laughs] oh I like that.*

Jenn: *So, so it's a bit like there's a clang in there... of the gold and then maybe... you know, like that noise you make [puts hand under armpit and looks at Rachel for help on words].*

Sam: *Oh that's right-*

Jenn: *-like a /whoopy cushion type.*

Sam: *Yeah it is, like [demonstrates the sound].*

Jenn: /Yeah /that's it! [Loud group laughter]

Sam: [Speaking over the laughing] Sorry, sorry, I shouldn't have done it. God that was /years ago when I did /that.

*Jenn: That's /exactly how it is Sam, yeah [demonstrates sound and **group laughter** continues].*

'Chitty Chitty Bang Bang' session, 6th December 2018



Figure 6.9: Visual sequence of the 'gold bullion' sound effects.



Figure 6.10: Group laughter in response to Sam's storytelling.

The attentiveness of both the facilitators and other participants was shown to aid the initiation and continuation of a meaning-making, storytelling experience, with Sam's verbal expression becoming interlinked with non-verbal actions and sensory engagements. Beginning to describe the visual imagery of the bodies of workers and the falling of gold plates from an industrial line, Sam light-heartedly moved beyond verbal communication when observing Jenn's body language. He performed the

sound correctly inferred from Jenn's actions, leading to reminiscence of the use of whoopy cushions and the bashful reconnection with bygone days. Storytelling was therefore not limited to words, but sustained the attention of participants through integrating sights, sounds, laughter, biography, and the body. Ultimately, Sam demonstrated that he could be both independently inventive and creatively collaborative at sessions.

Sam's storytelling skills were contextualised after interviewing his wife Deborah, who explained that imaginative stories were an integral part of Sam's identity:

'He was always good at making up stories when our girls were little, didn't you?... And [now] if the rambling starts, around teatime-ish... he can tell us the most peculiar stories. It's weird and wonderful what goes on in that brain... He's always been a deep thinker. But you wonder what's going on in his mind... sometimes he lies in bed at night and chatters away, speaking to himself...'

Deborah, dyadic interview, 22nd May 2019

According to Deborah, Sam continued to engage in storytelling outside of creative settings, even though his deep-rooted passion was becoming more difficult for others to understand. The multi-arts approach adopted at *Setting the Scene*, however, enabled the continuation of Sam's storytelling to be normalised, with many listening ears and watchful eyes to influence and interpret his imaginings. This demonstrated the relational level of participation and wellbeing that could be gained from Sam's expressiveness.

Broadly, verbal-based participatory arts can encourage participants like Sam to continue their passions with a 'can do' attitude, regardless of how their dementia symptoms may be impeding on their daily communication and vocabulary. Verbal communication was used by Sam to not only initiate conversations and encourage others, but to express his identity and long-standing creative interests. This self-expression demonstrated how storytelling can be more-than-verbal, multi-sensory, and socio-material. Objects and props, as depicted in Sam's engagements, can be the 'objects' of conversations and conversation starters; whether materialised and

tangible, or abstract and imagined. Moreover, exchanges between Sam and other members hinted at a larger involvement of humour and laughter as communicative tools, which require specified consideration.

6.4 Humour and Laughter in Dementia-Friendly Arts

Throughout my time at *Setting the Scene*, I realised that all sessions were underpinned by humour and laughter to some degree; observable states often deemed synonymous with happiness, enjoyment and wellbeing (e.g. Innes et al., 2021). It is, however, important to differentiate between humour and laughter, given that the former is usually an intentional means of direct communication, while the latter is an affective, behavioural reaction that can exist without humour, such as with fear, anxiety, or affirmation (e.g. Emmerson, 2017). This can be exemplified by the previously discussed wandering behaviours of Peter, which were often paired with a nervous laughter when discussing matters of separation anxiety with carers (see Section 5.4). This humour-laughter distinction can help to identify the ways that humour was used to produce laughter and wellness amongst participants, and to acknowledge when laughter was provoked by something else. Informed by the scope of this study, focus will be given to the positive impact of humour and laughter on community and wellbeing.

The humoured atmosphere at the programme was typically initiated by the facilitators' cheerful dispositions from the moment participants arrived at sessions. Yet, humour was also extended by the intentional or inadvertent comedy of participants, commonly linked to objects and props. Both of the captured interactions in Figures 6.11 and 6.12 show different spontaneous instances where costumes were able to support humorous performance. As well as stimulating laughter from observing members, the comedic interactions involving props led to more personal, one-to-one interactions, such as the eye contact and laughter shared by Carol and Rachel during 'Mexico' week (see Figure 6.11) or the laughter and touch between couple Ray and Molly at the 'Jeeves and Wooster' session (see Figure 6.12).



Figure 6.11: Participants and Rachel laughing during an activity.



Figure 6.12: Ray dressing up.

These images demonstrate the embodied, corporeal and affective facets of both humour and laughter, which can be fuelled by relationships with objects as well as with other humans. This ties with the previously explored group game in Chapter 5 (see Section 5.2.1), where participants exhibited positive engagements with props. In addition to exhibiting humour *through* and *with* objects, other humorous ideas were shared *about* the objects and costumes presented. During a 'Weddings' theme where facilitators wore vintage wedding gowns, participants were asked to design a gown for Jenn's upcoming wedding, which Rachel drew using the participants' design ideas. This led to numerous witty exchanges between participants:

Jake: *She should wear running shoes...*

Jenn: *So I can make a quick getaway if I change my mind!*

[Group laughter].

Carol: *Would you like a train? Do you think you would like a train?*

Jenn: *Well, you tell me!*

Ben: *But sparkly running shoes-*

Eric: *-what's a train? [Carol quietly explains what a train is] From here 'til Christmas* [referring to the length of the train drawn by Rachel].

[Lots of scattered group laughter].

Carol: *With a little heel? Or?*

Eric: *There's no heel at all-*

Rachel: *-well I've given her a wedge running heel there...*

Ben: *If you have a thick enough veil, people will have to guess who it is.*

[Group laughter].

Jenn: *Surprise/!*

Carol: *And the young bridegroom may be in fear and trepidation...*

'Weddings' session, 2nd August 2018

Playing on the personal attributes of Jenn – who is known locally for her fell running skills and achievements – participants began to permeate the drawing activity with comedic, personal remarks connecting to Jenn's identity, as well as other humoured comments made by Ben and Eric. This activity was participant-led, using humour as a communicative tool to bond personally together, as well as to create scenarios threaded with comedic effect. This example has comparisons with the storytelling and sound effects of Sam (see Section 6.3.1) and the normalising of Joe's sense of disorientation (see Section 6.3), which were more discursive and verbal-based than

the brief humoured interactions depicted in Figures 6.11 and 6.12. Nevertheless, all of these excerpts demonstrate the fundamental role of humour in the multiple forms of communication, participation and wellness expressed by people with dementia, carers, and facilitators.

To gain a deeper understanding of how humour and laughter interlinked, the following vignette considers Joe's distinctive humour and comedy at sessions. This example offers insights into the use of both objects and words in humour, as well as the extent to which behaviour influenced, and was influenced by, the group setting.

6.4.1 Vignette Five: Joe's Comedy

Joe was in his mid-80s and attended *Setting the Scene* as a member of the Amy's Care group. Not receiving an opportunity to meet with Joe's family and learn more about their life stories in an interview, Joe's core contributions to the research project came solely from his attendance at fieldwork sessions. Living with his wife in rural Wigton, north of Keswick, Joe often spoke about his house, garden, and caravan. During most sessions, Joe found a way to mention his days of digging and building as a manual labourer. This was reflected in his demographic form, where he listed his interests to include bowls, caravanning, and digging for work. In the majority of Joe's interactions at *Setting the Scene*, engagement with comedy and the sharing of humour stood out as his most characteristic form of expression.

At *Setting the Scene*, Joe showed that he could be physically active and observant of others, albeit selectively. This included participating in guided ballet arm movements (Figure 6.13) and often being the recipient of dress-up (Figure 6.14).



Figure 6.13: Joe [far right] participating in dance.



Figure 6.14: Joe dressing up during 'Switzerland' week.

Joe's open disposition and honest comments offered entertainment to the group during these dress-up events, which were made in response to the costumes given to him:

Jenn: *Can I put this hat on?*

Joe: *Yes, well.*

Jenn: *Aww /yes.*

[Sounds of affirmation from the group]...

Joe: *No cameras please [laughs].*

[Some group laughter]...

Laura: *I reckon Joe would suit the feather boa too* [places pink boa around Joe's neck]...

Joe: *I think I'm getting worse.*

[Group laughter]...

Jenn: *So we've Todd here who's been kicked out of the circus. We've got this one who's been in trouble with the ladies.*

[Brief laughter]

Joe: *I could always be the clown.*

'Jeeves and Wooster' session, 15th November 2018

Listening to Jenn's mentioning of circuses, Joe made the suggestion that his 'Jeeves and Wooster' inspired character could be a clown, which was a relevant reflection of his real life persona and comedian-like identity in the group.

Another member – Eric – demonstrated a comparable self-identity through humour, albeit affording a drier, sarcastic approach than that used by Joe. This was more often used to play on his intentional lack of cooperation with the facilitators. During the 'Country and Western' greetings game explored in Chapter 5, for instance, Eric decided to express his own character and rejected conforming to the 'howdy how' and 'yee haw' greetings that other participants were invited to say to each other:

Carol: [To Eric] *Howdy how how?*

Eric: *How do you do.*

Jenn: [With 'posh' accent] */How do you /do, we had a /how do you /do. There we go... the /poshest cowboy in the east [laughs].*

[Eric laughs]

Jenn: *Now you pass it to Howard.*

Eric: *Howard?*

Howard: *Yes?...*

Eric: [Tips hat] *Good afternoon.*

[Group laughter].

'Country and Western' session, 7th February 2019

Both Joe and Eric showed that the nuanced features of a social community and its interaction with material objects could assemble a platform for humour, lifting the spirits of others with ensuing wellbeing benefits. Whether cooperating or rebelling, both participants expressed something unique about themselves through the collaborative creative activities.

While some participants were inadvertently humorous, Joe was more conscious in his use of humour. At times when Joe was seemingly passive, he was often listening to conversations and waiting for an opportunity to make people laugh. During a conversation about Eric's past tea-tasting experiences, Joe picked up on the name of a sample tea company, 'Lyons' that Eric mentioned, and fed this back to the group:

Joe: *It would be interesting telling a lion what type of tea to drink.*

[Some group laughter].

'World of Work' session, 14th February 2019

Joe's play on words was displayed on numerous occasions, inspired by contributions made by others to the *Setting the Scene* community. There were, however, glimmers of meaningful social inclusion in Joe's humour, involving specific participants he was more familiar and friendly with from Amy's Care. This was usually Todd, who was quieter than Joe but who spent many sessions seated next to him. During 'World Food' day (Figure 6.15), Joe responded to a story told by carer Anthony about Todd baking as a child, at the weekend, for his parents. A humorous mood had already been cast by Jenn:

Anthony: /Yeah [baked] just on his own, but he doesn't do it anymore...

Sounded like fun.

Todd: Yeah... kept me out of trouble...

Anthony: ...He had the kitchen to himself...

Jenn: I can imagine Todd getting up to mischief [laughs].

Anthony: Yeah [laughs].

Todd: I would get into mischief any time [laughs].

Jenn: Look at that cheeky /face [laughs].

Joe: They [parents] came back and Todd's legs were sticking out of the oven.

[Extended loud group laughter]...

'World Food' session, 18th October 2018



Figure 6.15: Joe, Todd and Anthony working together during 'World Food Day'.

With Todd responding verbally, expressively, and amusingly to Jenn's humorous remarks, Joe saw an opportunity to add a visceral, imaginary scenario to the conversation, leading to an affirming group response. Although expressed in a different and more conscious way than Sam's stories (see Section 6.3.1), the stories and scenarios shared by Joe and Sam illustrated how imaginative, intangible concepts could be shared and accepted within creative settings and social atmospheres. Joe's comments, whilst not conventionally fitting into the unfolding activities, gave precedence to the quick-witted innovation necessary in comedy, signifying that it, too, is a performative art; one with socially powerful permeation.

Regardless of who initiated the interactions in the above examples – whether it was Joe, other participants, carers or facilitators – humour was a socio-material phenomenon with affective qualities able to bind and consolidate a social community. While humour often stemmed from a place of personal interpretation and self-identity, Joe demonstrated that communicating through improvised humour was dependent on the contributions of others. Comparable to the different arts-based activities discussed thus far, humour can be deemed more than a communication device or an indication of sustained attention; in practice, it can be used as a channel by which a larger social atmosphere of wellbeing and teamwork can be realized, though one with intangible, affective forces.

6.5 'Touch' Encounters: The Body and Material World

Previous sections of this chapter demonstrate how participatory arts in conversational contexts can aid 'in the moment' verbal, non-verbal, personal and humourous forms of communication for people with dementia. The vignettes of Sam and Joe invite further expansion on psycho-social-material relations and the presence of familiar or novel objects as communication aids. To do this, it is important to address the body's multi-sensory engagement with props, the agency of objects, and the extent to which these aid better creative, social, and person-centred interactions that can lead to wellbeing.

6.5.1 Objects and More-than-Verbal Props

Through a more-than-human perspective, the following two examples of a beach ball and a fedora hat illustrate the potential for non-human actants to generate 'in the moment' relations and initiate communication across multi-sensory channels.

6.5.1.1 Exemplar 1: A Beach Ball

During a 'Summer Holidays' session during the pilot phase of this study, a small group of participants were introduced to a beach ball game (Figure 6.16):

Jenn: You can't go on holiday without a beach ball, if you're going to a beach.

Rachel: So, we're going to pass the beach ball to each other but we're going to pass it like this [demonstrates how to pass and catch the ball]. And whatever [coloured] square your right-hand lands on, I'll ask you a question.

'Summer Holidays' session, 23rd August 2018



Figure 6.16: Visual sequence of Howard's response to a beach ball.

By combining a brightly coloured, mobile and familiar object with a meaning-entrenched, verbal question game, wider participation could be enabled through the senses of sight, touch and movement/proprioception. The activity became more inclusive and considerate of participants with different skills, including partially sighted and partially hearing Howard, who was able to actively participate with, and expressively respond to, the ball. Howard's peripheral vision was stimulated by the

bright flashes of colour created by the ball's motion, which related to other everyday contexts reported by his wife Peggy:

'Howard can see some things, on the floor, and I can never understand how that is, but apparently there's some sight out of that way [peripheral vision] of his eyes, so I think if he was looking that way, he'd see something. And he can see movement. So if there's a car coming, he knows. If someone's walking past he'll say there's something there....'

Peggy, dyadic interview, 30th April 2019

Howard's sight, though progressively deteriorating, was not necessarily defined by the types of objects he was able to identify, but rather by their mobilities, human or non-human. The movement of participants, and the inanimate objects mobilised by people, were a source of stimulation and inclusion for Howard, indicating the dynamic way that people informed each other's participation through the movement of bodies, things, and alternative senses (Bissell, 2010).

In the visual sequence of Figure 6.16, the beach ball performed as a touch encounter between Howard on one side of the table and Joe on the other, inciting laughter and gaze between the participants and from others at the table. This was absent prior to the beach ball's appearance and suggested the agency of assemblage in creative arts for dementia, referring to the ways that all types of actants – human or object – could perform and influence each other's participation (Barad, 2003; Tan, 2020).

Whilst Howard's participation was predominantly non-verbal, another more interactive and verbal connection was made between Carol and Emily, who had varied stages of dementia:

Anthony: *Shall we pass it? Who will we pass it to?*

Emily: *Who am I going to pass it to?*

Anthony: *How about Carol over there?...*

Jenn: *Carol give her a wave, that's it.*

[Carol waves towards Emily; Emily begins to throw the ball towards her].

Emily: */Woof/woof/woof/woof. Woofety, woofety woofety, woofety.*

[Carol reaches forward. Emily says her last 'woofety' as Carol's hand touches the ball].

Emily: [Claps for every syllable she says in a rhythmic manner]. *And thank. You. Very. Much. Thank you very much, and thank. You. Very. Much.* [During this time, Carol moves the ball/dances with it in time with Emily's claps].

Emily: [Stops clapping while she speaks]. *Thank you.*

‘Summer Holidays’ session, 23rd August 2018

The example of Emily and Carol showed how an object's agency could be utilised to bridge an interaction, even those who were seated out of reach across a large table, similarly to Howard and Joe. Without requiring in-depth conversation or physical touch, Carol and Emily listened to, and watched each other, to form a multi-sensory, improvised, more-than-verbal performance initiated by the ball (Figure 6.17).



Figure 6.17: Visual sequence of Carol and Emily's multi-sensory interaction.

With limited verbal communication skills due to her dementia, Emily used the phrases of 'woofety' and 'thank you very much', which she was known to use sporadically to express excitement or enthusiasm. Accompanying her dialogue, Emily used rhythmic clapping to match the timing of her spoken syllables, in addition to joyous facial expressions and an extended attentiveness on the ball and Carol. Carol, once in possession of the beach ball, accurately moved the ball to harmonise with Emily's clapping and general sentiment. Meaningful participation can therefore be stimulated by object use, enriched with vocalisations, and broadened by varied forms of multi-sensory improvisation.

Without the use of objects, these across-the-table haptic interactions would not have unfolded. In this case, communion was channelled and social inclusion promoted through the use of the beach ball for people with dementia and with sensory impairments (Vogelpoel & Jarrold, 2014). This exemplar positioned wellbeing as an experiential, shared, and more-than-verbal expression of self.

6.5.1.2 Exemplar 2: A Fedora Hat

'It was Country and Western day, and the first member to walk through the doors was Harry, prepared wearing his own fedora. With the scene set by Brooks and Dunn's song 'Boot Scootin' Boogie'... Harry began dancing with the facilitators to the music... when reaching the table, he recreated a spontaneous movie gunfight with Rachel using props, improvisational acting, and making sound effects as he went along. He continued this when others arrived, tipping his hat to non-verbally greet them, watching members wide-eyed, laughing, as well as tapping the table and whistling to the music.'

Fieldnote extract, 'Country and Western' session, 7th February 2019

This fieldnote excerpt from the 'Country and Western' session describes how the mixture of sounds, visual props and the general atmosphere created by the facilitators influenced Harry's arrival and subsequent spontaneous activity, even before the session had officially begun. The hat worn by Harry partially informed his more vibrant behaviour upon entering the room, in addition to the positive reactions

of others to his fedora (Figure 6.18). The musical soundscape also aided him contextually and led to finger tapping comparable to Isaac's response to the hula music in Chapter 5.



Figure 6.18: Visual sequence of Harry's arrival and pre-session behaviour.

The facilitators were already aware that Harry had an interest in Country and Western film and music, through information shared by his wife Patricia. His personal interest in this genre may, therefore, have played an important role in his increased verbal, facial, and embodied participation during this themed session.

I noted that other participants also displayed greater engagement and participation throughout this session, which particularly emerged during the 'yee haw' turn-taking greetings game previously mentioned (see Section 5.2.3). Before any props or objects were introduced, all participants were shown to actively partake in the activity and hold eye contact with each member they greeted. Participants' engagements reached a perceivable peak during the second stage of the greetings, when actions were introduced to accompany verbal greetings. Some participants

found it difficult to act out a hat-tipping gesture without using a physical object, which led carer Janet to spontaneously reach for a fedora and pass it to a participant for their turn (Figure 6.19).



Figure 6.19: Janet reaches for a fedora hat.

By replacing the imaginary hats with something constructive that could be felt, worn, and tipped, participants showed improvements in how they communicated their greetings. This suggested that participants were better able to engage with the activity through the physical object, their touch encounters with it, and the attached meaning that the fedora represented.

The group's responsiveness – characterised by focused attention and joyous laughter – may also have encouraged quieter participants to get involved (Figure 6.20). Peter spoke a loud and clear 'howdy how' while putting the hat on, smiling towards the participant who handed it to him and passing it on to others who continued its journey around the table.



Figure 6.20: Visual sequence of the greetings game with the fedora.

When arriving at Howard, another quieter participant, he projected his voice much louder than on previous sessions (Figure 6.20b]. Maintaining more eye contact with those around him and exaggerating his facial expression, Howard passed the hat to Isaac, actively cheering him to participate and wear the prop:

Howard: [Takes the hat off and passes to Isaac). *Next.*

Isaac: [Takes hat from Howard slowly] *Are we?*

Howard: *Try it on.*

Isaac: *-eh?*

Howard: *Try it on.*

Isaac: *Try it on?*

Howard: Yeah.

Isaac: [Looks around and feels the hat, taking his time with this activity. The group stays quiet]. *Then, go like this then* [puts hat on].

Jenn: There we go.

[‘Ooh’ sounds from the responding group].

Isaac: There we go.

Patricia: Yes.

Isaac: [In country accent] Okay.

[Group laughter and Isaac keeps hat on].

Patricia: John Wayne [laughs].

‘Country and Western’ session, 7th February 2019

Isaac portrayed subtle moments of unintended humour, getting into an improvised character – influenced by the wearing of the fedora and an impromptu accent change – and resulting in an atmosphere of laughter and attentiveness. Although Isaac’s impression comprised one word, it moved away from the repeated phrase being used by the group. The simplicity of Isaac’s unpredictable response assembled one of the strongest group laughter responses during this activity (Figure 6.20c]. The sustained attention and stronger participation of these quieter participants gained momentum through the non-human facilitation of the fedora hat. Participants not only communicated *to* other members ‘in the moment’, but also communicated *through* the fedora hat and what it symbolised once it was on their body. This suggested a ‘co-fabrication of socio-material worlds’, whereby active individual participation within the group-based activity was strengthened by the presence and uses of objects (Whatmore, 2006: 604).

In both the exemplar events addressed, objects sought to support the verbal communication and expression of participants within activities, whether done intentionally – as with the beach ball – or spontaneously – as with the fedora. The

role of non-human actants strengthened the opportunity for participants to connect with one another physically and socially. Guidance on what to say and do may have been offered by facilitators on occasion, but members of the group elevated the success of the activity by improvising and encouraging other's participation. Stanley, Isaac, Howard and Harry in particular managed to expressed aspects of their individuality that set them apart from others and created affirmative responses from the group to their spontaneity. Being 'in the moment' naturally placed worth on the role of the individual, making self-expression more accessible and easily understood, even when centred around one simple phrase, object or broad topic. Here, the effectiveness of participatory arts can be exhibited by incorporating person-centredness into a community setting, in which participants are key players in the process and exchange of selfhoods and relational wellbeing.

6.5.2 Communicating Selfhood and Identity through Objects

Expression of self was not strictly based around words and conversation at *Setting the Scene*, but also through body and materiality. Todd, who was an Amy's Care member, was often encouraged by care staff to share knowledge about his specific wood carving skills with the rest of the group. Whilst carving could not be supported in the programme due to health and safety, Todd's hand-carved walking sticks were occasionally brought to sessions for a brief 'show and tell' (Figure 6.21).



Figure 6.21: Carer Anthony showcasing Todd's carved walking stick.

The walking sticks instigated communal conversations about Todd's skills and held narrative memories of his rural Cumbrian upbringing, locations within which Todd found his materials of horn and wood. Although bringing carved walking sticks to *Setting the Scene* were premeditated decisions, they equally created 'in the moment' discussion and praise for a creative skill that Todd could not demonstrate within the programme setting. In a future session, though, the facilitators drew on Todd's carving interests to overcome a displayed lack of participation in an imaginative art-making activity. The activity invited participants to paint a pretend painting in the air using hand and arm movements, which the rest of the group were asked to imitate. Observing his reservations, the facilitators and carers adapted the activity to include an 'in the moment' tutorial from Todd on the process of carving wood. This increased Todd's attention, who offered verbal directions, albeit brief, to the room:

Jenn: Okay, Todd? Pick up your paint brush and draw us a picture, an imaginary picture.

Rachel: Or you could carve your... walking stick...

Liz: Yes carve your walking stick ...

Jenn: Can you show us, with your hands? And we can copy you? ...

Todd: Ah well, you've to warm them first...

Jenn: So go on then. How would we do it? So show us how you would warm it.

Carol: Do it a bit higher so they can see you.

Todd: It's secret.

[Group laughter]

Jenn: Todd... it's alright, I don't think we could emulate what you do Todd. So do we rub then? Are we rubbing, warming?

Todd: We warm it with a heat gun.

Jenn: The heat gun...

Todd: Put it in a pan of boiling water.

Jenn: Oh right Todd, have a pan of boiling water on the go. Get our heat gun [Jenn acts out boiling a pan of water and using a heat gun for the group to copy]. And how... would you carve the shape... get the shape you wanted?

Todd: Use different files.

Jenn: /Ooh okay. Right, so let's file it.

Todd: Aye. [The group remains quiet while they follow Jenn's movements].

'Inspire Your Heart with Art' session, 31st January 2019

Although not offering a physical, embodied demonstration, Todd offered verbal guidance, stimulated by the facilitator's questions, to the room of participants who attempted to embody his craft. Taking a leadership role in determining the actions of others, the social environment enabled Todd's long-term hobby to be recognised and personified by others. While his form of participation was not originally envisaged for this movement-based imaginative activity, he demonstrated how different participants can be engaged with and attended to through words and imagination, adapting activities to make them personally relevant. These individualised *Setting the Scene* experiences demonstrated that no activity or form of interaction is entirely verbal, but that verbal content was continually entangled in other more-than-verbal elements of movement, objects and bodily communication as influenced by an individual's own perspective. While some participants were more action-based, others were inclined to express themselves verbally. Todd, however, showed that verbal and action-based interactions were at times relational, such as during a Tai Chi activity. Having been previously passive, Todd expressed a brief creative interpretation of a Tai Chi movement:

During a movement Jenn described as 'picking fruit from a tree', Todd saw the resemblance to a more familiar action and said out loud 'or changing a lightbulb', causing laughter amongst the quiet concentration. It was at this point he started to do more of the movements... carefully watching Jenn...

engaging with the concept in his own way which made it more understandable. This was a clever observation that caused supportive laughter...

Fieldnote extract, 'New Year New Experiences' session, 3rd January 2019

Todd displayed unintentional creativity and humour while observing Jenn's actions, communicating the traditionally masculine and manual labouring side of his self-identity. His improved engagement suggested that interpreting an activity in a personal way – and furthermore sharing these thoughts aloud with the rest of the group – made it seem more approachable and easier to engage with (Figure 6.22). Again, this reflected the idea that 'creative arts can remind us of who we are' (Hayes, 2011, p.16) and suggested that person-centred methods of facilitating participatory arts are relevant to heterogeneous group settings, differentially sustaining the attentions and interactions of participants living with dementia.



Figure 6.22: Todd 'changing a lightbulb'/'picking fruit from a tree' during Tai Chi.

Other participants subtly immersed aspects of their self-identities within activities without the participants or facilitators being aware. Touching again on the intangible rather than material world, such an illustration can be drawn from Sam's storytelling, as discussed earlier. During a group-based creative writing task, he contributed the topic of ravens spontaneously outside of his turn:

Jenn: She's been locked up... in a tower. Okay...

Sam: I think there should be the word 'raven'.

[‘Ooh’ responses from the group]

Jenn: /Ooh Raven /Tower.

Sam: Yes, because that has power, within itself, /anyway, don't they?

Jenn: Raven Tower.

‘Chitty Chitty Bang Bang’ session, 6th December 2018

It was not until a dyadic elicitation interview with Sam and his wife Deborah that I learned of Sam’s special interest in ravens:

Deborah: Oh he’s mad on ravens.

Researcher: Oh /are you?

Sam: Yes.

Deborah: The narrowboat was called ‘Raven’.

Deborah and Sam, interview, 30th May 2019

Sam’s suggested imagery of ravens during group storytelling expressed an important aspect of his interests, which at the time was unknown. The magnitude of ravens within his life’s work connected to his handmade narrowboat and adventures within it, in the same way that Todd’s walking stick encapsulated his identity and skills. Hence, the open and non-judgemental approach adopted at *Setting the Scene* encouraged self-expression not only *with* but *about* inanimate objects. The sessions established aspects of self within a creative and accepting setting, even those that went unnoticed, which helped to uphold a sense of personhood, strength and wellness for those participants living with dementia.

Sam and Todd revealed parts of their identities through their use of words in regards to object or material concepts, while other members embodied their interests

through their behaviour and interactions with the material world, as indicated by Harry, his fedora, and the multi-sensory set-up. These fieldwork observations hint at the significance of relational selfhood when living with dementia, in that participants were able to continue aspects of their self-narratives (Synnes et al., 2020) and express their identities through creative ventures. Drawing these topics together, a more in-depth example to close this chapter can be presented by Molly and husband Ray, who offered insight into the extent to which thoughts, feelings and self are recognised through the body's interaction with participatory arts.

6.5.2.1 Vignette Six: Molly and Ray

Molly and Ray were a married couple who celebrated their diamond (60 year) wedding anniversary in March 2019. Originally from Newcastle, Molly worked as a clerk while Ray's careers spanned multiple hands-on professions. Soon after Molly was diagnosed with dementia, the couple moved to Keswick to live with their daughter and son-in-law, though Ray remained Molly's primary carer. The couple previously sang in choirs and had a shared talent for dancing, having attended sequence dance classes six days a week in their youth. This linked to Molly's love of fashion, jewellery, glitter and 'bling'. Molly routinely came to sessions adorned with brooches and glitter nail polish, which Ray revealed he sometimes painted. The couple were inseparable, spending most of everyday together despite the related challenges of Molly's dementia – which included memory loss, repetition, communication difficulties, and reduced focus on tasks – and how this impacted their marriage dynamic. Conversations were mainly led by Ray, with short contributions from Molly. Considering her dementia symptoms and non-verbal interactions at *Setting the Scene*, Molly offered insight into more-than-verbal, arts-based communication, chiefly through touch encounters.

Throughout the couple's attendance at *Setting the Scene*, Ray was more dominant and active in sessions. This was partly due to his spousal caring responsibilities for Molly, but also because of his genuine enjoyment of *Setting the Scene*. He was often observed attempting to encourage Molly to engage alongside him, with mixed

results. The most effective and beneficial activities for the couple, however, were sing-alongs, reflective of their previous choir memberships (Figure 6.23).



Figure 6.23: Ray and Molly singing from lyric sheets.

Molly consistently participated in singing activities, even with songs she was unfamiliar with; this was enabled by following lyric sheets handed out at sessions that could guide participation regardless of whether a melody was familiar or not. Whilst general conversations were testing for Molly, reading words from a stimulus enhanced her verbal communication. When handed lyric sheets, Molly and Ray often read the lyrics together or began singing them quietly before backing tracks began:

Molly: [Pointing to the lyric sheets]. *Which one are we to sing?*

Ray: *This... [sings to self] I see trees of green.*

Molly: [Reads the lyric sheets] *Trees of green, red roses too.*

'Inspire your Heart with Art' session, 31st January 2019

Molly's reading sometimes went unnoticed because it often took place on the periphery, either before, inbetween, or in the background of activities. It also

extended beyond musical contexts to any type of image or object in front of Molly that contained words. This behaviour hinted at the importance of the material world in providing stimulation for communication, particularly in cases where spontaneous conversation is more difficult to initiate or maintain. Molly therefore supports the earlier discussion on objects as conversation starters, though in this case the verbal content was predetermined by what was printed and thereby read.

Beyond word-based activity, it was common for Molly to respond passively; either sitting quietly watching others or reaching for items on the table (Figure 6.24).



Figure 6.24: Molly's hand reaching towards a printout.

While passiveness could be interpreted as showing a lack of interest in the programme, it indicated something more fundamental - that Molly's preferred way of communicating was often through her hands or through the written word. In both cases, having visual and haptic access to relevant objects helped to facilitate Molly's attention and participation, given that she would regularly reach for props on the table that she found intriguing or read them aloud. Molly was particularly drawn to period, vintage and colourful costumes worn by facilitators. This was first noticed during a 'Weddings' session, while the group designed a wedding dress for Jenn:

Throughout the dress activity led by Rachel, Molly was especially engaged with Jenn's vintage wedding dress. She touched the fabric, counted the bows, stroked the pleats, and fixed the veil. With Molly's known interests in beauty, makeup, and jewellery, her intrigue with fashion was well drawn out in this session. After the session ended, the facilitators and I reflected on how Molly was making more sense in the sentences she constructed during and following this activity.

Fieldnote extract, 'Weddings' session, 2nd August 2018

While Molly's contributions to the group dress design were limited, she showed stronger engagement in other elements of the activity; most notably, reaching to touch the dress materials on impulse and fixing aspects of it in a caring, maternal manner (Figure 6.25).



Figure 6.25: Molly touching a wedding veil.

During these haptic interactions, Molly commented on the dress:

Molly: *I like, I like that length because you can't trip over it* [speaking quietly].

Jenn: *Molly likes this* [points at a section of the dress] *so I don't trip up, so she likes the kinda tea dance length...*

Ray: *I like the bows.*

Rachel: *You like the bows.*

Molly: *Yes, like, like on the dress* [Molly, seated next to the standing Jenn, looks at and touches the dress, pointing out the bows].

Jenn: *Oh yeah!/ Bows, well spotted...*

Molly: [Makes comment to Jenn and fixes dress that is sitting out of place].

Jenn: *Mollys sorting me out.*

‘Weddings’ session, 2nd August 2018

Accompanying her touch response, Molly’s emergent verbal communication became more understandable, when previously she had found it challenging to construct sentences or answer questions. Molly was able to convey her thoughts and had a more personal understanding of the activity, because she was given freedom to follow her intrigue through sight and touch. This signified the wellbeing potential of curiosity and meaningful themes, which ensured that people with dementia were treated with dignity and autonomy in supporting their communication capabilities.

The insights made during the above wedding dress activity were applied by the facilitators at later sessions, particularly during a ‘Joseph and his Technicolour Dream Coat’ art-making activity where Molly was not participating. Jenn engaged Molly’s interests by showing her the fabrics on the dream coat costume she wore, while others were creating artwork (Figure 6.26). Molly became quickly focused on the coat’s materials, maintaining extended focus while flipping through the differently textured and coloured layers, all while discussing and engaging warmly with Jenn. She continued to engage in the activity alone when the facilitator took the coat off

and moved to help another participant, showing the facilitation power and agency of objects to sustain arts engagements. Molly's material interactions promoted alternative versions of participation that were equally valid and possible, with more significance to her individuality.



Figure 6.26: Visual sequence of Molly's engagement with the Dream coat.

I also observed moments when Molly's haptic interactions extended beyond session props, to the clothing and belongings of participants. On one occasion, Molly turned to Howard sitting next to her and said '*I like your bow tie*' before reaching out to touch it without hesitation. Vision and touch were not only important senses for Molly's arts-based participation, but also for her social communication with others.

Although expressing interests through her sight and hands, Molly nevertheless presented passively throughout visual art-making, instead watching others being active. In contrast, arts and crafts were one of Ray's favourite activities and he often shared his love of abstract art at the sessions (Figure 6.27).



Figure 6.27: Ray and Molly during a visual art-making activity.

During an activity on visual art themes near the end of fieldwork, I sat next to Molly, who was seemingly distracting Ray from taking part in the activity. By this point, Molly's dementia symptoms had progressed, predominantly characterised by repetition and poor attention. Having witnessed Molly's touch encounters throughout the fieldwork and her interest in beauty, jewellery, and fashion, I took the opportunity to adapt the art-making activity to merge these aesthetic and haptic interests. Taking on a more participative role, I guided Molly's attention by tracing around her hand and suggesting she colour in the nails, inspired by her own manicure (Figures 6.28 and 6.29).



Figure 6.28: Molly participating in visual art.

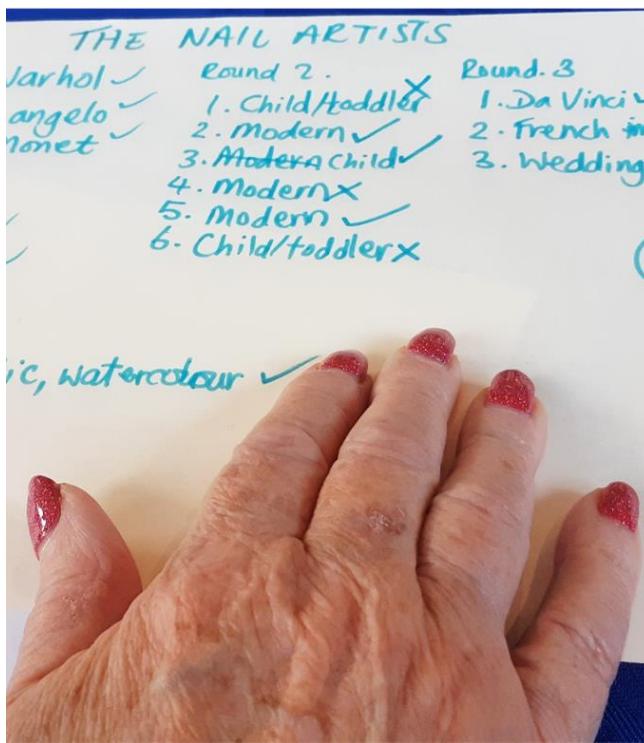


Figure 6.29: Molly's nails during a quiz.

Molly's participation improved, having been given one-to-one support and the adaptation of the activity to suit her interests, recreating a piece of art from an animate, relatable, and felt part of her own body. Inadvertently, this nail-colouring

task integrated Molly's aesthetic interest in nail painting with her hands as her most dominant sense and bodily component. As indicated earlier in Chapter 5 when discussing person-centred arts approaches, participation in less-preferred activities can improve when stimulated by a theme or topic enjoyed by the participant. Molly's active participation extended beyond simply 'being active' towards 'being well', since it communicated personal information integral to her lifelong passions and demonstrated her enduring strengths. Although her dementia symptoms had progressed, Molly was able to maintain attention and participation in an activity that she otherwise disliked, suggesting the benefits of taking person-centred, 'in the moment' and strength-based approaches to arts engagement for dementia.

Whilst human-object interactions seemed integral to Molly's participation, there were events when her memory loss required her to seek help from others. This usually involved asking her husband Ray about the objects in front of them, sometimes repeatedly, having forgotten their purpose or why she was using them:

Molly: [Turns to Ray] *Ray?... Ray?*

Ray: *Yeah?*

Molly: *How did I get those petals?*

Ray: *How did you get them? The facilitators put them there. They put them there. They're plastic. Those are paper petals.*

'Inspire your Heart with Art' session, 31st January 2019

Ray's reassurance and clear answers about the materials helped to settle Molly's confusion, who subsequently continued to physically and non-verbally engage with the props being used in their collage on the table (Figure 6.30).



Figure 6.30: Molly touching petal props on her table.

Molly's experiences can be compared to other participant examples and events explored earlier in the chapter, whereby a hands-on approach with the material world was shown to enable participants' 'in the moment' learning and plurality of contributions. Molly's utilisation of touch – supported by vision, hearing and identity – encouraged her participation and aided in communicating an aspect of her self-identity within the group. Molly's communication was better induced by the tangible world, rather than defined by imaginative concepts that dominated the abstract visual arts enjoyed by Ray. Although she was often observed to be passive or less engaged than other participants, the participatory arts setting facilitated subtler moments for Molly's more-than-verbal communication that often occurred on the margins of the participatory arts. Yet, the contrasting behaviours of verbally expressive Sam, for instance, and the less conversational Molly, could both be supported and communicated within the same participatory arts programme, through different creative channels. Viewing these contrasting engagements arising from the same space, it can be argued that programmes like *Setting the Scene* can uphold the heterogeneity of participants through creativity, materiality and self-identity, all whilst ensuring social engagement can be maintained.

6.6 Conclusion

This chapter has illustrated the variable ways that people with dementia can participate and communicate within arts-based activity, using a range of verbal, embodied and sensory means. While ‘participatory arts’ aim to encourage participation, as the title suggests, what is determined as active or effective participation is dependent on individual participants and their needs: whether it is Sam’s active imagination; Todd’s verbal descriptions; Harry’s theatrical improvisations; Carol’s embodiment of objects; Molly’s dominant haptic and visual engagements; or Howard’s enablement through motion. Exploring participant vignettes and additional fieldwork examples, *Setting the Scene* has exhibited the multiplicity of communication and the emphasis on ‘in the moment’ approaches. Described as a ‘*play without a script*’, the *Setting the Scene* programme has demonstrated the social, psychological and emotional wellbeing benefits of maintaining person-centred and ‘in the moment’ approaches within group-based settings: where ‘individualised yet collective understandings of living with dementia’ can be attended to (Clarke & Bailey, 2016: 449). Participants felt encouraged – whether by the facilitators, another member, a type of activity, or an object – to communicate their creativity, sociability, and self-identity. While participants varied in their participatory, communicative and sensory preferences, they each demonstrated desires to be self-expressive and considered as ‘more-than’ their dementia symptoms. With humour as an unforeseen facet of communication, Joe and other participants further aided in the assembling of wellbeing encounters, through use of comedy and results of group laughter and positive affect. Indeed, this chapter also sought to present the argument that people with dementia are better supported through their relationships with the material world – whether tangible or imagined – and that responses can often be specific to different individuals. Activity types, the sensorial elements they afforded, and the materials they involved, all aided the immersion of participants and their exchanges across the arts setting.

Participation and communication at the programme could not be discussed without the interdependency of the collective factors as recognised above, suggesting that communicating and living well with dementia is enhanced through the interplay of

the psycho-social-material. *Setting the Scene* - comprising facilitators, participants, and materials – promoted a more-than-verbal approach to communication, whereby participants could engage according to their different sensory, verbal, physical and creative strengths. Furthermore, participant communication exemplified the effectiveness of blending person-centred needs with group-centric participation, highlighting the relationality of selfhood and self-narratives in arts practice (Conradson, 2005; Synnes et al., 2020). Given the glimpses this chapter has presented of the importance of social behaviour and the agency of people and things, the following chapters give further consideration to the broader social, physical/place-based and sensory landscapes of the programme.

Chapter 7: Sensing Place and Social Space: *Setting the Scene's* Physical, Relational and Sensory Landscapes

7.1 Introduction

Tying together psycho-socio-material themes examined in Chapter 6, this empirical chapter focuses on participants' place experiences through the broad physical, social and sensory landscapes of *Setting the Scene*. This entailed moving beyond the arts activities and considering other spatial and relational factors – natural, built, social, aural, creative or symbolic – that had potential to facilitate, promote or potentially demote wellbeing and arts engagement. The chapter begins by exploring the impact of The Lake District's natural landscapes on participants' arts-based engagements, framed through the windows of the session venues. This is followed by exploration of the more anthropogenic, interior theatre and creative settings of the Friends Gallery and Crosthwaite Sunday school, where sessions were located. The chapter illustrates the importance of thinking carefully about the physical setting when delivering participatory arts activities and how these places or spaces can inform participants' responses. This is framed by the therapeutic landscapes concept, bringing attention to the interplay and aliveness of different aspects of 'landscape' afforded by these environments, including visual scenes, soundscapes and social atmospheres. The latter of these relates to the sense of community enabled by *Setting the Scene* venues in addition to the programme's intimate social and relational components, as defined by relationships and friendships within the social space. This subsequently formed an important closing section of this chapter, regarding how the programme's social dynamics stimulated, or were stimulated by, arts engagement. This socio-spatial section engages with themes relevant to previous topics in this thesis, but that warranted special attention when considering the over-arching *Setting the Scene* community and layered landscapes.

7.2 The Backdrop: Natural and Built Scenes

Over the course of the fieldwork, the *Setting the Scene* programme was conducted in two spaces – the Friends Gallery at Theatre by the Lake (Figures 7.1 and 7.2) and Crosthwaite Sunday School (Figures 7.3 and 7.4).



Figure 7.1: Friends Gallery windows.



Figure 7.2: View of the lake from the Friends Gallery.



Figure 7.3: Crosthwaite Sunday School windows.



Figure 7.4: Crosthwaite view.

The landscape of the *Setting the Scene* rooms, and the events emerging within the arts activities, were often influenced by what lay beyond the room. Both locations were framed by large windows, overlooking natural landscapes such as farmland, Lake Derwentwater and neighbouring peaks, enlivened by the presence and sounds of people and animals. Throughout fieldwork sessions, these windows acted as a

focal point and conversation starter, much like the stimulation gained from internal materials and objects (see Chapter 6). This was illustrated by Isaac during a conversation-based activity on 'World Food Day' in the Friends Gallery, an activity type he typically found challenging. Outside, the weather was bright and autumnal, while inside Isaac was invited to discuss his favourite foods with the group. Finding it difficult to concentrate on the topic, Isaac began spontaneously commenting on the scenery beyond the windows, as he watched from inside the gallery:

Isaac: I could eh [4 second pause]. /Eh I don't know [2 second pause]. Look-

Jake: Your wife 'Julie' is a good cook isn't she? She cooks you all kinds of different things.

Isaac: /Yes, yes.

Jake: Lots of things.

Isaac Yes [4 second pause]. I think, just looking at this [gestures towards the windows and the outdoors] that we, what we've got in front of us, that, here, eh I think that that's just one of the things that eh... that is, that is very good.

Jenn: Yes.

Jake: It's nice isn't it, the colours?

Jenn: You're right, it's absolutely beautiful.

'World Food' themed day, 18th October 2018

Previously finding this conversation challenging – even with Jake's person-centred encouragement – Isaac turned to what was '*in front of us...here*' and expressed his 'in the moment' gratitude for the vibrant scenic view grasped from his partial sight, which was aided by the brightness of the sun on the trees (Figure 7.5).



Figure 7.5: Isaac [left] speaking about the outdoors.

Isaac's contribution was mirrored by other participants on separate occasions. On a contrastingly dark and foggy January day at the Crosthwaite Sunday school room, Eric spontaneously pointed out the passing mist over nearby peaks, prompting me to quickly capture a photograph through the steamy window (Figure 7.6).



Figure 7.6: Mist rolling over Cumbrian peaks, pointed out by Eric.

Regardless of the weather, natural landscapes captured the attentions of participants, formed accessible ways of initiating conversations, and demonstrated the importance and immediacy of weather and scenery beyond the arts-based activity. While these engagements may point to the cultural significance of the outdoors to Cumbrian residents, scenic views were capable of stimulating positive affect and contributing towards emotional wellbeing (Ulrich, 1984). Indeed for others, the sight and sound of poor weather created an additional sense of accomplishment for the day. Sam expressed such feelings while in the Friends Gallery, speaking with a facilitator at the end of a session:

Sam: It's a wonderful place to be at, isn't it? This site?...They'll have been very few people who've even gone out of their houses...

Rachel: Today?

Sam: Today yes.

Rachel: Yeah a lot of people will have stayed at home when they looked out their doors.

Sam: But it's been nice... to /do this. To go out...

'Chitty Chitty Bang Bang' session, 6th December 2018

Watching stormy scenes through the window, Sam acknowledged that his morning at *Setting the Scene* was more enjoyable because he was able to 'go out' from his everyday home environment and daily routine, to participate in something '*different*' in a '*wonderful place*'. This suggested the importance of embodying new spaces, trying new things and finding alternatives to habituated practices in a bid to live well with dementia; in this case, by joining a new socio-creative community. Moreover, Sam indicated that maintaining an active lifestyle – particularly on days of poor weather – contributed to feelings of accomplishment, resilience, and value. Indeed, while significance is often placed on routinised spaces and daily experiences of people living with dementia (e.g. Clark et al., 2020), Sam's excerpt is suggestive of the wellbeing benefits that novel creative activity and freshness of perspective can

produce. Subsequently, well-managed novelty can be beneficial for wellbeing with dementia (e.g. Camic et al., 2013; 2014; 2019).

Beyond the weather, Joe reflected on the distant peaks as viewed from the Friends Gallery window, during an end-of-session ethnographic interview. Having previously discussed his work memories of digging in the group, he hinted at experiences of mining while we spoke together:

Joe: I mean, we worked here, before we retired. And we used to come down here and it was lovely. The trees and that were a different colour every morning. It was absolutely beautiful... The only thing, we had to go to /work.

Researcher: Yes. So you had a small amount of time to enjoy the outdoors?

Joe: Yeah... we went down that hole... and that was you for the day... when you felt like it, you went out again... and it was still just like this when you went out.

Researcher: Lovely.

Joe: Yes, it was lovely then, it's just you hadn't time to... [laughs] to look at it.

Joe, ethnographic interview, 15th November 2018

Sitting in his wheelchair, Joe recalled his working day and his attentiveness to the landscape's changing colours, as triggered by the views before him. Unlike his youth, he now had time to appreciate the scenic peaks and discuss his thoughts with others, although he could no longer physically engage with the land as he had previously. This brief interaction indicated the ways that people can connect to the physical world without physical engagement with it, and how landscapes can contribute a sense of belonging or wellbeing even when viewed from afar. Frustrations with his mobility, however, were also expressed during this conversation:

'I seem to be there [home] on my own. I can't... my legs won't /move... whenever you go to the hospital... they just say you're alright today.'

Joe, ethnographic interview, 15th November 2018

Between activities or at the end of sessions, Joe intermittently shared concerns with his physical wellbeing; concerns he felt were not recognised by others. Having been accustomed to an active manual labourer's life, Joe implied that his existing physical impairments created a sense of loneliness and decreased wellbeing. Whilst these thoughts were often stimulated by the outdoor views or connected to other landscapes like home or hospital, *Setting the Scene* nevertheless gave Joe a space to comfortably disclose his anxieties. Indeed, his previously explored active participation during sessions provided 'in the moment' creative activity to nurture his humour and strengths, temporarily distracting from his physical limitations.

For other participants, the physical body could be a vehicle to embody connections to the windows and ambient outdoor landscapes beyond. Carol illustrated this during a spontaneous dance with facilitator Jenn to Kenny Rogers' and Dolly Parton's 'Islands in the Stream' track at a Crosthwaite-based session. Carol began pointing to the church building outside and to emblems on the window – comprising a bell, bird, fish and tree – without clear indication of what this meant at the time (Figure 7.7).



Figure 7.7: Visual sequence of Carol gesturing to/beyond the window.

She later explained herself, feeling embarrassed, during a video elicitation segment of an action learning meeting:

Carol: When they were playing that, because I noticed the... the Keswick... thing... [makes reference to pointing towards something in the video recording].

Researcher: Yes, on the windows?

Carol: And the relationship between my life and this church and everything, I was just exaggerating a /bit, pointing at that because it's the whole ambience of the whole building.

Researcher: Yeah?

Carol: Which took me back to when I came back and I got married there... so it was me being a bit... exuberant.

Jenn: We enjoyed your dancing, didn't we?

Rachel: /Yeah.

Carol: But I was a /bit exuberant [laughs].

Rachel: It's alright.

Extract, action learning group, 10th January 2019

Again displaying self-consciousness upon re-watching her spontaneous self-expressions (see Section 5.5), Carol also reflected on how her body movements expressed her lifelong connection to this local site. Her fascination with connecting things – in this instance, between life events, the window's illustrations, and the church as seen through the window – merged to form her interpretive dance. This demonstrated the importance of communication through moving bodies, as a way of linking 'the lived and the abstract' (McCormack, 2008, p.1822). The lived and abstract elements exaggerated through Carol's dance were integral to her selfhood and sense of home, showing how participatory arts can give people with dementia

inspiration to express their life stories beyond words, instead through music, dance, or landscapes (Kindell et al., 2018).

Irrespective of dementia, Carol and Joe were both able to associate different landscapes with visual prompts for their pasts. While the windows were important on an individual level for such participants, they were also a positive trigger for group improvisation. At the end of a session in the Friends Gallery, after the group ended their rendition of 'Bring Me Sunshine', Jenn began to comment on the weather outside in connection to the song lyrics:

Jenn: .../Just as we were singing that, the drizzle came down.

[Group laughter]

Carol: Because it's coming over the top.

Jenn: Yes. The sun is yonder hither over there and it will be coming, appearing round the mountains at some point, this afternoon.

Carol: We'll be coming round the mountain?...

Anthony: [Begins to sing on the spot] 'She'll be coming-

-[The group joins in with loud singing, hand clapping and dancing movements].

'Summer Holidays' session, 23rd August 2018

By quickly interpreting Jenn's words about the external landscape, a spontaneous and wider group rendition of 'She'll Be Coming Round the Mountain' was initiated by Carol and Anthony. The familiar melody and words were quickly carried by other participants, accompanied by smiling, clapping, eye contact and dancing (Figure 7.8). The group applauded at the end of their 'in the moment' sing-along, displaying a shared sense of accomplishment that had originated from the outdoors. As with examples of participation in Chapter 6, this event demonstrated the agency of individual participants over the unfolding events within the larger group setting. Moreover, the event showed that nature-based or external stimuli could influence

music and song, going beyond examples of conversation, visual artwork, and dance presented thus far.



Figure 7.8: Spontaneously singing 'She'll Be Coming 'Round the Mountain'.

Venue windows formed a connection between the interior setting and the outer world, which impacted participant preferences for either Theatre by the Lake or Crosthwaite Sunday School. When discussing both locations at an action learning meeting, a larger number of participants shared their preference for Theatre by the Lake's external atmosphere and environment, while some carers spoke highly of Crosthwaite's practicalities, including easier parking. Harry explained his liking of the theatre by stating '*you can see more of it*', referring to the windows and outdoor scenery. During the same discussion, Carol shared a liking for both spaces, but expressed particular enjoyment for the liveliness, motion and semi-public atmosphere of the Friends Gallery:

'But it's still lovely to be there, because of the ambience of the lake and the movement going on, so, it brings the outer world in... and, so I just like that.'

Carol, action learning group, 10th January 2019

While Harry enjoyed being able to see more of the outdoors while sitting inside, Carol admired the ways that the external atmosphere was brought inside, suggesting an impact on participants' mood and disposition. Indeed the arts activities were designed to be intrinsically stimulating, yet the interactions with what lay beyond the

room reiterated the positive roles of open, naturally bright, community spaces on participation at *Setting the Scene* and ideas shared during sessions. The windows acted as a permeable boundary between the indoor setting and the natural environment; the private and public spaces; and the human and non-human components of those spaces. Most participants discussed the natural landscape through the perspective of the window in both venues, suggesting that it was somewhat out of reach and appreciated from afar, albeit with 'in the moment' meaning and predominantly positive implications for wellness (Ulrich, 1984), with the exception of Joe's anxieties. Having now explored the external visual landscapes, attention can now be paid to built, interior and sensory experiences.

7.3 Sensory Venues: Familiarity and Sense of Space

Both venues where sessions took place were 'semi-public' in nature, which recognises their public location and potential busyness, as well as the private 'cordoned off' space dedicated to the *Setting the Scene* group. This set-up has also been used in previous participatory arts literature (e.g. Selberg, 2015). Whilst both *Setting the Scene* locations shared similar external landscapes, inside the Friends Gallery had a wider accommodating space for movement (Figure 7.9), compared with the more cramped Crosthwaite space, where participants were seated along the room's edge (Figure 7.10).



Figure 7.9: The Friends Gallery on a busy day.



Figure 7.10: Crosthwaite Sunday School on a busy day.

The physical spaces had practical implications for participants from the moment of their arrival. Ground floor access at Crosthwaite improved the accessibility of this location according to carers Liz and Laura, with particular focus given to people with limited mobility. This contrasted to Theatre by the Lake's first floor setting, accessed via elevator or stairs, with competitive, paid public parking on its grounds.

Keswick and Theatre by the Lake's site, more specifically, acted as a place of familiarity for many participants, given that it was the original *Setting the Scene* venue. This was indicated during a period of disorientation experienced by Joe, who expressed his sense of being lost from his morning journey, as well as assuring his new-found sense of familiarity and security:

Jenn: [Sings] /Morning, good morning. How are we?

Joe: Well, we've come a different way, so we're sort of lost.

Anthony: [In background sitting away from the group]. Yeah we took a different way.

Jenn: Aww [laughs]. So you lost your way. Ah, well we'll find our way again Joe.

Joe: No we know where we're at now.

Jenn: Good.

Joe: *But we came a different way, therefore we're going to be lost for the rest of the day.*

[Some group laughter]

Jenn: *But you're safe now. You know where you are now.*

Joe: *Keswick.*

Jenn: *Yeah.*

Joe: *Yes.*

'Chitty Chitty Bang Bang' session, 6th December 2018

Despite his confusion over the different route taken by Amy's Care, Joe went on to verify his present location and sense of place in Keswick and Theatre by the Lake. This incident contrasted to other positive participant engagements with Cumbrian landscapes, suggesting that unfamiliar places could have disorienting and 'untherapeutic' outcomes for some participants, even when based in scenic and revered landscapes. Specifically, this contrasts to Sam's previous positive account of novelty in his daily routine – regarding the activities and his physical location – suggesting that responses vary across individual participants. Indeed, changes to routine may create disorientation for some people with dementia who benefit from regularity, routine and familiarity (Clark et al., 2020). Nevertheless, this can be worked through by facilitators to ensure that weekly participatory arts attendance becomes a regularity, in order for such participants to have new experiences with benefits over time.

Less noticeable but relatable experiences were observed when participants attended Crosthwaite Sunday School for the first time. Some participants were temporarily confused by the unfamiliar venue, which impaired their recognition of the facilitators and I inside. Harry's arrival with his wife Patricia was recorded in fieldnotes:

I opened the door and Harry and I spoke to each other. There was a sense that he didn't know who I was or what we were doing because he asked me if I was one of the big ones in charge. He also asked Jenn what they would be doing and initially seemed reserved. This was not only expressed through

words, but through an observed uneasiness from Harry and watchful facial expressions. When he got into deeper conversation, however, he said it was nice to see us again. Speaking to the facilitators after the session, they think the location initially confused him but that he came around to it with further information and conversation.

Fieldnote extract, 'New Year, New Experiences' session, 3rd January 2019

Familiar places can facilitate the arts engagement of participants by offering them a sense of continuity and security. In the above example, the location change impacted Harry's understanding of the event and his initial interactions with facilitators. Harry settled a few weeks into the new temporary venue, but still mentioned Theatre by the Lake's Friends Gallery in conversation during sessions:

Harry: [Turns to speak to Molly]. *Are we still having the... hmm... the people upstairs?*

Molly: *I don't know.*

Harry: *I don't know... it doesn't seem like it does it?*

'Inspire your Heart with Art' session, 31st January 2019

This overall 'Crosthwaite' response contrasted to a later experience Harry had during the 'Country and Western' session (see Section 6.5.1.2), where he warmly greeted the facilitators and engaged theatrically from the moment he stepped into the room. This happened to be the first session back at the Friends Gallery after a month at Crosthwaite. This may indicate how people living with dementia can continue to decipher the function and ambience of locations, based on past events there. The material and embodied memories of the Friends Gallery remained with Harry whilst being based at Crosthwaite, indicating its impact on his *Setting the Scene* experiences. As a whole, the group reflected similar collective feelings when they gave a celebratory response to being told they would be based at Theatre by the Lake for the foreseeable future:

Jenn: Yeah so we're back here in the theatre next week... we should be back here for quite a number of weeks now...

[Various random cheers from the group of 'hooray', 'wayhey', 'yahoo', and 'yee ha' followed by laughter from Harry and Todd].

'Country and Western' session, 7th February 2019

While Sam's earlier viewpoint demonstrated the opportunities for innovation afforded by participatory arts and the accompanying sense of achievement outside of habituated daily practices, the location or venue where these activities are conducted may be best received by a collective group when familiar and routinised.

When sessions were based at the Friends Gallery, participants often mentioned the colourful exhibition artworks that lined the interior walls (Figure 7.11). Exhibitions changed on a monthly or seasonal basis, drawing the gaze of arriving participants but typically consisting of small enough changes to not cause confusion. Tying again to the local Cumbrian landscapes, carer Ray expressed his liking of the Friends Gallery artworks during an action learning meeting, showing appreciation that the exhibitions were '*all about people in this place, it's their versions of the countryside.*'



Figure 7.11: A sample exhibition on display in the Friends Gallery.



Figure 7.12: Painting [far right] that caused some controversy.

There were, however, isolated incidents where the artwork displayed on the walls had a negative impact on participant mood and/or behaviour, such as an exhibition between November 2018 and February 2019 (Figure 7.12).

Harry, for instance, shared concerns about a newly featured painting in the gallery:

Harry: *Some of them aren't [laughs] very good... And I'm glad most of the people... have their back to me [making reference to one nude image]...*

Patricia: *You know what, I'd never appreciated that so much until... well, now, that we're getting this reaction to the, to the paintings and things...*

Harry: *I'm worried about that lady [gestures towards artwork on walls in front of us] with the thing sticking out of her...*

Harry and Patricia, interview, 6th December 2018

This excerpt was from a dyadic interview based at the theatre, where Harry became distracted by the wall art and vocally expressed his distaste. According to Patricia, the painting clashed with his traditional values and contrasted to the landscapes decorating his home. Yet, other members also responded negatively to the same exhibition, with Molly studying it at closer range at the end of a session:

Molly talked about the art on the walls with me as Ray walked over to get their coats. While I couldn't fully grasp her sentences, she was talking about the

confusion of one particular piece, pointing to it and walking over. She didn't seem to understand what it was about...

Fieldnote extract, 'Beauty and the Beast' session, 29th November 2018

Whilst seemingly trivial and highlighting the artistic differences of participants (many of whom were not affected by the artwork), the few negative reactions indicate the nuances of place experiences and the strong responses of people with dementia to subtle features. Small changes in the 'set up' of a space therefore warrant sensitivity, given the evident roles that material and spatial factors play in wellbeing. It should be noted that exhibitions were out of the control of creative facilitators, but this emphasises why facilitators' props and costume choices for sessions were valuable and needed to be informed.

Attention can also be drawn to the more-than-visual aspects of *Setting the Scene*, in particular the accompanying multi-layered soundscape. Whilst there were often distractions from outdoor vehicles and foot traffic filtering through the gallery windows, the interior space could generally be differentiated by the background music tracks chosen by facilitators to set the scene or suggested by participants in advance. Music and sound elements were shown to be integral to the ambience and atmosphere of the programme, shown in two music and movement activities below, where greater participation was achieved from people who were generally less involved in these activities. These included a ballet-inspired dance accompanied by an acoustic cover of the 'Doll on a Music Box' song from 'Chitty Chitty Bang Bang' (Figure 7.13) and a Tai Chi activity accompanied by an ambient piano and synthesizer piece (Figure 7.14). External noise was limited during these activities, and the group itself quietened as they concentrated on moving and listening.



Figure 7.14: Ballet-inspired activity accompanied by music.



Figure 7.13: Participants follow Tai Chi movements to ambient background music.

Although the group was usually conversational and often had background noise coming from broken-off discussions, the group grew silent during both of the gentle, slow, musical activities. Fieldnotes from the Tai Chi activity further illustrated this:

...there was a calm quiet amongst the group during this activity. Some people closed their eyes... Howard couldn't see the actions due to his sight so Rachel sat next to him to explain things to him better and he began to engage when he had this additional aural support. Before the activity ended, Stanley was making his own movements with his eyes closed. Jenn told me afterwards that she was afraid to end the activity and turn the music off because he appeared to be engaging in a unique way... she didn't want to disrupt this.

Fieldnote extract, 'New Year, New Experiences' session, 3rd January 2019

Even though Jenn was physically and verbally guiding the group with actions, the emotionally moving and thoughtful music choice afforded an atmosphere removing the necessity for sight, instead encouraging the movement of bodies intuitively to the immersive sounds. This extended practically to Howard, whose sight loss meant his most effective way of participating was by listening to guiding words, quietly and personally given by Rachel. Although this created a social togetherness, I argue that these experiences transpired from the physical, sensorial session landscapes and the 'sonic ambience' they afforded (Bell, 2017).

There were also examples when the soundscape experienced was unpredictable and characteristically 'untherapeutic'. One such session became marked by an extended fire alarm and automated announcement played throughout the Theatre by the Lake PA system, stating *'This is a staff announcement. Can the Centre Manager please contact the management team'*. Delaying the session, the alarm startled some existing participants, creating a lasting sense of tension and causing particular distress to a new member in the Theatre by the Lake foyer. Her carer, who was also attending with Clint, explained the reasons for the new member leaving before entering the Friends Gallery; the lady decided not to return to any future sessions. Hence, soundscapes within participatory arts settings require thoughtful consideration, given their roles in both relaxation and distress. There is a lack of freedom and control, however, when based in semi-public settings, given that this alarm was triggered by a smoke machine being trialled for an upcoming matinee performance in the main auditorium. This demonstrates how 'sonic intruders' are possible within larger spaces of activity (Bell, 2017). Nevertheless, this was a rare occurrence, and the reassurance provided by facilitators was important for bringing the group back to a sense of safety and normality.

Overall, the outside environment and the interior place experiences were both important contributors to how participants related to the programme. Whilst routinised landscapes and spaces of familiarity were beneficial for some participants with dementia, others highlighted the benefit of newness and novelty in living well with dementia. Visual, aural and atmospheric facets within the external and internal

physical spaces could have both positive and negative influences, affecting an individual's engagement with the place, people, and activities unfolding within it.

7.4 Social Atmospheres of Community, Belonging and Non-Judgement

The final component impacting the atmosphere, sense of place and community perceived by participants was the overall socio-spatial landscape of the sessions. More specifically, this section considers how social atmospheres were developed, maintained, and enhanced by and through the people attending *Setting the Scene*. Whilst arguably external to the sessions, I also explore how social activity surrounding the programme's internal setting contributed to a wider theatre community and mingled with the session's internal community.

The social activity at Crosthwaite Sunday School was almost entirely dependent on the *Setting the Scene* community on a Thursday morning, with occasional walkers, church visitors and maintenance workers passing by the small building. Conversely, the Friends Gallery was a contrastingly busier atmosphere, given it was a room within a larger theatre building. Theatre and catering staff regularly walked through the gallery, adding motion and occasional distraction (Figure 7.15).



Figure 7.15: Staff member walks through/speaks to the facilitators mid-session.

Although typically closed off from visitors during sessions, the Friends Gallery had an internal glass door and windows separating it from the foyer. Whilst creating some

peace and sense of security, this also offered a partial connection between staff or visitors in the theatre, other ongoing activities, and *Setting the Scene* (Figure 7.16).



Figure 7.16: View from outside the Friends Gallery glass doorway.

This sense of connection to the wider theatre community was accentuated during the Christmas season, when the theatre displayed a Christmas tree in their foyer, inviting staff and visitors to write messages of gratitude on blank tree decorations. This activity was made accessible to *Setting the Scene* members by incorporating it into the session circle, enabling participants to contribute to the wider theatre while seated in the gallery space. Furthermore, the contents of the gratitude decorations indicated the importance of social networks and connection with others: Carol thanked the programme for 'centering' her and giving her a sense of belonging (Figure 7.17); others thanked their friends for helping with hospital visits; and Ray thanked local Keswick residents for helping Molly off public transport (Figure 7.18).

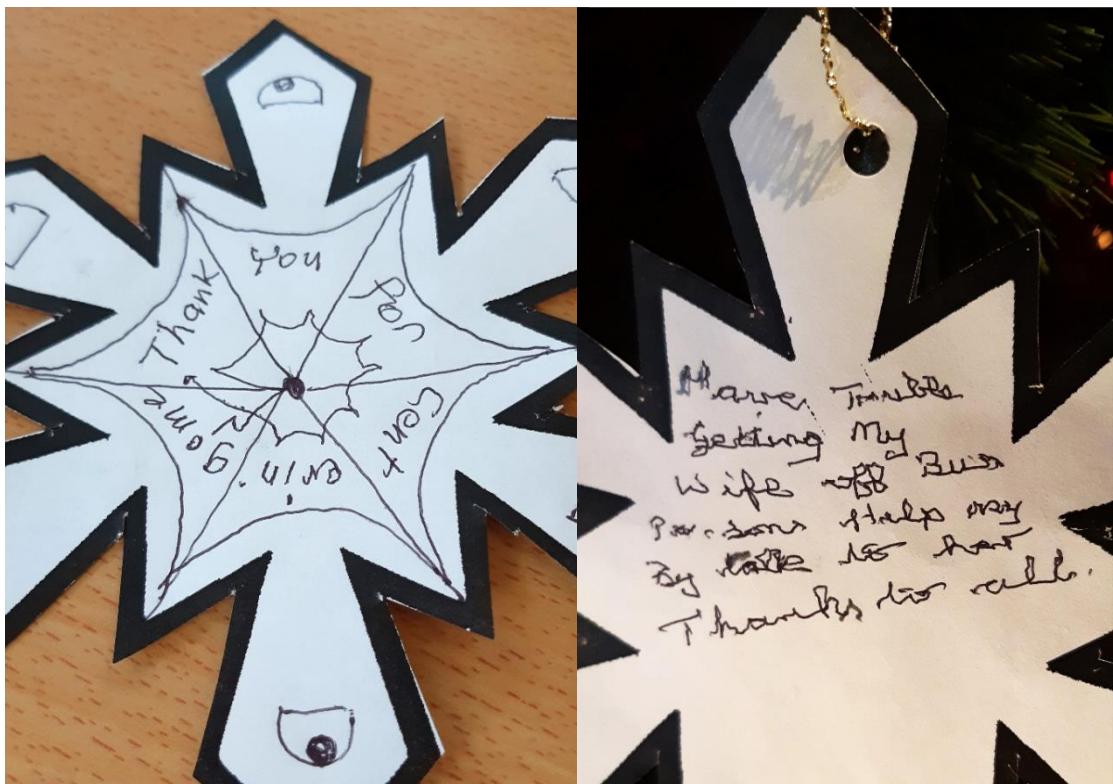


Figure 7.17: [Left] 'Centering' gratitude decoration.

Figure 7.18: [Right] 'Bus' gratitude decoration.

Focusing on the internal programme space, aspects of the room set-up impacted the socio-material relations of participants, as would be the case for a theatre production's set design. Indeed, the participation and interplay between human and non-human actants has been discussed in Chapter 6, but objects also played a central role in creating what was likened to a multi-sensory '*party*' atmosphere, as detailed in other research programmes (Hafford-Letchfield, 2013). At *Setting the Scene*, this included the regular use of costumes; physical table décor, bunting and props; welcoming background music; the taste and smell of cake, biscuits, tea and coffee; and a room of seats ready to be filled with social activity from familiar or new faces and voices. This was felt by Todd, who stated at the end of a session that the programme '*livens things up*', especially given that '*some people take life too seriously*'. The party atmosphere was useful in bringing a light-heartedness to the lives of people living with dementia, who can face a limited events calendar and social withdrawal (e.g. Flatt et al., 2015). Collectively, the socio-spatial scene was set

during immediate arrival to the room, showing that how the internal session space is structured – and indeed the peripheral space surrounding it – can influence the success and atmosphere of the programme.

Upon arrival, participants were invited to take a seat at the table. The table set-up was mentioned by Amy's Care staff members during an action learning meeting:

'Anthony: It's nice to sit around a table isn't it? I think... to sit around a big table, I think everyone quite likes that.

Researcher: Yeah?

Laura: /Yeah it's eh... I, I don't know, round the tables really good because no one is sitting with their back to someone else.

Anthony: Hmm true.

Ray: Yes.

Researcher: Yes, everyone has eye contact-

Laura: -because people miss so much, you know, some people maybe can't hear properly or-

Anthony: -it's good for conversations around the table isn't it?... It's like sat round your dinner table... it's always nice.'

Extract, action learning meeting, 10th May 2019



Figure 7.19: The round table set-up at Friends Gallery.

The carers reflected on the Friends Gallery table as enabling inclusion and active listening, since everyone shared the same focal point and received the same observational opportunities when based in a circular fashion (Tsekleves et al., 2020). Anthony compared this to being '*sat round your dinner table*', suggesting a sense of intimacy, comfort and togetherness accompanying the round table (Milligan & Mossabir, 2018: 33). This was particularly beneficial for those with sensory impairments, whose oral and visual participation could be better stimulated. It is therefore important to ensure that the structure of participatory arts settings consider participant strengths, to uphold a welcoming social atmosphere.

The presence of participants remained the central influence over how group dynamics were defined and embodied in sessions, which predominantly encompassed a sense of community and shared understanding. During an elicitation interview with Sam and his wife Deborah, Sam commentated a video clip of a group balloon game (Figure 7.20):

Sam: There's a girl there, there... and another relative has, has got Alzheimer's or something like that... And we all try to... to... /stick, /stick... we all... want to be... we're with her and everything. And we give her 'come on come on', you know?

Deborah: Oh to encourage her?

Sam: Yes, encouragement-

Deborah: -oh that's kind.

Researcher: Aw yeah-

Deborah: -so you're all sort of sticking together and encouraging each other?

Sam: Yeah and this is... [4 second pause]. Just the /odd, sort of... you know? Just 'try, try having that colour... of balloon.'

Deborah [carer] and Sam, interview, 22nd May 2019



Figure 7.20: A screenshot of the balloon game video clip watched by Sam.

With Deborah's verbal support, Sam explained that participants offered support and encouragement to one another during games, using terms such as 'stick' and 'with her' that indicate a sense of closeness, empathy and attunement to other's needs.

The helpful and friendly environment created by and within *Setting the Scene* can also be understood through other, more elaborate activities. During a Jeeves and Wooster name game, outlined earlier in the thesis (see Section 5.2.1), a sense of comradeship and positivity was felt during turn-taking and the passing of dice. Since the game combined multi-sensory engagement, playful humour, improvisation and novelty of objects, participants demonstrated intrigue and cheered others around the table to participate. Carol encouraged another member to participate, stating '*it'll be fun... it'll be funny*'; this not only pointed to the game as a joyful, '*fun*' experience for an individual, but one that was also '*funny*' for the rest of the watching group. These verbal comments, as well as the overall process during game-playing, glimpsed at the significance of positive affect in living well with dementia, demonstrated by the reliance on others to effectively and '*affectively*' create a positive space for wellbeing. Hence, the group dynamics and larger social landscape were reinforced during particular activities of communal interaction.

Although it was his first session, Sam communicated his thoughts on the Jeeves and Wooster group game with optimism and positivity:

'As long as we work together, then this should be effective.'

Sam, 'Jeeves and Wooster' session, 15th November 2018

Though only new at the time, Sam spoke positively about the importance of teamwork, expressing his gratitude to Rachel at the end of the session both for the activities and for being with '*a pretty good lot*' of people. In doing so, he illustrated how achievement and a sense of community can be facilitated by creative activity and can lead to a sense of relational wellbeing from the early stages of attendance, even for participants who have engaged in more solitary activities in their pasts.

Stanley was also reminded of the sense of purpose each participant had at the group during an elicitation interview. When asked if he was happy during a Tai Chi activity that was being rewatched on-screen, he responded:

'Oh we are, it's a full set, everybody has a... you know, it goes all the way round the room...'

Stanley, interview, 15th July 2019

Stanley attached value to the group, describing them as a '*full set*' and indicating the fair turn-taking that occurred around the table space. Notably, when asked to interpret his own emotional experiences, he instead referred to the group as '*we*'. He interpreted them as expressing positive affect as a collective, which displayed a relationality with others and a sense of belonging that Carol also previously inferred by her use of words (see Section 5.5).

This linguistic '*we*' sense of group membership was also observed with negative connotations. During a 'Ride Out' themed session, that intended to create a fun and energetic social atmosphere, Harry became downbeat and irritable. The reasons for this were not clear at the time, but were felt and recognised by others. Harry's behaviour included clear negative expressions shown on his face, a stern tone of voice, and lack of eye contact with others throughout the session. The footage from this session was replayed to Harry during a video elicitation interview, to ascertain what impacted from his own viewpoint:

Patricia: Yes you weren't happy last week, we know that.

Harry: Well he was useless that fella [Clint], he shouldn't have come in our bit [referring to the session and space].

Patricia: Harry... shh shh shh, you /can't say that.

Harry: You /can, because most people knew that they couldn't speak to him...

Patricia [carer] and Harry, interview, 6th December 2018

Harry made continued reference to, and uninhibited comments about, a new participant called Clint who had Down's Syndrome and dementia. Harry promptly identified Clint's differences, picking up on changes to the overall atmosphere and soundscape of voices. Jenn and Rachel accommodated for Clint's needs by adjusting their volume, tones, and inviting Clint to contribute to activities, though his verbal responses were difficult to decipher. Harry considered Clint as not being welcome in '*our bit*' as though speaking on behalf of the group, suggesting that whilst he felt a sense of belonging with the existing members, he believed Clint did not fit in or was not welcome because of his differences. This may, in part, have reflected Harry's long-held views; yet, the situation also suggested that Harry's desire to live well with dementia felt compromised when seeing others with more advanced symptoms or varied skill sets than his early-stage dementia. Given that people with varied stages of dementia typically respond differently to activities (e.g. Peeters, Harbers & Neerincx, 2016), Harry's judgement may therefore have stemmed from fears about his future with dementia. Still, as previous chapters of this thesis have illustrated, the participatory arts setting created opportunities for more-than-verbal communication that could aid Clint. Even though he did not regularly attend or feature heavily in the research, no other participants made negative comments about his attendance; on the contrary, the atmospheric changes to the group were observably positive, welcoming and non-judgemental. Warm and jovial farewells from every member of the group were given – with the exception of Harry – when Clint and Natasha had to leave a session early (Figure 7.21).



Figure 7.21: Visual sequence of Clint's jovial farewell, with a distracted Harry.

The openness and acceptance of Clint as part of the community encouraged him to give a thumbs up to everyone, which was returned with smiles and extended gaze. From the outset, this event suggested the potential ripple effects that a single participant's behavioural and social responses can have within a larger network, reflecting the importance of attending to outliers in small group settings. Harry's response to Clint was an anomaly amongst the group, however, with others embodying an overall atmosphere of acceptance, hospitality, and adaptable communication. This was a positive outcome, but Harry's responses hinted at the reasons for designing dementia activity groups to meet the needs of people in specific dementia stages, where concerns and skills are more relatable.

The participants at *Setting the Scene* often displayed an air of acceptance towards each other as opposed to questioning contributions on grounds of correctness. This 'no right or wrong' approach was recognised early as a key intention of the

facilitators (see Chapter 5) and was well captured when participants created their own nicknames and back stories during a ‘Country and Western’ storytelling activity:

Jenn: *Hmm and finally, Eric. What would your cowboy name be?*

Eric: *I don’t think so.*

Jenn: *You wouldn’t /have one?*

Eric: *No, I don’t think it would be-*

Carol: *-what’s wrong with ‘I Don’t Think So’?*

‘Country and Western’ session, 7th February 2019

Rather than assume Eric was refusing to participate, Carol interpreted his words as a suggested nickname, demonstrating the non-judgemental approach promoted in sessions. This was also exhibited from the group when Stanley was uncertain about the appropriateness of sharing his hospital experience:

Stanley: *Well if I tell you what I thought.*

Carol: *Go on-*

Jenn: *-/go on then.*

Stanley: *No no I can’t, because it’s-*

Carol: *-/why not?*

Stanley: *No, because it’s...*

Laura: *-it’s alright, we’re all adults-*

Carol: *-we’re all adults-*

Sam: *-because it’s copyright?*

[Group laughter]... **‘Chitty Chitty Bang Bang’ session, 6th December 2018**

Instead of responding with hesitation to Stanley saying '*I can't*', the group collectively reiterated the no-right-or-wrong openness of the programme's social landscape. The support offered to Stanley led to the sharing of his hospital visit that, whilst unrelated to the ongoing storytelling activity, was made relevant by other participants and led to a sense of contribution (see Section 6.3). The shared attitude of the *Setting the Scene* community gave a person-centred edge to group dynamics, thereby creating more opportunities of relational wellness for individual participants.

Participant heterogeneity was also demonstrated in the varied ways that people acted or reacted in the group. This awareness of difference – contrasting to Harry's response to Clint – was generally seen as a positive facet, as reflected by Carol:

'It [the programme] has helped me to understand how, we all react with each other in different ways, so it has been very moving, to actually, join in... Because I don't want to get put in a home, you see... so that was my little attitude [brief laugh].' **Carol, action learning group, 10th January 2019**

Carol's desire for independence and freedom was fueled by her fear of moving into a care setting. On a positive note, she experienced a sense of liberation by being part of *Setting the Scene* sessions: by seeing and feeling participants' '*different ways of being*', as she described it. The diversity of participants' '*in the moment*' social and creative experiences not only led to a strength-based approach and respect towards those others, but also towards oneself, as shown by Carol.

The social landscape at *Setting the Scene* has been addressed for its material qualities, but this section has also emphasised the responsibilities of the collective members to create social atmospheres of encouragement, non-judgement and community within those landscapes.

7.5 Concluding Thoughts

I have demonstrated the ways that encounters with natural, physical, and social landscapes are felt through the bodily senses in addition to the nuanced 'senses' of self, community, and belonging, which can each contribute to relational wellbeing experiences. Sights, sounds, smells, tastes, or touch-based occurrences within

Setting the Scene had agency and affect, positively or negatively impacting a person's overall experience. Natural Cumbrian landscapes and the scenic views available through the windows, played predominantly positive roles in how participants communicated, interacted and engaged with others 'in the moment'. For some participants, the familiarity of the peaks and woodlands incited conversations about the past – with both positive and negative implications – while others felt inspired and productive when viewing stormy weather from the creative, safe indoors. The built environments of *Setting the Scene* were varied in their influence on the mood and behaviour of participants, with familiarity and regularity of space being deemed important for creating a sense of belonging while participating in a programme of novelty. Subtle elements of built and social landscapes, such as the wall art or individual participants, demonstrated the swaying influence that these factors could have on how atmosphere, affect, and responsiveness unfolded within participatory arts engagement. Positively, the interactions and communications within the group dynamics and overall social landscape were observed to be predominantly welcoming and non-judgemental, established collectively by members and facilitators. Overall, this chapter shows how selfhood, creative engagement, social endeavours, and ultimately the experience of relational wellbeing, emerges in and through relations with other people and landscapes.

Chapter 8: Perspectives of Caring in Participatory Arts

8.1 Introduction

This final empirical chapter builds on the previous chapter's social landscape content, attending in further detail to the experiences, perspectives and relationships of carers within the *Setting the Scene* programme. This chapter considers how both professional carers and accompanying family members help to facilitate the programme, as well as their role as independent participants in their own right. The latter point seeks to address whether it is beneficial for carers to be considered as participants alongside their loved ones within participatory arts contexts, taking into account their own enjoyment of arts and the role of the arts in improving or enriching their spousal or family relationships. I draw on further exemplars to illustrate the extent to which carers' contributions at the programme benefited others and/or reaped benefits for themselves, as well as any challenges that this may have presented. The chapter's closing section considers the desires of participants with dementia to care for or about others, and the extent to which opportunities of responsibility and care help to consolidate community, sense of control and relational wellbeing for these members. Overall, this chapter seeks to address the outcomes and complexities of care within participatory arts.

8.2 Carers as Facilitators

The *Setting the Scene* programme was led by two paid creative facilitators, Jenn and Rachel, whose practices have already been reflected on for influencing unfolding events and participants' responses (see Chapters 5 & 6). Yet, the large turnout of participants at sessions often led professional and family carers to take on ad-hoc facilitator-like roles within activities. This has already been demonstrated in previous examples between Isaac and Jake (Section 5.3) and with Ray and Molly (Section 6.5.2.1). Another instance unfolded during 'The World of Work' session, when a less participative member called Eric became a lead contributor to conversation. While the group were discussing unusual careers and job titles, carer Jake shared interpersonal knowledge about Eric's past, which he remembered from his time

working with him at Amy's Care. Eric's surfacing expertise on tea, and the intrigue of listening participants, sustained a longer communal conversation:

Jake: *Eric used to be a tea taster.*

Eric: [Towards Jenn] *Are you talking about tea tasters?*

Facilitator 1: *Are you a /tea taster?*

Eric: *I was.*

Liz: */Were you?*

Eric: *Yes.*

Jenn: *So what kind of tea did you taste?*

Eric: *Just all sorts... everything.*

Jenn: *Every different type of tea?...*

Eric: *Every type of tea. You tasted it all, and then you recommended, which blend to go with.*

[Positive comments and responses from the group].

Eric: *Because it's always changing. The waters changing... it's quite complicated...*

Liz: *Did you work for a company?... Like Brewbound Tips?*

Eric: *I worked for a company yes.*

Liz: *Which one?*

Eric: *It was called C.S. Smith.*

Patricia: */Oh ...*

Carer3: *Do you recommend you put your milk in first, before the tea, or the milk in /after the tea?...*

Eric: *The milk went in first, to save the china from cracking and breaking.*

[Loud responsiveness from the group].

Eric: *No other reason at all.*

Noleen: *I didn't know that.*

Eric: *The bone china would crack, so they'd put the milk in first and then slowly came to heat.*

Carer3: *Well that's fascinating...*

'World of Work' session, 14th February 2019

These selected excerpts from a larger conversation reveal the ways that Eric's responsiveness was facilitated by carers' questions. In admiring his knowledge and showing keen interest in learning from him, carers offered Eric a sense of control and respect that had meaning for his selfhood and wellbeing. As shown in Figure 8.1, the entire group attentively watched and listened as Eric gave his most extensive contribution to the programme, displaying clear intrigue on their faces.



Figure 8.1: Group responses to Eric's answers about pouring tea.

Eric's behaviour during this activity illustrated a sense of pride and self-worth, that his experiences were being valued by others. This created an additional sense of purpose and empowerment for him that had not previously been displayed.

Given the daily roles required of carers, they often thought consciously in session activities about how to encourage other members to engage. This was portrayed through verbal instructions or word-based activities – like the improvised ‘She’ll Be Coming Round the Mountain’ song initiated by professional carer Anthony (see Section 7.2.1) – but also unfolded through touch-based support for participants requiring practical guidance (see Figure 8.2). During a ‘Mexico’ session, Isaac had difficulty understanding the function of a hand-crafted moustache that he had coloured in alongside Rachel, consisting of a piece of card on a lollipop stick. At one point, Isaac placed the lollipop stick into an unfinished cup of tea sitting in front of him. Seeing his confusion, Jake helped Isaac use the object as intended by touching and guiding Isaac’s hand, simultaneously offering a visual guide using his own moustache creation in the other hand.



Figure 8.2: Jake helps Isaac with motion, touch, and visual guidance.

Similar haptic interactions occurred with Emily, whose dementia had advanced quickly after experiencing a stroke during the fieldwork period. Amy’s Care staff member, Janet, interacted by placing objects in Emily’s hands and holding them together (see Figure 8.3).



Figure 8.3: Janet and Emily interact with small objects.

Both instances indicate the significance of touch as a mode of communication, but particularly when instigated one-on-one by carers. This was most applicable to professional carers, who typically had their 'on duty' hat on at sessions. Staff from Amy's Care – such as Anthony and Laura – participated in training during *Setting the Scene*'s early development stages and were therefore well-versed in both arts and care practices. Similarly, Janet had supported facilitator Jenn in other creative projects outside of *Setting the Scene*. Yet, family carers also played intuitive social roles in the continuation of activity and gained value from giving their time to others at sessions. This was true for Ben, who continued attending irregularly after his wife went into a care home and later passed away. Although he took his place as a participating member, he spoke about the help he hoped he brought:

'I see my role as going in, helping out and telling little stories, you know [laughter] either to their amusement or to 'eugh' [laughs]... /In a way, it keeps me in touch with my wife when I haven't been able to see her and in a way it is to say thank you for what they've [Setting the Scene] already done... I /enjoy it.'

Ben, interview, 13th September 2018

Ben experienced personal benefits by considering *Setting the Scene* as something that kept him emotionally close to his wife, who (at the time of interviewing) was living too far away for regular contact. He also felt he was giving back to the facilitators who had helped create a framework for valuable moments with his wife. He did this by sharing his storytelling passions, often standing and telling personal and sensory accounts that encouraged attentive listening around the table (see Figure 8.4). This was reflective of his past career as a teacher and lecturer. He spoke of the '*stained glass windows*' of an old renowned Keswick hotel where he and his wife got married; an area where they once lived that was notorious for its pungent '*pig farm*' smell; and the feeling of climbing local fells like '*Fleetwith Pike*'. Ben took spontaneous opportunities to be an ad-hoc storytelling facilitator, making him distinct from other participants, but approached with an inclusive, attentive air.



Figure 8.4: Ben's storytelling.

Ben's contribution to the enabling social landscape was also manifested through his personable manner with individual participants. During a hands-on, individualised, dough creation activity during 'World Food' day, Harry and Ben sat next to each other, spoke with each other, and Harry went as far as to add detail to Ben's piece (see Figure 8.5). Ben reflected on this during a 'show and tell' after the activity:

Ben: Eh... well as we were talking about foreign food, I made a croissant.

Jenn: /Ooh.

Harry: A croissant.

Ben: And... [puts hand on Harry's shoulder] my friend here put a cherry on top.

[Group laughter, including Harry, Ben and Patricia].

Jenn: Aww fantastic.

Harry: It's dead now.

Ben: So it's a croissant with a cherry on top.

'World Food' session, 18th October 2018



Figure 8.5: Visual sequence of Ben and Harry interacting together.

Considering Harry a 'friend' and placing a hand on his shoulder, both men demonstrated the ways that carers and people with dementia can help each other; be it socially, creatively, or both. While Harry was the initiator of most of their spontaneous interactions, Ben's openness and sociable nature facilitated Harry's repeated, positive exchanges, contrasting to other experiences that negatively impacted Harry's engagement (see Sections 7.3 and 7.4).

A smaller number of family dyads attending sessions offered further insight into the extent to which close family carers can offer supportive facilitation for those they attend with. A vignette exploring this is of mother-daughter dyad Noleen and Liz.

8.2.1 Vignette Seven: Liz and Noleen

Noleen was in her mid-80s, living with early-stage dementia and a cancer diagnosis, and was supported by her husband and other local family members. She joined *Setting the Scene* from January to March 2019 with her daughter Liz, before sadly passing away from a short illness. In her short time at the programme, Noleen shared about her past career as a civil servant and how both her and Liz were active church goers in their community. While Noleen enjoyed sudoku puzzles and bird watching, Liz loved dancing, theatre, reading and classical music. With some differences in interests, Noleen and Liz both shared a passion for music, which was reinforced during *Setting the Scene* sing-alongs.

Noleen and Liz first arrived at *Setting the Scene* during 'Inspire Your Heart with Art' day in January 2019. I noted that Noleen was somewhat reserved and apprehensive during the art-making, crossing her arms in front of her body, which she occasionally repeated throughout future sessions (see Figure 8.6).



Figure 8.6: Noleen [dusty pink cardigan, arms folded] during group work.

At times, Noleen expressed a subtle distaste for particular activities:

Liz: *Oh we're getting creative again.*

[**Noleen** makes an undesirable expression briefly when facilitators aren't looking].

Liz: *Put a smile on* [laughs and rubs Noleen's arms; Noleen smiles/laughs].

'The Romans and Hadrian's Wall' session, 14th March 2019

Contrasting to Noleen's art-making reservations, Liz took on a leading role in facilitating the artwork being created by their group, easing her mother's apprehension by being creatively pro-active and physically affectionate. Liz was an important influence on Noleen's participation, being observably optimistic, chatty and encouraging when her mother was uncertain:

'Well, it doesn't matter, you put them /wher/ever you like... there's no right or wrong love. You put it where you want.'

Liz, 'Inspire Your Heart with Art' session, 31st January 2019

Liz's non-judgemental approach to arts participation facilitated reassurance for Noleen, who often required repeated encouragement before engaging. Indeed, Noleen's lack of interest in art-making activities or large communal conversations remained over time, both of which had dominated her first two sessions at *Setting the Scene*. Although she engaged intermittently, Noleen often became withdrawn and occasionally responded to her daughter's ideas with reluctance. It was difficult to know whether Noleen's response to art-making would have improved with more time spent getting comfortable at the group, or whether her response was integral to her personality and preferences. Nevertheless, when prompted during other activities, Noleen regularly interacted with a friendly and positive demeanour, which was mirrored by Liz's enthusiasm and willingness to participate in most, if not all, session activities (Figure 8.7).



Figure 8.7: Laughter during 'Mexico' themed session.

Noleen showed more eagerness during movement and music-based activities. During an Italian-inspired dance activity, Liz began actively participating, given her long-standing passion for dance outside of *Setting the Scene*. Noleen ended up participating alongside Liz, and afterwards shared her sense of amusement and achievement with her daughter:

Noleen: [To Liz] *I did it [laughs].*

Liz: *You did it, I'm proud of you [laughs with Noleen]. You're a star pupil.'*

'The Romans and Hadrian's Wall' session, 14th March 2019

Whilst not being Noleen's preferred activity type, it offered the mother-daughter dyad a chance to move together non-verbally and contribute to wellbeing through a sense of accomplishment and receipt of praise. Although exemplifying the ways that *Setting the Scene* could help carers achieve personal benefits as participants in their own right, the experience also indicated that watching her daughter Liz responding positively helped to facilitate Noleen's eventual involvement.

In contrast to art-making, the engagement of Noleen and Liz during music-based activities was compelling and positive from the outset. Seated side by side during sing-alongs, the mother-daughter dyad often mirrored each other's body movements while singing jovially. They rhythmically tapped their feet and leaned in towards each other' bodies with eye contact, warm smiles, and facial expressiveness matching the song lyrics. This was particularly pertinent during a Doris Day 'Que Sera Sera' sing-along, on what ended up being Noleen's last session (Figure 8.8).



Figure 8.8: Visual sequence of Noleen and Liz singing 'Que Sera Sera'.

The engagement between Noleen and Liz – through private comments and laughter – displayed their close familial bond and highlighted the significance of shared or paired activities between people with dementia and their family carers, where creative wellbeing can be jointly experienced. Similar, though more subtle, experiences were exhibited by Ray and Molly, who had a passion for singing (see Section 6.5.2.1). Ray and Molly were not as expressive as Noleen and Liz, but remained jointly absorbed by sing-alongs and focused on lyrics sheets (Figure 8.9).



Figure 8.9: Ray, Molly and Ray's brother singing together.

During Noleen and Liz's sing-along, both members spontaneously extended their non-verbal interactions to include others in the group at the same part of the song, holding their gaze until the song's ending; seconds apart from each other, they offered a 'thumbs-up' to these members. Noleen's interaction happened to be with me while I was standing outside of the camera frame (Figure 8.10):

Noleen looked up from the lyric sheets and made eye contact with me. We smiled at each other while singing the final chorus, not needing to read the lyrics very much. At the end, Noleen gave me a thumbs-up with a big smile. I found it very touching to connect with someone in this way through music.

Fieldnotes from 'The Romans and Hadrian's Wall', 14th March 2019



Figure 8.10: Interacting with others across the room.

Unlike other art forms, music activities showed particular relevance to Noleen's experience of wellbeing, aided by having Liz by her side. Their intimate musical moments demonstrated the significance of having a loved one present, for comfort and for social interactions. Through a familiar song that held potential meaning and memory, Noleen and Liz could creatively connect with each other and extend these connections to others in the room, 'in the moment', beyond that which had been ascertained through visual art-making. Art-making dynamics unfolded with Noleen's apprehension, which nevertheless created opportunities for Liz to facilitate and encourage her mother's participation. Whilst not being entirely dependent on Liz, Noleen's experiences showed the contributions that family carers made to the social landscape of creative arts, suggesting that they extend the practice of main

facilitators and professional carers. This mother-daughter dyad often gained benefits of fulfilment and satisfaction from different types of activities, albeit together in the same setting, thereby showing the capacity of participatory arts to create 'in the moment' joint respite whilst reinforcing relationships. Ultimately, the sessions offered moments of connection and meaning for family dyads, where carers could experience gratification, facilitate relational wellbeing, and gain their own sense of empowerment beyond conventional caring duties.

8.3 Carers as Participants

Carers demonstrated their facilitating support through verbal guidance, physical touch, and their enabling attitudes at *Setting the Scene*. However, carers also experienced benefits as participants in their own right, as the above experiences of Liz began to demonstrate. This matches the premise behind *Setting the Scene*: to foster a space for both carers and people with dementia to be considered as equal participants and experience personal benefits alongside one another. Carer wellbeing was observed in multiple forms, including their independent enjoyment of activities and how participatory arts aided their existing partnerships.

8.3.1 Carer Individuality and Enjoyment

Laura, an Amy's Care staff member, illustrated her enjoyment of the programme activities during a 'Jeeves and Wooster' storytelling game explored in Chapter 7 (see Section 7.3.1). Laura is presented as asking: '*Oh can I have a go?*' followed by stating '*I love this game*'. After helping members seated next to her, Laura stood up at the table to roll her dice, visibly smiling while participating for herself (Figure 8.11).



Figure 8.11: Laura playing the 'Jeeves and Wooster' name game.

Laura's verbal and visual pleasure during participatory arts activities had an ensuing 'affect' on the rest of the group, who became quieter and more attentive as they watched their carer taking a turn. Laura displayed an understanding that sessions did not intend to distinguish between people with dementia and their carers, therefore taking the opportunity to seek enjoyment on an equal level with her clients. Rachel's innovative 'Jeeves and Wooster' game showed ways of making something as entertaining for carers as for people living with dementia, by 'playing' on the unknowns and learning new things collectively as they occurred 'in the moment'.

Like Laura, another Amy's Care staff member called Anthony also contributed to aspects of activities where his behaviour suggested an interest and benefit to taking part. During an action learning meeting, he stated his particular enjoyment of the 3D collage activities, which he was pictured participating in with Peter in Chapter 5 (see Section 5.4, Figure 5.25). His engagement with arts had a more personal, skill-based explanation, given that he had a Fine Art degree; information that was only revealed part-way through the fieldwork. Anthony's presence at the programme therefore helped to blend two important aspects of his identity – caring for others and working with aspects of art-making (Figure 8.12).



Figure 8.12: Anthony and Stanley with a piece of their art.

Carers showed particularly heightened levels of engagement in conversation-led activities. This often took the form of storytelling contributions, the description of

life experiences, and sharing knowledge relevant to session themes; this has so far been touched on by Ben, who considered himself aiding with storytelling and facts. Other carers also shared stories relevant to different sessions: Jake spoke about his wedding ceilidh during 'Love and Marriage' week; Patricia spoke of her career as a Home Economics teacher during 'World Food' week; and Laura described her family trip to Bavaria during 'The Sound of Music' week. Hence, participatory arts with discursive underpinnings were important to the selfhoods of carers, many of whom had taken on their new roles voluntarily or informally and had other life skills or experiences they were keen to share. Expressing more imaginative storytelling, Liz took an opportunity during a 'show and tell' to give an in-depth interpretation of a 3D collage she created alongside Noleen and Stanley (see Figure 8.13):

Liz: Right well we just looked at the dark and light in life... these were yellowy shells?... Sort of like good. And the /star. We /even thought that might be religious, but, anyway, and there's three up here. It could be trinity, or it could just be three.

Harry: That's nice.

Liz: And then we've got the /evil one lurking, I don't know if you can see this one. It's really interesting, look at it...

[Group laughter]

Carol: Oh that's brilliant.

Liz: Isn't that amazing?

[Sounds of agreement from the group as Liz shows prop to everyone].

Stanley: It's a nice piece of stuff that is.

'Inspire your Heart with Art' session, 31st January 2019



Figure 8.13: A sea-inspired 3D collage by Liz, Noleen and Stanley.

When her group were hesitant to speak, Liz showed extended interest in the creative interpretation of the objects they had worked with, feeling comfortable to draw her religious background into the discussion. Whilst personally enjoying the activity, she also took care to show the objects to the other group members, to create communal inclusivity. This, in turn, encouraged comments from Stanley, Harry and Carol.

Carers were typically more vocal than people living with dementia and were therefore beneficial for augmenting conversations during moments of silence or hesitation. However, carers occasionally became unintentionally dominant and spoke over those who took longer to respond, which could, at times, disadvantage the participation of those with dementia. During a discussion on Latin phrases, multiple smaller conversations began unfolding, one with Molly and another between a carer and Eric; members who were typically briefer in their verbal communication. Nevertheless, these were overshadowed by professional carer Janet:

Jenn: Molly, you did Latin did you?... But you can remember your roman numerals can you?

Ray: Molly?

Molly: *Sometimes [laughs].*

Jenn: *Yeah? Sometimes yeah.*

Ray: *Molly-*

Janet: *-I can remember two things. I remember [continues in Latin phrases]-*

Eric: *[Quietly speaks to a carer next to him] I can remember [Latin phrase].*

Carer2: *You did Latin Eric?*

Liz: *[Listens to Eric speaking]. /Oh go /on then, tell everybody. [Eric laughs].*

Janet: *[Continues in Latin].*

Carer2: *What does that mean Eric? I am, you am-*

Eric: *I am, you am, eh.*

Liz: *[Makes eye contact with Jenn and points to Eric]. He knows some.*

Janet: *[Continues in Latin]. And that's about it, that's the end of my Latin.*

Jenn: *Wow.*

Carer2: *Eric can-*

Janet: *-[begins another Latin phrase in the background]-*

Carer2: *-/Eric can conjugate a verb.*

Jenn: */Eric!*

‘The Romans and Hadrian’s Wall’ session, 14th March 2019

Although Janet demonstrated an interest in the topic and an eagerness to share school day memories, her enthusiasm overshadowed the voices of Molly and Eric. Similar incidences of carer participation, although brief, also occurred in other sessions, highlighting the challenge of balancing the voices of different members within a creative programme which seeks to benefit all. Whilst typically involving carers, this issue was also true of more vocal people with dementia overshadowing

quieter members. These incidences required facilitators to recognise and make room for different perspectives to be expressed. In the current example with Janet, other carers in the group – who acted as additional facilitators – helped to alert Jenn and steer attention back to Eric and his memory of Latin phrases.

As with Eric's tea tasting knowledge considered in Section 8.2, the evading of power dynamics at *Setting the Scene* enabled the group as a whole to be open to new learning and knowledge sharing. During 'World Food' day, the group learned about exotic foods and their places of origin:

Rachel: *They [falafel] are the national dish of Israel.*

Ray: *Israel?*

Anthony: */Israel, hmm... I /didn't... \know that actually.*

Patricia: *I didn't know that either.*

'World Food' session, 18th October 2018

Professional and informal carers in this instance demonstrated interest in learning new information, showing that whilst participants with dementia can benefit from learning new skills – even if it is just for the moment – so too can carers experience similar cognitive, psychological and intellectual benefits from participating.

8.3.2 Carers within Husband-Wife Dyads: Hobbies and Ageing Bodies

When Ben was asked if he thought there were benefits to attending participatory arts, he replied that the sessions were '*therapeutic for the dementia and therapeutic for the carer as well... I think it has a double edge to it*'. Although he was attending sessions alone from the fieldwork commencement date, he used the arts to reflect on his marriage. On the first main fieldwork day, Ben opened the session by reciting a poem he wrote, inspired by a 'Wellbeing' themed session prior to the fieldwork.

The poem described the benefits of climbing fells with his wife. His final stanza read:

'We descent silently, with the sadness of leaving a friend.

For a time we have lived a deeper life, breathed a cleaner air, seen with a sharper eye.

Put our hand into the hand of God.

For that brief moment we have touched another world.

Have we conquered the mountain?

In truth we have but conquered ourselves.'

Ben, 'The Sound of Music' session, 11th October 2018

Through creative means, Ben captured the sense of 'in the moment' wellbeing that climbing once provided him, attending to emotional wellness, sensory experience, and personal development. His words about climbing could be viewed as an analogy for *Setting the Scene* and the opportunities for multi-sensory stimulation, achievement and process-oriented wellbeing held within the '*brief moment*' of attending them. There were, however, melancholy aspects to Ben's poetic climbing, given that it was something neither he or his wife could do anymore. Living with deteriorating sight, arthritis, and having experienced a recent myocardial infarction, Ben's positive attitude and resilience included going for short walks to *Setting the Scene*, meeting friends near Lake Derwentwater, and walking into town for the morning newspaper. Throughout his pilot phase interview, Ben spoke sentimentally about climbing across Europe with his wife, indicating its importance to his self- and marital-narrative. Sharing his wife's achievement at age 61 of climbing 75 peaks in 75 days for the 75th anniversary of Save the Children Fund, Ben became emotional when considering the present-day circumstances of their bodies:

'And that's the woman who lies in a /nursing home [begins to tear up].'

Ben, interview, 13th September 2018

The limited mobilities of Ben and his wife prevented them from being able to embody their passions for climbing, indicating the shared health challenges that older adults can face, regardless of dementia, and the sense of loss it can generate. This was why the alternative activities and forms of self-expression promoted by

Setting the Scene enabled and benefited couples or partners to continue with a strength-based approach to body, mind, and skill. Despite the relocation of his wife to a care home, Ben continued to feel valued as a carer at *Setting the Scene*, contributing positively and achieving personal wellbeing benefits at a programme that had emotional closeness to his wife.

Other partners, such as Ray and Molly, also had overlapping health concerns that occasionally impaired their activities. Having previously reported weakness in his legs, wrists and lower back during sessions, Ray was nevertheless willing to perform a dance with Molly during a 'Wedding' session, to a personally meaningful Vera Lynn song that Ray had suggested to facilitators. However, during the dance, Ray's leg began to cause difficulty while guiding Molly's direction, leading to a painful fall for both partners in front of the group (Figure 8.14).



Figure 8.14: Visual sequence of Molly and Ray's dance and subsequent fall.

After this event, Ray appeared more cautious during movement-based activities, but continued to participate in seated dance activities wherever possible. Molly also remained seated and did not take part in energetic activities. Assuming the fall may

have impacted their confidence, I asked the couple during an interview if the incident had been off-putting:

Ray: /No.

Researcher: *You were okay about it?*

Ray: *Take it... as normal, because I could be walking along the street even, and I'll catch my shoe in some hole or something like that, and I'll go-*

Molly: *-you can trip over.*

Ray: *Mollys got a big bruise on her leg. She went out walking with our son-in-law, which she does, and she fell down, and her knees all bruised.*

Researcher: *Oh dear, okay.*

Ray: *It's just, one of those things.*

Molly: *[Rubs area of leg that is bruised through her trousers and starts pulling her trouser leg up to show me]. It's a big thing on my knee.*

Ray and Molly, interview, 4th December 2018

Molly spoke clearly and openly about her bruised leg, but with a generally positive demeanor like Ray. Rather than feeling downhearted about the risk of falling – whether in creative or everyday contexts – Ray and Molly indicated that the risk followed them wherever they went. The incident warranted a cautious yet pragmatic approach that maximised their ability to take part in things they both still enjoyed. Displaying resistance, they continued to walk to and from sessions, and when asked about the impact of the sessions on their wellbeing, Ray remarked '*I can walk along with Molly slowly when we come out, and we walk back into town, quite happy.*' Regardless of his injuries, Ray still aligned *Setting the Scene* with contentment, physical wellbeing, and a positive mindset.

This optimistic attitude was shared by other couples, including Stanley and Agnes, regarding the psychological magnitude of living well with dementia. Agnes and Stanley explained that the laughter and humour engrained in their marriage helped

them to cope with dementia-related changes. This included incidents where Stanley woke Agnes up in the middle of the night to ask if she wanted to brew tea, or moments when he forgot why he was wearing a catheter, which was related to a recent operation. Although Agnes did not attend sessions, their interview highlighted the importance of laughter for overcoming potential obstacles:

'...we've had some real good laughs... we've made everything we've done really funny ain't we?... Our glasses are half full not half empty... That's how we look at life, ain't it?'

Agnes, interview, 22nd July 2019

Whereas for those attending *Setting the Scene* together, such as Ray and Molly, a sense of joy and social belonging could be shared with others through the arts. The programme had such an impression on the couple, that Ray asked to celebrate their diamond wedding anniversary at a session, taking place on the final day of fieldwork. With their family's help, they arrived wearing formal attire with a sparkly personalised cake, party glasses, sparkling juice, edible glitter and a collection of Molly's jewellery for an ad-hoc 'show and tell' (Figures 8.15 and 8.16).



Figure 8.15: Ray and Molly cutting their cake.



Figure 8.16: Molly's jewellery.

This was one of the strongest expressions of self and belonging made by participants at sessions, given their desire to share an important milestone with the community and present themselves through the materiality of their clothes and possessions (Buse & Twigg, 2016; 2018). Ray and Molly demonstrated the importance of maintaining social networks for both partners in circumstances with dementia and showed the social wellbeing potential of participatory arts groups for upholding selfhood, personhood, as well as spousal identity. The event enabled Molly's interests to be shared through possessions, taste and touch, and gave Ray an opportunity to celebrate their marriage; and likewise, to celebrate Molly.

Whilst it was important to promote self-identity within activities, spousal dyads indicated that it was also important to acknowledge aspects of identity interdependent on their lifelong relationships. Finding participatory activities that supported couple's shared interests not only maximised physical wellness, but also reinforced the husband-wife dynamic over the caring dyad. Ray reiterated this statement by saying he was not a carer, but was '*Molly's husband*'.

As equal participants, carers experienced their own wellbeing through creative freedom. This was displayed between carer Patricia and husband Harry during an art-making 'Joseph and his Technicolour Dream Coat' session activity. I took on a

participatory role on this occasion, seated next to Patricia, and was able to have more personal conversation with the couple during the creative process:

While speaking to Patricia, she expressed her own eagerness for taking part in the sessions... while heartily laughing, she stated 'it's the highlight of my week'. She followed this up with a sense of guilt for feeling this way, but I assured her that the sessions were for carers too...

Fieldnotes, 'Joseph and his Technicolour Dream Coat', 10th January 2019

Patricia gained joy and satisfaction from partaking in the arts, though accompanied by guilt for enjoying something she initially envisaged was conceived only for people with dementia. For other family carers like Ray, *Setting the Scene*'s creative freedom and the mutual gratification with his wife encouraged their continued attendance.

Yet, during the paired dream coat activity with Patricia and Harry, further insights were made into the challenges of balancing activity benefits for carers and for people living with dementia (Figure 8.17).



Figure 8.17: Harry and Patricia in the process of dreamcoat-making.

Deep in concentration and flow, Patricia overlooked a ‘no right or wrong’ attitude when working alongside her husband and began correcting him:

Patricia: *So we'll stick these on, and these will go round... oh no, you're not /doing them /right.*

Harry: *What?*

Patricia: *I want them all screwed into little balls. That's /all you've got to do, is to screw them-*

Harry: *-I've done them, look here-*

Patricia: *-well there's a hole, look, there you go, all those. All want screwing into balls. None of these are in balls. They're in... funny shapes. Just roll them in your hand like that, that's all you've got to do, screw it up in your hand.*

‘Joseph and his Technicolour Dream Coat’, 10th January 2019

Harry had been quietly busying himself with the task Patricia had previously suggested for him, but he became disengaged after receiving criticism. Not meaning to upset or demean her husband’s contributions, Patricia showed that there may emerge discrepancies between the facilitators’ focus on the creative process and a carers’ outcome-oriented focus on creating an aesthetically pleasing finished product. This makes it more challenging to achieve well-rounded person-centredness for both carers and people with dementia.

This type of situation also unfolded between Ray and Molly, with Ray occasionally displaying frustration during sessions. I noted in my fieldnote reflections:

Ray and Molly's dynamic has changed over the past few months, since Molly's dementia has progressed. Ray is showing more frustration from Molly not being able to do certain things or follow instructions... The facilitators have been on hand to defuse any negative affect with humour and reassurance.

Fieldnote extract, 28th February 2019

During the 'Jeeves and Wooster' character game activity, Ray attempted to hand dice to Molly and guide her to roll them, only to be met with a blunt 'no' and a glare. This tension was quickly resolved by calm reassurances from Jenn and Molly's eye contact with a warmly smiling Rachel, leading to exchanged smiles and subsequent activity engagement (Figure 8.18). Facilitator presence therefore helps to negotiate any differences or tensions that may occur between members.



Figure 8.18: Transforming tension into positive affect.

This challenge was more common with spousal dyads than with professional carers or other familial relations, which may point to the strain of dementia on close relationships or indeed existing couple dynamics. However, the earlier example with Janet demonstrates the possibility of professional carers dominating activities or conversations, even when unintentional. I noted that these types of events need careful negotiation, given that both Ray and Patricia were caring for their spouse on a 24-hour basis and had less support than may be available to others being paid for care. While the positive experiences of both couples at the programme outweighed the negative, their brief experiences of tension offered insight into what is important to some members in creative activity – be it the process or product – and how to negotiate discrepancies between carers' needs and those of people with dementia.

Looking beyond the art itself, carers within dyads often shared similar perspectives on the social and community support gained while attending the programme. Ben explained that carers reaped social and relational wellbeing benefits from the group:

'...for old people, husband and wives, you can become so /isolated when you are looking after someone, and yet you've got no... connection, no communication with other people.' **Ben, interview, 13th September 2018**

Likewise, Patricia gained a sense of confidence, hope and 'opening' from the group, predominantly fuelled by the presence of other people with dementia:

'...there was something, fairly positive, about seeing other people, in the same condition as Harry... because there is a huge feeling at the beginning of a diagnosis to, sort of, put your arm around them and shelter them from everything and everybody... and that [Setting the Scene] was such an opening. /All these people are exactly the same. Is anybody making a fuss? Nobody is making fun of them, everybody's... engaging with them and they're engaging with everybody...' **Patricia, interview, 23rd April 2019**

By decreasing social isolation or easing the fears attached to a dementia diagnosis, carers exemplified that their attitudes and their relationships with their spouses or family members were improved by finding solace and belonging in a group of like-minded people, facing the same worries and unknowns as their own family.

8.4 Participants with Dementia: Caring for and about Others

The distinction between carers and people with dementia has been narrowed by considering the benefits, enjoyments and challenges of carers beyond their 'carer' status at *Setting the Scene*. Likewise, it is also noteworthy to discuss the caring natures reciprocated by people with dementia and how the participatory arts setting facilitated them. Throughout sessions, participants offered help to others, physically and verbally, and showed the importance of feeling useful. Small examples included helping facilitators clear the table after sessions without being asked (see Figure 8.19). This was common from Harry, who liked to keep busy while his wife Patricia spoke to facilitators at the end of sessions. Patricia confirmed that Harry continued doing this after moving into a specialist care home in February 2019, with care staff noticing that he preferred cleaning up after dinner time than sitting down.



Figure 8.19: Carol [left] tidied sheets, Ray and Molly [right] collected cups and saucers.

However, the following two events below illustrated more in-depth perspectives on participants as carers, unrelated to the arts, but generated through them, to impact the relationships between carers and participants: Joe's momentary emotional distress and Anthony's sprained ankle.

8.4.1 Exemplar 3: Joe's Distress

As a 'Summer Holidays' session was coming to an end, some participants were leaving while others were being guided to the toilets. During this time, an emotive moment unfolded between Joe and Carol (Figure 8.20):

Joe was the last member seated while the rest of Amy's Care made toilet trips. Upon seeing Joe, Carol stopped tidying the table and sat down beside him. A touching moment was captured on camcorder, where Joe became visibly emotional.... According to Carol and his carers, Joe was crying about his wife's death, who was in fact still alive. A physical gesture between Carol and Joe signaled a change in roles. Carol became a caring figure, comforting Joe by stroking his shoulders, listening attentively, with concerned expression and strong eye contact.

Fieldnote extract, 'Summer Holiday' session, 23rd August 2018



Figure 8.20: Carol comforting Joe.

The attention that Carol gave Joe – through touch, gaze, and active listening – temporarily transformed her role from a participant with dementia, to that of a carer comforting a distressed member. This moment exemplified the capabilities of people with dementia to care about others (Milligan & Wiles, 2010). Over two weeks later, during an elicitation section of our interview, Carol spontaneously recalled the incident with Joe:

Carol: *And this lovely man... and I was sitting next to him at the... yes, he's different-*

Researcher: *-that's Joe. He was just new.*

Carol: *Yes Joe. Yes. And then... he got quite emotional, didn't he?*

Carol, elicitation interview, 8th September 2018

Agreeing to re-watch the video clip, Carol began to cry as she watched herself putting an arm around Joe's shoulder. Pausing to check she was okay, Carol

responded: '*/No /no, it's not making me cry, it's just... that wherever you are... whatever we're all doing, you touch different things.*'

Carol reflected on the array of people and how they emotionally affected each other. She had previously spoken about connections in our interview and felt '*like... I wasn't there for my family, in the way that, I'm here, for other families*'. Carol showed that the *Setting the Scene* programme went beyond offering creative opportunities, also delivering a platform for people with dementia to help others, to feel useful and to form meaningful connections through a sense of care, control and purpose. As in this example, dementia does not halt the experience of empathy, understanding and concern when observing another's pain or distress. Carol indicated the emotional rawness yet sense of wellness that can come from the immediacy of caring about those in participatory arts-based communities.

8.4.2 Exemplar 4: Anthony's Sprained Ankle



Figure 8.21: A distracted Todd [far right] watching Anthony [outside of frame].

The screenshot above (Figure 8.21) exhibits a busy group environment talking amongst themselves, drinking refreshments, listening to others, and picking out props for the 'Jeeves and Wooster' character game. On the far right of the image is Todd, who was distracted by carer Anthony propping his sprained ankle on a chair outside of the camera frame. Anthony had arrived at the *Setting the Scene* session with a running injury sustained that morning, not having enough time to swap shifts

with other Amy's Care staff. I reflected on Todd and Anthony's relationship, and the onflow of this event, in my fieldnotes:

'Todd often gets distracted watching Anthony walking around the room or working in the background. They seem to have a good relationship and Anthony is a familiar face at the Amy's Care group... so, upon seeing Anthony's injury today, there was clear concern on Todd's face. Still distracted later in the session, Todd tried to get out of his seat to approach Anthony at the other side of the room. Even with the reassurance of Laura and other participants, Todd wanted to get closer and speak to Anthony personally. Laura helped him do this while facilitators were still leading the group in activity. When Todd eventually got to Anthony, he asked if he was okay and began offering him his own walking stick.'

Fieldnote Extract, 'Jeeves and Wooster' session, 15th November 2018

As with the interaction between Carol and Joe, when someone was observed in emotional or physical pain, participants with dementia were proactive and expressed concern. Anthony's observable injury may have caused Todd additional worry, given that he was a carer for whom Todd spent much of his week alongside; someone typically active, reliable and protective of others. Laura's assistance in the situation, whilst not necessarily contributing to the creative or physical needs of the Todd, embodied a person-centred approach by helping him fulfil his desire to help (Figure 8.22). Anthony kindly declined Todd's walking stick, reassuring him that he was okay.



Figure 8.22: Todd walking towards Anthony.

In both exemplar events, elements of a participant's personality were revealed in ways beyond what could be afforded within arts participation but were nevertheless generated from the programme's social network. Todd had previously been acknowledged for his carving of walking sticks, having shown one to the group and explained the process of making it on another occasion (see Section 6.5.2). Yet, the strongly visual cues displayed by Anthony's sprained ankle prompted Todd to offer his own walking stick, an act of care achieved through the agency of an object which formed part of Todd's self-identity and disregarded his own mobility and physical wellbeing needs. A role swap occurred, whereby Todd extended the emotional aspects of caring about Anthony to caring for him through physical assistance (Milligan & Wiles, 2010); a connection between the emotional and physical also shown by Carol. Carol's caring role with Joe offered reassuring touch and was more in terms of emotional attunement, which had a long-term impact on Carol that emerged during our interview. These events, and others like them, took place while people with dementia were effectively being looked after by professional or informal carers. Subsequently, participatory arts enable a reciprocity of caring for or about others that can unfold amongst people with dementia, as well with their carers.

8.5 Conclusion

This chapter has presented the experiences and perspectives of caring while being a part of the *Setting the Scene* programme, offering insights into the multi-layered identities that informed arts-based engagements. The varying roles that both carers and participants with dementia took on during different events empowered the heterogeneity of peoples' needs, their creative interpretations, and the types of participation that they felt entitled to present; this included whether they were facilitating, caring or attending to elements of self through the arts.

Carers exhibited different sides to their session presence, contributing towards the facilitation of others, their own individual participation, and occasionally disrupting other participants' contributions. Participants with dementia also felt able to help and adopt caregiving approaches when other participants were in need. The main argument here is that the programme's non-distinguishing approach to participation led to the lines between carers and people with dementia becoming blurred, which had both benefits and shortcomings, though the former was mostly felt. This was important for older adult carers, who had their own health and wellbeing challenges alongside their partner's. Eliminating the centrality of dementia from the setting, carers often felt on a par with their loved ones, experiencing similar benefits to them. Their interests and identities were acknowledged as both individualised and interdependent on their spouses, suggesting the importance of designing arts activities that are inclusive of carers not just as aid, but as equal participants with desires to express their own selfhood and relationality with others. Indeed, people with dementia could be acknowledged for their strengths, rather than dementia symptoms, when sessions accommodated for both types of participants.

There were, however, instances when carers became more dominant in their involvements, be it a spouse or professional carer. This indicated the complexities of catering to the needs of varied participants, but one that was worth the opportunity for promoting joint respite: by decreasing the isolation, confusion, and relationship tension faced by carers and their family members with dementia alike.

Chapter 9: Dementia-Friendly, Participatory, Multi-Arts Landscapes: Wellbeing, Selfhood, and ‘Voice’

9.1 Introduction

This thesis has explored the impact of participatory arts activities on the wellbeing of people living with dementia and their carers. Focusing on Theatre by the Lake’s *Setting the Scene* programme, this study sought to:

- 1) Explore the effectiveness of the *Setting the Scene* model’s multi-arts approach in assisting wellbeing experiences;
- 2) Examine how to best sustain the attention and engagement of participants during sessions;
- 3) Identify the contributions of material and relational factors – such as space, place, setting and objects – to *Setting the Scene*’s effectiveness; and
- 4) Consider how group relations, family relationships and friendships during sessions contributed to, or were benefited by, arts engagement.

Responding to an opening for more inclusive dementia research in this area, this study adopted a multi-method sensory PAR framework and drew on theoretical influences from more-than-representational theory, assemblage theory, relational wellbeing and therapeutic landscapes. The previous four empirical chapters of this thesis have portrayed narratives of participants’ ‘in the moment’ experiences at *Setting the Scene* and offered new insights into the embodied, sensorial, material, relational and spatial elements of arts engagement. This penultimate chapter draws on the key empirical, theoretical and methodological contributions of this thesis, whilst also providing a critical reflection on the adopted methodology. The chapter closes with an overview of the study’s limitations, with future research ideas followed up in Chapter 10.

9.2 Empirical Contributions: Participatory Arts and Living Relationally Well with Dementia

This thesis has demonstrated the importance of capturing the heterogeneous voices and experiences of people living with dementia and their carers, in a bid to better understand participatory arts and their associated wellbeing benefits. The overall empirical insights show the importance of shifting focus away from being outcome-oriented and towards 'in the moment' engagements. This section collates the key empirical findings of this thesis in connection to the wider literature, drawing on how they allude to relational wellbeing, which has so far been sparsely applied to dementia research (e.g. Zeilig et al., 2019).

9.2.1 The Benefits of Multi-Faceted Programme Designs

This thesis illustrates the importance of examining a participatory arts programme not as an intervention of singular parts or activities, but as a whole, immersive, assemblage contributing to place-specific therapeutic encounters and creative wellbeing experiences. As revealed in Chapter 2's review, most community-based participatory arts programmes in the literature thus far are based on singular art forms – like music, dance or visual art (e.g. Zeilig et al., 2014; Young et al., 2016; Windle et al., 2018; Hendriks et al., 2021) – with few adopting multi-arts concepts (Tseklevs et al., 2020; Innes et al., 2021). Yet, when considered collectively, the benefits provided by these programmes generally remain similar, indicating that the underlying design and facilitation processes involved in participatory arts may be key to better understanding their effectiveness (Scholar et al., 2021). Observations made during *Setting the Scene* sessions illuminated the wider opportunities that a multi-arts approach provides to its participants, looking beyond *what* art form was used and considering *how* and *why* it was being meaningfully applied.

The effectiveness of *Setting the Scene* was associated with the merging of three core design components – multi-arts, multi-modal, and thematic – that contributed towards the decision-making of facilitators and the responsiveness of participants. Study vignettes further revealed how the interplay of these components elicited varied levels of engagement and wide-ranging benefits. For instance, whilst some more social and conversational participants engaged better in larger communal set-

ups and storytelling activities, others benefited from personal or one-to-one set-ups that involved non-verbal activities and familiar topics. Although these personal experiences are complex and therefore difficult to summarise in this discussion, the overall insight is that the flexibility and holism of the multi-modal, multi-arts, and thematic design helped to ensure that every individual in attendance could engage with some elements of the programme. Indeed, this ensured that creative and social needs could be met side by side. These components therefore fed into how well the participatory arts sessions achieved an environment of person-centredness – focusing on what participants enjoyed, liked or needed – strength-based approaches – attending to the unique and enduring skills and abilities of participants – and an ‘in the moment’ focus – whereby each session built upon emerging and often unpredictable interactions between the arts and the people present. Each of these will be further unpacked in the following sections.

9.2.1.1 Person-Centred Designs

By combining different art practices, set-ups and topics, the *Setting the Scene* model sought to connect with participants on an individual level, all the while facilitating group-based activity in a social community. This reaffirms past literature acknowledging the importance of balancing individual and communal needs in arts settings (Ullán et al., 2013; Belver et al., 2017; Chauhan, 2018; Windle et al., 2018; Tseklevs et al., 2020). Being person-centred was not only about acknowledging the generalised needs and skills of a collective ‘people’ with dementia, but about recognising an individual’s preferences, hobbies, and complexity of identity outside of their dementia diagnosis. This idea, in practice, promoted wellbeing by encouraging participation in activities that were thematically relevant and meaningful (Innes et al., 2021); aiding the fulfilment of personal needs (Andrews Chen & Myers, 2014); and ultimately enabling people with dementia and carers to feel able to ‘share, create and connect’ in what I consider a creative assemblage of unique individuals (Theatre by the Lake, 2020).

Setting the Scene evoked different responses from individual participants throughout sessions and exemplified that a heterogeneous, multi-faceted design can support an equally heterogeneous group of participants with varied individual, social and creative

desires. The programme's multi-faceted approach offered choice at the level of the individual and enabled people to be self-selective in their participation, rather than having an expectation of consistent active engagement. Whether performing to the group, following dance instructions, or subtly tapping one's fingers, the benefits of arts-based participation were not derived from being regularly active, but rather from participants being granted freedom of choice/self-selection and sense of control; important facets of human experience that can be compromised by dementia. These findings therefore call for greater consideration into how participation is defined and subsequently how the effectiveness of participatory arts design is measured. They suggest that individual case-by-case evaluations can better illuminate this, as has been demonstrated in recent musicking research (Dowlen, 2018). Overall, the findings reveal the benefits of multi-arts programmes over single-based interventions to meet the person-centred needs and strengths of a diverse community, who happen to have dementia in common.

9.2.1.2 'In the Moment' Communication and Strengths

The 'in the moment' approach promoted by participatory arts activities supports the strengths and skills of people with dementia; indeed, 'process-oriented' and 'in the moment' were found to be definitive terms for the overall *Setting the Scene* model. Recent dementia studies have been acknowledging the centrality of being in the 'here and now' for living with dementia (e.g. Burnside et al., 2017; Keady et al., 2020). This thesis therefore reaffirms the well-established notion that 'in the moment' participatory arts remove pressure from memory recall, thereby supporting people with dementia in more emergent activity with a 'no right or wrong' attitude (Petrescu et al., 2014; Tsekeleves et al., 2020). Given the effectiveness of being process-oriented versus outcome-oriented, participatory arts are also indicative of relational wellbeing – of 'being-well' – as something that unfolds and emerges during sessions, rather than as an outcome achieved at a session's close (Andrews et al., 2014). With few studies having considered this perspective, I argue that relational wellbeing can help illuminate the 'in the moment' value of participatory arts, and likewise 'being in the moment' can enable relational wellbeing to be felt.

The unfolding manner of *Setting the Scene* supported people with dementia and their carers to spontaneously share life stories and memories in the group, inspired or stimulated by on-going creative activities. Sessions had flexibility engrained not only in their contents, but in the spontaneous and improvisational manner that they were facilitated. Subsequently, this allowed ‘in the moment’ contributions from participants to direct the session narrative, with guidance given by facilitators. This insight helps reveal the strengths of people with dementia to express themselves in personal or discursive ways without the intentional use of reminiscence strategies, instead being stimulated by the safe, processual nature of participatory arts design (Tseklevs et al., 2020).

Beyond more-than-verbal communication, ‘in the moment’ participatory arts can support the enduring skills of people with dementia and their carers, as demonstrated in past research (e.g. McCabe et al., 2015; Chauhan, 2018; Tan, 2018). The strength-based attitude promoted at *Setting the Scene* meant ex-joiners were able to actively use their hands; amateur painters participated in visual art-making; storytellers were invited to share their imaginative ideas; and singers/dancers could perform with/for others. These dually affective and embodied wellbeing experiences show how participatory arts can endorse ‘being well’ emotionally or personally (Andrews et al., 2014), but also ‘doing well’ through bodily engagement (Kaley, 2017). These skills were indicative of participants’ past careers and hobbies, some of which had been impacted by their dementia. Building on physical, cognitive, and creative strengths, participants’ authenticities could be sustained within the creative, communal setting (Ferretti, 2020), ultimately aiding people in ‘continuing to participate in the dance of life as oneself’ (DeWitte et al., 2021, p.8).

Multi-arts benefits are associated with the range of self-expressive mediums they provide for people with dementia. The novelty of this thesis is in its broader, more-than-verbal definitions of participation, communication and voice, which will be delved into further in Section 9.3.1. Empirically, some participants were found to communicate predominantly through embodied, non-verbal means, including touching props designed to express self-identity or by dancing to musical stimuli. Others communicated through oral storytelling, singing, and by initiating

conversations, often using non-verbal means to strengthen these contributions. Evidently, communication is not a clear-cut dichotomy of the verbal and non-verbal but is better understood by a more-than-verbal lens as promoted in *Setting the Scene*'s multi-arts, multi-modal, and multi-thematic contents. This provides confirmation to previous studies outside of arts research that have acknowledged everyday conversation in dementia as 'not just a range of verbal connections, but embodied and emotional connections... built on abilities outside of language' (Kindell et al., 2018, pp.176-177). Hence, this thesis argues that participatory arts can facilitate wellbeing by broadening how people with dementia communicate and engage with others through alternative creative and meaningful channels.

Other elements of communication observed within participatory arts (and within the personal lives of participants) were humour and laughter, which had social, affective and atmospheric connotations at *Setting the Scene*. This supports previous literature theorising laughter as being 'more-than-representational; as having transpersonal and atmospheric spatialities' within care home settings (Emmerson, 2017, p.2082), but extending this to community settings. At *Setting the Scene*, improvised or intentional humour led to shared laughter, an open environment and upbeat atmosphere. Consequently, every session involved some interpretation of humour, be it from facilitators or participants. Outside of care settings and comedy-centric programmes (Stevens, 2012; Hafford-Letchfield, 2013), few published studies explore the improvisational and everyday uses of humour and/or laughter in living well with dementia. This study therefore contributes initial ideas on the importance of recognising humour alongside other self-expressive means that contribute to shared wellbeing encounters. I suggest that humour be considered as a stand-alone form of communication and performative art, requiring the presence and contributions of others to give it meaning, function and positive affect.

9.2.1.3 Narratives: A Fourth Component

So far, this discussion has touched on the three core components of the multi-faceted *Setting the Scene* model and how they collectively contributed to person-centred, strength-based and 'in the moment' wellbeing experiences. In light of the findings around person-centredness and identity, I propose that a fourth more

nuanced component of the programme exists, which is that of participants' narrative engagements. Whilst some could argue that participants' contributions were an outcome, rather than a core component of the activity design, I would contend that the 'in the moment' approach adopted by facilitators positioned participants as collaborators in determining how sessions would unfold. Participants are an essential part of a participatory arts programme and their narratives can benefit from being consciously threaded into the overall design (Synnes et al., 2020).

The *Setting the Scene* programme was described by carer Ben as '*a play without a script*' and it also compelled Sam to invite others to '*just express yourself... with your own artistic way*'. Both indicated the person-led and self-expressive threads that embedded *Setting the Scene*'s effectiveness, placing the programme as theme-centric and person-centred, but also narrative-driven. For instance, during themes on weddings and marriage, participants shared stories about their relationships, explained details of their own wedding days, and engaged with wedding dress costumes or ceremony music. This reaffirms recent indications that a programme's effectiveness relies on making sure participants are involved in the stories and spaces throughout a session (Scholar et al., 2021, p.10). As articulated by Randall (2009), 'we make meaning through the continual imagining, interpreting, and telling of stories, including 'the story of my life' as a whole' (p.322). This thesis therefore highlights the narrative nature of participatory arts, which can influence how the 'narrative citizenship' of people with dementia is portrayed, as previously researched through poetry (Synnes et al., 2020). This thesis extends this to a multi-arts programme, suggesting that narratives are not reliant on discursive content but can also be linked to more-than-verbal, material means.

Evidently, a strength-based approach to facilitating participatory arts not only supports what participants can still *do* physically and cognitively, but more so who they still *are* personally. As previously stated, 'creative arts can remind us of who we are' (Hayes, 2011, p.16). At *Setting the Scene*, this meant attending to individual experiences and spontaneous recollections of the past, within a present-moment setting, where the implications of dementia make for an uncertain future.

Empirically, participants were observed learning something new about themselves,

as well as maintaining their long-standing sense of self through contributions to sessions. People with dementia were not characterised by their symptoms, but by their personalities and '*ways of being*' within participatory arts. This also applied to carers, who demonstrated interest in learning new skills, sharing memories, sustaining their own attentions, and finding joint respite that offered personal 'in the moment' wellbeing; independent yet connected to their cared-for partner or client. I align these findings with the concept of 'identities-in-process' (Rose et al., 2020), where what participants say and do 'in the moment' can be an ongoing expression of self. Arts-based environments therefore encourage a strength-based continuation of life narratives for people living with dementia, whose life plans and social networks often feel disrupted by their diagnosis (Alzheimer's Society, 2021).

9.2.2 More-than-Human Factors: Places, Spaces, Objects

9.2.2.1 The Agency of Objects

This thesis has shown particular interest in recognising non-human actants – whether familiar or novel in nature – as conversation starters, multi-sensory prompts, expressions of creative self-identity, and outlets for positive human connection. Recent dementia studies have explored items such as clothing, personal belongings and care products in daily experiences (e.g. Buse & Twigg, 2016, 2018; Araujo et al., 2020), but few have considered the agency of objects in participatory arts contexts. Studies have acknowledged that objects and arts materials can stimulate participant engagement (Morrissey et al., 2016; Chauhan, 2018; Tan, 2018; Tsekleves et al., 2020), but there is an opening to further recognise why material things aid arts engagement and promote the 'voices' of people living with dementia.

Objects and costumes are engaged with through use of the body and senses – be it sight, touch, smell, hearing or taste – and subsequently encourage increased more-than-verbal communication. During *Setting the Scene*, this was not only supportive for people with more advanced dementia who found verbal communication challenging, but for people in earlier stages to express themselves more actively. Participants demonstrated increased attention in activities when props were used as a core focus, whether it was something to be viewed – a wedding dress – touched – a beach ball – or listened to – during Tai Chi activities. Physical objects helped to

consolidate the process-oriented focus of sessions and maintain participants' immediate attention. This is in contrast to relying solely on abstract or intangible concepts that other studies have flagged as more cognitively challenging in dementia (Branco, Quental & Ribeiro, 2017). Yet, this thesis has highlighted that people with dementia are also capable of working imaginatively and abstractly, exemplified by participants who shared detailed and visceral stories in the group, albeit with references to the material world, such as hospital beds, jewellery, fashion, or the process of making gold. Multi-sensory engagement has therefore shown to be integrally linked to objects and props, which are important elements of 'in the moment' participatory arts stimulation, involving both embodied and imaginative engagement. This contributes to literature that has begun to consider the sensorial features of arts materials and the creative potential of objects (e.g. Chauhan, 2018).

Furthermore, non-human actants were conversation starters and prompted interactions between members of the group by offering tangible and visceral content, making discussions more approachable. People with dementia often expressed their voices and ideas to others in the group whilst a prop mediated or stood in as an additional member of the social network. With object aid, participants not only improved their communication to other people, but showed that they could communicate *through* an object and what it symbolised or suggested, such as wearing a wedding dress or holding a steering wheel. This is demonstrative of meaning-making with objects, and how such factors can promote non-verbal and verbal responses (Swinnen, 2016).

Familiar and popular props such as beach balls, fedora hats, print outs, or walking sticks aided in the relationship development and social interactions of *Setting the Scene* members, showing that everyday objects can be as useful in creative sessions as novel props or artefacts (Tan, 2018). They were introduced as social agents either as static objects that stimulated visual and oral responses, or objects that were projected with motion and aliveness by the non-verbal movements of participants. This important finding indicates that participatory arts are not entirely about conventional art-making but create opportunities to channel the viewpoints of people living with dementia. This relates to previous anthropological work that

considers the 'direct materiality of people's shared senses' (Stewart, 2011, p.447) and can broaden the social significance of multi-sensory, material engagements to group-based participatory arts settings. Whilst these insights were gained in a group-based setting, they also have potential to be transferred to other non-participatory arts settings, as a means of maintaining and improving meaningful relationships between people with dementia and their families, friends or carers in everyday contexts. This is in light of the COVID-19 pandemic, where the shielding of vulnerable adults impacted their wellbeing and highlighted the importance of finding meaningful ways of stimulating voice, improving communication and reinforcing family/spousal relationships (Simard & Volicer, 2020; MacDonald & Hülür, 2021).

9.2.2.2 Physical and Social Landscape Interactions

Looking outside of the immediate material environment, limited community-based arts research has engaged with wider landscape implications. This thesis has contributed to understanding the nuances of the physical and social landscapes in which participatory arts are emplaced. While some recent, site-specific participatory arts have shown that setting can help contextualise session content (e.g. Innes et al., 2021), few other ideas are shared in the literature beyond practical considerations.

It has been previously stated that 'nature behaves as a subject' (Serres, 1995, p.36; in Lea, 2008: 91) and this was demonstrated in the places surrounding *Setting the Scene* sessions. As with the agency of objects, the outdoors was felt through the 'windows' of the Friends Gallery and Crosthwaite Sunday school venues during arts sessions. The windows acted as a permeable boundary between the indoor setting and outdoor environment, influencing the activities and ideas being shared. As a 'backdrop' to the venue, the outdoor setting gave context to the arts activities by enabling participants to draw the 'aliveness' of the weather into conversation (Thrift, 2008); stimulate childhood and workplace memories; express the landscape through interpretive dance; create poetry about climbing far-off peaks; and inspire spontaneous group sing-alongs about mountains. These window-related interactions would not have been fulfilled in other spaces at Theatre by the Lake, such as their dark and windowless main auditorium or circle theatre spaces, which other theatre-based arts programmes have had to work around (e.g. Milligan & Mossabir, 2018).

Although participants were distanced from the landscapes and only able to view them from afar, the findings revealed that the programme setting had positive implications for participants' wellbeing, including supporting their self-identities, belonging, offering reminders of participants' skills, and creating a sense of gratitude. This thesis therefore reaffirms Ulrich's (1984) findings that having nature-based views can aid wellness, though extending his focus on hospital settings to include creative community-based locations for people with dementia. The interesting views and natural light coming from the windows also fostered connection to the wider landscape and community, inspiring group-based activities such as sing-alongs. This therefore expands Ulrich's work further from being individual-focused to considering how scenic views can inform and benefit groups. It should be noted, however, that the significance of the natural landscapes may, in part, be due to their symbolism and familiarity to the predominantly Cumbrian participants, which made them personally meaningful. In theory, then, towns or cityscapes may also generate similar responses from participants as the nature scenes of Keswick did in this case, but this is beyond the scope of this study.

The surrounding busyness of *Setting the Scene* sessions – whether indoor or outdoor – showed how semi-public venues can help people with dementia feel connected to something bigger and communal, to prevent feelings of isolation. This was exemplified when participants were invited to contribute to material aspects of the theatre, such as their Christmas tree decorations. Participants occasionally reflected on the anthropogenic sights and sounds being generated from the outdoor or indoor landscapes of Theatre by the Lake – such as the creaking gate, passing vehicles, interior décor and indoor staff activity – that occurred on the periphery of the *Setting the Scene* space and demonstrated the body's inseparability from place (Davidson & Milligan, 2004). Indeed, senses of community and belonging not only emerged from the specific programme, but could also be fed by the surrounding physical, social and communal landscapes (Innes et al., 2021). This suggests that the spaces used for participatory arts have an influence on how sessions run.

This thesis presents how place-based engagements can embody experiences of wellbeing and self-expression, as well as lay the foundation for potential

‘untherapeutic’ encounters for people with dementia. Familiar landscapes offered a sense of continuity and community belonging, offering reassurance to some participants when arriving at Theatre by the Lake. This contrasted to initial uncertainty at the temporary Crosthwaite location. Other place-based nuances arose that were differentially beneficial and/or distracting, demonstrating the challenges of creating one programme for a heterogenous group, and the influence of individuals within larger communities. For instance, within the Friends Gallery, adorned artworks were both complimented and criticised, leading to changes in some participants’ mood and focus. Although indirect and often unintended, the visual, aural and atmospheric facets of these landscapes were accompanied by both positive and negative affect depending on participants’ responses, indicating the importance of considering spatial factors in setting up participatory arts.

9.2.3 Care Perspectives and Relationships with/through Participatory Arts

In this thesis, social relations were considered on different levels, including the larger social or community landscape, as well as the intimate relationships that participants engaged in with family members, paid carers, facilitators and others with dementia. Broadly, the unfolding of creative sessions would not have been ‘participatory’ without the presence of its members. Subsequently, participatory arts enable the forming of new social networks by combining creative and social components within a single context (Zeilig et al., 2014; Stickley et al., 2018). Through creative forms of self-expression, participatory arts can aid the development and maintenance of friendships and relationships, by creating a common ground and shared focus, as suggested in existing literature (e.g. Unadkat et al., 2017; Zeilig et al., 2019). Subsequently, *Setting the Scene* enabled the establishing of ‘shared meanings so as to be able to act in a socially meaningful way’ (Örulv, 2010, p.39).

Setting the Scene’s social landscape was flexible enough to accommodate for participant differences, whilst also promoting an overall atmosphere of tolerance, support and morale (Tan, 2018). Although predominantly positive, there were isolated incidents resulting in tension or difference amongst participants – whether involving a participant with Down’s Syndrome or a louder personality – that temporarily shifted the mood of the overall group mid-session. This insight gives rise

to atmospheres of 'otherness', which *Setting the Scene* was created to resolve. Whilst the individual participants involved in these affective changes may be viewed as outliers compared to the positive responses of others, they highlight that participatory arts circles and wellbeing spaces can be sensitive and everchanging, where each individual has the autonomy and opportunity to influence the atmosphere for those surrounding them: whether that be by showing physical affection or by disapproving of their presence. The latter of these can be detrimental to the underlying wellbeing-promoting objectives of participatory arts, which were quickly responded to and resolved by facilitators and carers. Hence, it is important to allow for individual self-expression, but equally important to have an ongoing awareness and flexibility when working with groups of mixed abilities.

This thesis provides new insights into programmes that are designed for both people with dementia and their carers, demonstrating that a single setting and programme can provide joint wellbeing encounters. Variation in benefits were experienced for different members according to their relationships and personal circumstances, given that older adult carers – such as spouses – often indicated having their own health concerns or limitations. Dyads in sessions demonstrated shared positive attitudes, even after having accidents or falls within sessions. Whilst a person with dementia benefited from the familiar faces and encouragement of their paid or family carers, the carers also experienced their own positive affect when watching their family member or client improving their responsiveness. Carers personally enjoyed activities and avidly participated where possible, demonstrating that caring relationships – even those that are professional – can benefit from joint respite (Burnside et al., 2017), which overcomes the medicalised nature of dementia and the job of caring. In this light, participatory arts make beneficial contributions to relationships at risk of strain (e.g. Burnside et al., 2017; Unadkat et al., 2017).

Indeed, the roles of carers and of people with dementia at *Setting the Scene* often blended to create a sense of equality and oneness that omitted the dementia diagnosis that had initially brought the group together, instead viewing the group as an assemblage of unique individual participants. Whilst this benefited arts engagements, the participatory arts setting also facilitated other capabilities and

needs of people with dementia. Specifically, people with dementia remained actively caring and responded in moments where others required help, contributing to previous work that differentiates between caring for and caring about others (Milligan & Wiles, 2010). Although these took place on the periphery of activities, the social landscape afforded by participatory arts empowered people with dementia to show how they cared about others, through their words, physical affection, and other actions. This, in turn, blurred care perspectives by recognising the emotional responses of people with dementia and ultimately showed that people being cared for can, at times, disregard their own needs to show care to or about others.

It is important to note that occasional tensions and family carer strain was observed as dementia symptoms advanced, occurring during paired activities where the 'no right or wrong' approach of the programme was not extended by the caring spouse. Some carers showed a desire to create aesthetically pleasing or more technical artworks, which may have been more suited to their own skills and interests. These events could also be interpreted as attempts to encourage people with dementia to perform activities as they may have done prior to dementia, therefore resisting to recognise their changing self-narratives. This is indicative of the responsibilities of caring for a loved one predominantly alone, on a 24/7-hour basis, and the difficulties of tuning out these tensions even within spaces of non-judgemental shared arts. Much of the participatory arts literature to date focuses on the decrease of carer burden from attending activities (e.g. Unadkat et al., 2017), but does not often delve into brief tensions that may begin appearing in programmes after extended periods, given that much of the literature focuses on shorter programmes. Although such events were short-lived and quickly resolved by the guidance of others, these findings help illuminate the additional support needs of carers in the long-term.

9.2.4 Relational Wellbeing and Self

The empirical findings presented in this thesis – alongside the influence of theoretical underpinnings – ultimately inform what living well with dementia may entail. Whilst terms other than 'wellbeing' have been used throughout empirical chapters of this thesis – including resilience, self-identity, accomplishment, connection, personhood, and other psycho-socio-spatial-material factors in

individualised experiences – they all address a different dimension of wellness. Wellbeing, as maintained by Conradson (2005), Atkinson (2013), Andrews et al. (2014) and other human geographers, can usefully be moved away from the individualised definitions to make room for a greater understanding of relational, collective and situated wellbeing. This has been touched on in previous literature (Zeilig et al., 2019), but remains an uncommon interpretation of wellbeing in dementia research. This does not infer that subjective or individualised experiences are to be ignored, but rather that concepts of selfhood and subjectivity are made more meaningful and ‘well’ through connections and relations (Rose et al., 2020). Through the empirical findings, *Setting the Scene* has shown that relational wellbeing can be facilitated and realised through group-based arts participation with consideration given to person-centred needs. Section 5.2.1 shared insights from arts facilitators on how they aspire to create a ‘*feeling*’ and ‘*atmosphere*’ of wellbeing, suggesting that it is something affective, collective, intuitive and fleeting. Additionally, participant observations indicated that participatory arts encouraged self-narratives and authenticities to be shared, through the identities of storytellers, comedians, painters and designers, handy men, dancers, singers, mothers, daughters, husbands, and wives. This invited the continuation of skills and incited an ‘in the moment’ way of meaning-making that is central to wellbeing.

Another indication of relational wellbeing was in how the lifelong partnership of some couples impacted the selfhoods of the individuals involved; specifically, that selfhood in older age is not only important for wellbeing, but that identity can be interdependent on spouses, partners, or other close members of one’s social networks. Participatory arts offer a channel to maintain and enhance these relationships, with the *Setting the Scene* programme creating a landscape for wellbeing to be enabled and emplaced (Barron, 2019). Hence, Conradson’s (2005) conception of the ‘relational self’ within social landscapes can enlighten how the individual and the group simultaneously informed one another. Viewing people with dementia and their carers through the ‘relational self’ construct offers greater insight into how participatory arts – and all of the accompanying actants and

landscapes within them – feed into a sense of contentment and wellbeing. As theorised by Conradson (2005):

‘...the self is generally understood... as something that emerges within and through its relations to other people and events... these ‘significant others’ have the potential to shape the contours of the self, making themselves felt both through material encounter and the operation of memory, longing and desire’. (p.340)

This excerpt is particularly poignant and applicable to this thesis. Wellbeing – not as a goal-orientated concept, but as one that emerges and permeates the everyday geographies of people – cannot be effectively captured in simplistic definitions. Wellbeing is an experience felt and expressed by an individual, but beyond this, it is reliant and interdependent on people, objects, landscapes, novelty as well as familiarity, and affective engagements that are also partially influenced by our own ingrained experiences and ‘identities-in-process’ (Rose et al., 2020). This nuanced and wider-reaching wellbeing conceptualisation usefully collates all of the empirical findings discussed thus far, going beyond seeing it as something that can be quantifiably measured pre- and post-intervention. Rather, this thesis argues that experiences of wellbeing, particularly for those affected by dementia, can emerge through the opportunities afforded by multi-arts, their relationality, shared experiences, ‘in the moment’ interactions, and ultimately the more-than-representational nature of ‘being’ and ‘doing’ well.

9.3 Theoretical Contributions

Having adopted an integrative social, material, and human geographical framework encompassing more-than-representational theory – including Deleuzoguattarian assemblage concepts – therapeutic landscapes and relational wellbeing, this thesis offers novelty in terms of how these theories collectively contribute to new dementia insights. Relating back to empirical findings, the central contributions of these theories include engagement with selfhood, body, senses, the material world, and above all, a reconceptualization of ‘voice’.

9.3.1 The Reconceptualization of 'Voice' within Dementia Narratives

Seeking to re-establish the meaning of 'voice' has become a central insight of this project, providing the foundation for a larger theoretical contribution towards understanding communication for people living with dementia. The term 'making their voices heard' is often used with regards to vulnerable or marginalised groups, including people living with dementia who may face exclusion from research processes or health care decision-making (Alzheimer's Society, 2016). When used in these contexts, voice typically refers to the idea of being acknowledged and having one's own needs and viewpoints recognised. Contrastingly, the word 'voice' is most prominently aligned with verbal or linguistic expression, with other forms of communication being supplementary, unrelated or unrecognised within its definition (Mazzei, 2009). A conventionally linguistic approach to what consists of voice can neglect the additional communicative needs of people living with dementia, whether in research participation, health decision-making, or everyday interactions. Consequently, it can be difficult to effectively capture the perspectives of people with dementia whilst contending with these 'voice' assumptions. In light of the findings of this thesis, people with dementia can benefit from being considered for having more-than-verbal 'voice' and narrative, informed by faces, bodies, creative expression, and material engagements. Participants throughout *Setting the Scene* demonstrated that communication is as heterogeneous as the participants themselves, illuminating aspects of self-identity, personhood, and emotional awareness through *what* they communicated, *how* they communicated, and *why* they communicated it. Adopting a holistic reconceptualization of 'voice' can therefore be empowering for people with dementia.

Literature on 'voice' being anything other than verbal remains limited in dementia research, but the idea has been previously discussed within non-representational and more-than-representational literature. Specifically, Mazzei and Jackson (2017) called for an agential reconceptualization to draw attention to other communicative actants, in the same way that Barad (2003) claimed 'language has been granted too much power' and needs reconstituting in terms of performativity and matter (p.801). This thesis responds to these claims around voice by presenting other forms of

communication as captured ‘in the moment’, that are more inclusive of all agents, human or non-human. Yet, this thesis also demonstrates the use and importance of the spoken words of participants, and of how words are given more meaning when understood within present-moment contexts, alongside other bodies and socio-spatial-material means. In this way, I argue that while language is typically given too much power, it is dependent upon the temporal nature in which it is being used. Expression of self through words within supportive emergent atmospheres of assemblage can be supportive of people with dementia, whilst reflective-based settings can hinder communication (Stevens, 2012). Language is therefore context-driven and necessary to be understood alongside more-than-verbal forms of communication, being aligned with ‘more than’ geographies that recognise ‘the co-functioning of words, passions, things’ (Anderson & McFarlane, 2011, p.125). In this light, the discursive, embodied, material and thematic contents of *Setting the Scene* enabled the connecting of participants through interests, passions and activities. Participants demonstrated how verbal or language-based communication alone can lack depth of meaning than when it is understood alongside other factors – be it storytelling with sound effects, imaginative scenario-based humour, or improvisational dance with meaningful music. The multiplicities of communication therefore not only aid how people are understood, but also present an expression of selfhood through ‘in the moment’ participation encouraged by the arts. Being more-than-representational rather than wholly non-representational offers a balanced consideration of voice and choice of expression, accounting for multi-sensory components of communication (see Section 9.3.2). Performativity and communication in everyday contexts is fulfilled through varied channels of the body, and research perspectives should also be supportive and mindful of these heterogeneities, particularly for participants with additional needs.

As mentioned previously, the vitality of voice is not only in *how* it is communicated, but in *what* or *why* it is being communicated to others. This theoretical consideration – referred to in this thesis as ‘narrative’ or self-narrative – has featured sparsely in past research in relation to dementia and identity (Dupuis et al., 2016; Synnes et al., 2020). Through the findings of this thesis, personalities and self-identities of

participants were often ‘voiced’ through kinship and community, as facilitated by the arts. This therefore proposes further engagement with anthropological and narrative perspectives of dementia that can illuminate the importance of how participants alternatively express and communicate their self-narratives through more-than-verbal means (Hashmi, 2009; Randall, 2009). In this way, voice and narrative are reliant on the active listening of others, therefore arguing that it is not only about communicating through the arts but communicating with *others* through the arts.

9.3.2 More-Than-Representational Theory: Assemblage, Bodies, Materials, Selves

More-than-representational perspectives have shown promise in progressing understandings of wellbeing, dementia, and the philosophical underpinnings of arts practice, all of which have been addressed in this thesis. Having been applied to nursing home contexts in past research (Tan, 2016), assemblage theory and other more-than-representational tenets can contribute to arts-based social research seeking to examine the heterogeneity of dementia and of the people impacted by it.

The initial inspiration for choosing a more-than-representational framework in this study was to highlight the importance of the material world for facilitating participatory arts. Retrospectively, this has enriched how I came to watch and understand the involvement of participants within fieldwork and helped to tease out the emphasis placed on ‘voice’ and its multiplicity. The findings of this thesis build on previous research by addressing how people with dementia are better supported through their relationships and ‘co-fabrications’ with tangible and imagined material worlds (Whatmore, 2006). The sensorial and meaningful elements afforded by accessible props and materials aided the immersion of participants within the arts-based setting. Collectively, living well with dementia can be enhanced through the interplay of the psycho-social-material, in considering the body as social, creative and equally as communicative as voice (Simonsen, 2013). Through a ‘more-than’ theoretical perspective, non-human objects have been recognised for their potential to aid the daily living, participation and communication of people with dementia.

In view of the entanglement of components at *Setting the Scene* – be it the variety of participants, props, topics, or art forms – the programme’s effectiveness can be positioned through assemblage theory and the words of Latour (2010):

'Things have to be put together... while retaining their heterogeneity... built from utterly heterogeneous parts that will never make a whole, but at best a fragile, revisable and diverse composite material' (pp.3-4).

Indeed, the process-oriented rather than outcome-oriented nature of this project has addressed how more-than-representational theory 'connotes emergence rather than resultant formation' (Anderson & McFarlane, 2011, p.125). *Setting the Scene* embodied the conceptualisation of assemblage, seeking to creatively bring together a group of heterogeneous members – with different personalities, behaviours, past experiences, interests, and health concerns – to construct a new sense of community and togetherness for a brief time, using arts as a means of connection. This lens also acknowledges that participants, once leaving *Setting the Scene*, may have contrasting daily wellbeing experiences in the physical and social environments beyond the programme. Hence, viewing participatory arts programmes as emplaced creative assemblages, rather than static models, accounts for their temporality and equally the fleeting nature of wellbeing and its relationality. Indeed, assemblage theory also enlightens the ever-changing nature and potential disruptions that can occur during creative sessions, such as varying turn-out; accidents or unpredictable responses; and variable social dynamics.

More-than-representational thoughts can progress theoretical ideas on living well with dementia and engaging with arts-based activity for self-expression. In past arts-based research that has adopted assemblage theory, expressions through creativity are understood as enabling the sharing of 'identities-in-process' (Rose et al., 2020, p.19) or for enlightening the 'individualised yet collective understandings of living with dementia' (Clarke & Bailey, 2016, p.449). Indeed, the experience of dementia in itself is a continued process, encompassing a sense of change within oneself and as experienced by others (see Section 6.5.2.1). Demonstrated by *Setting the Scene* participants, arts can contribute to wellness, resilience, and empowerment, by overcoming visual or physical impairments, maintaining one's independence, and sharing aspects of self-identity with others. As argued in Chapter 5, arts-based activities are neither the sole focus nor the outcome of *Setting the Scene*. Instead, they are the process through which the engagements, interactions, and becoming of

self can be made possible, and where the ‘encounters of objects, bodies and practices... produce transformations’ (Hellman & Lind, 2017, p.208). With this theoretical stance, it becomes clearer that wellbeing in dementia – in particular a socio-spatial-relational-material understanding – is about valuing ‘being-well’ ‘in the moment’, as promoted by more-than-representational and assemblage theories (Andrews et al., 2014, p.212).

9.3.3 Dementia-Friendly Therapeutic Landscapes and Everyday Geographies

The introductory chapter of this thesis pondered on how impressions of The Lake District were influenced by the romantic and picturesque depictions made by artists and writers in earlier centuries; yet, this contrasted to the wilderness experienced by many locals. This background information was intended to reflect the impressions that landscapes and the arts can make on one another, which was indeed relevant to how participants interacted and created at *Setting the Scene* (see Section 9.2.2.2). However, this information was also suggestive of my perspective as a researcher. Being an outsider researching in the Lakes, I was seeing the natural and built landscapes from fresh and captivated eyes, whilst participants attending sessions typically viewed these as part of their everyday geographies. For most participants, Cumbria was their homeland, full of familiarity connecting to their pasts and unfolding presents that held personal significance beyond aesthetic beauty. Hence, the environments within and surrounding *Setting the Scene* exemplify the therapeutic magnitude of everyday geographies.

The outcomes of this thesis argue for greater consideration of how everyday familiar scenes play a part in what people and other entities do within them, maintaining that this should be an important part of all participatory art programme designs. Recent research has considered this idea in disability studies, whereby a ‘sense of place, of feeling “at home” in comfortable and familiar surroundings’ was an important ‘stabilising force’ for participants (Kaley, 2017, p.160). Hence, therapeutic landscapes can be routinised, everyday spaces of belonging, if they meet the needs of people with dementia. In saying this, new members of *Setting the Scene* complimented the change of scenery from their home environments, enjoying the sense of achievement and newness it created. Subsequently, understandings of

therapeutic landscapes in the context of dementia and arts may involve finding a balance between familiar surroundings and novel activity. A change of scenery –but one that instils stability and familiarity – can distract from habituated, home-based experiences, benefiting richer, ‘in the moment’ experiences for participants.

This thesis has further highlighted the importance of understanding therapeutic encounters through relational and embodied standpoints (Conradson, 2005; Lea, 2008). When theorising the potential of *Setting the Scene* as a therapeutic landscape, this thesis reinforced the importance of understanding landscape through the relations that participants have with and within it. The group- and site-specific programme – whether at Theatre by the Lake or Crosthwaite Sunday school – exemplified the more-than-verbal, multi-sensory and embodied engagements that help to ascertain wellbeing experiences. Other therapeutic landscapes studies engaging with the acting body have discussed performative and repetitive movements as aiding and retaining skills in a manner of ‘learning through movement rather than verbal instruction’ (Kaley et al., 2019, p.14). This concept can be extended in this thesis to ‘socialising through movement’, demonstrating the body’s therapeutic and social potential in creative spaces for those with cognitive impairment. As considered by research on therapeutic landscapes and activity retreats (Lea, 2008), the body’s mobility and proprioception can be engaged with while ‘in nature’, which can extend to how the Friends Gallery interior and exterior were experienced through body movement and active participation. This is also related to work on mobilities and vibrations of materiality, considering the fragility but continuity of engagements with ‘materials, movements, shapes and gestures’ (Dewsbury et al., 2002, p.437; in Bissell, 2010, p.479). This is reflective of Howard’s inclusion to the creative landscape, by engaging his peripheral vision through motion (see Section 6.5.1.1). Hence, our own bodies do not necessarily need to proactively move to interact with an environment, but instead may ‘be thrown into a realm of potential’ (Stewart, 2014, p.122) by the interactions of others within that landscape. In this way, I argue that participants are an integral part of the *Setting the Scene* therapeutic landscape, making meaning of its tangible contents through body,

movement, senses, and assembled ‘aliveness’ that can lead to the inclusivity of others and relational wellbeing potential (Thrift, 2008).

Though only limited discussion of soundscapes is made within this thesis, sensescapes and multi-sensory engagements were emotional and sensitive for participants within the setting. Hints of both ‘sonic intruders’ and ‘sonic ambience’ (Bell, 2017, p.831-833) were demonstrated throughout sessions, whether it involved a sudden fire alarm emitting strongly affective responsiveness from the participant group (and affecting potential members in the foyer) or the pleasant harmonising background sounds of nature, visitors, the outdoors, theatre activity, chatter, and chosen ambient music. Whilst the former distracted from the participatory arts and resulted in negative responses or lasting mood changes, the latter were positively perceived, shaping participant attention and unfolding participation. This indicated how people can understand an environment through sensory perceptions of it, and indeed how the senses are necessary for place-based interactions to be felt (Davidson & Milligan, 2004; Bates, 2019). These concepts also relate to other senses, such as ideas of alienation resulting from disorientating visual surroundings or controversial paintings (Örulv, 2010), or the therapeutic encounter of arriving into the energetic and dressed-up *Setting the Scene* programme space. Overall, then, the theoretical contributions of therapeutic landscapes to participatory arts settings can advocate places and spaces as neither inherently therapeutic or untherapeutic, but dependent on perspectives of everyday geographies, individual interpretations, and the unfolding of multi-sensory moments that shape participant responses within those given places.

9.4 Methodological Contributions and Reflections

Insights into ‘being in the moment’ and the reconceptualization of ‘voice’ not only make contributions to the empirical and theoretical components of this thesis, but also reinforce the accompanying methodological contributions. With the adoption of a participatory action research (PAR) approach, alongside sensory ethnography and multi-methods, this thesis provides further insights into the ‘in the moment’ inclusivity of people with dementia in research. The following sections explore PAR’s

potential in dementia research, the significance of sensory ethnography and the usefulness of video and photo elicitation. This section also contains reflections on the successes and shortcomings of the overall methodology and how my own positionality as researcher was negotiated.

9.4.1 Participatory Action Research [PAR] for Participatory Arts and Dementia

Participatory or action-based methodologies, such as PAR, are limited in dementia-based research but not entirely novel, with study examples produced over the past decade (Pipon-Young et al., 2012; Goeman et al., 2016; Swarbrick et al., 2019). However, PAR is further uncommon in research specifically exploring community-based participatory arts and dementia (Dupuis et al., 2012; Morrissey 2017; Tischler et al., 2019). Hence, this thesis contributes to a small but growing sub-field.

In the *Setting the Scene* study, PAR promoted the inclusivity of people with dementia by valuing their communicative strengths and recognising their 'voices' as fundamental to the findings (Kara, 2015). Participants – including people with dementia and carers – were able to inform the direction of my observations and contribute to insights on how wellbeing can transpire for different people. Whilst the management of interviews and group discussions was at times challenging (see Section 9.4.3), participants had more balanced opportunities to communicate whilst engaging in creative, 'in the moment' session activities, which represented the majority of data collection. This demonstrated that there were benefits to recognising the creative and emerging words or actions of participants for contributing towards PAR research objectives, as opposed to relying on conventional, reflective interviewing methods. Previous practice-led dementia research has hinted at this insight, with some studies using art-making processes or final artworks as forms of data (Chauhan, 2018; Synnes et al., 2020). However, additional benefits came from video-recording 'in the moment' creative engagements in this study, given that the footage could be used as a data collection tool during reflective PAR discussions, adapting these processes to be more supportive of people with dementia. Hence, this thesis demonstrates participants' capabilities of engaging in PAR studies and conversations when accessible designs are used and more-than-verbal actions recognised as valid forms of self-expression.

Indeed, this study confirms the ways that participatory arts complement participatory methodologies, both of which share values of community, collaboration, process-oriented learning and active involvement (Pamelia, 2015). *Setting the Scene*'s creative practitioners also contributed their expertise throughout this project and helped me gain insight into their design intentions, learn from their practices, and subsequently include their voices alongside other participants to produce more informed research. As previously discussed, it was the act of engaging in arts that created an environment for people with dementia to be more responsive contributors to the research. PAR methodologies can therefore complement research and arts practices, by utilising the arts for novel research participation and communication (Tischler et al., 2019).

PAR also acknowledged the practical needs of CASE partner Theatre by the Lake, who sought a participatory evaluation of their *Setting the Scene* programme. Like previous PAR studies that have created non-academic, user-friendly practical outputs (e.g. Pipon-Young et al., 2012; Milligan & Mossabir, 2018; Tischler et al., 2019), this project developed a *Setting the Scene* descriptive toolkit, summarising the programme design components, participant responses, and other material and spatial factors relating to its effectiveness. Initially intended to support the maintenance or expansion of the programme, this toolkit evidence can also play a post-pandemic role in regenerating the *Setting the Scene* programme. The COVID-19 pandemic disproportionately impacted the arts and theatre sector, as well as people with dementia in general (Alzheimer's Society, 2020), halting all social and creative community services previously available. Hence, these practical outputs can be beneficial for advocating the wider use of arts for dementia and wellbeing.

9.4.2 Sensory Ethnography, Visual Data and More-Than-Verbal Involvements

To effectively support the rolling nature of this project and the improvisation involved in facilitating *Setting the Scene*, supportive visual data collection methods and thick descriptive fieldnotes were adopted, drawn from a sensory ethnography methodology. Previous authors, such as Hellman and Lind (2017), have discussed the extent to which visual ethnography and field note methods make it possible 'to think differently about the unfolding of the process' and how 'the use of multiple senses

to map' particular settings can generate knowledge of 'human, material and visual entanglements' of performance (p.210). Likewise, this *Setting the Scene* project demonstrated the potential of sensory and visual ethnographic methods to expand knowledge of dementia and participatory arts beyond elementary representations, instead attending to 'in the moment' relationalities and more-than-verbal engagements. This suggests the complementary integration of theory and methods in this project, which was previously raised as a gap in existing literature.

Given the emphasis placed on strength-based approaches to focusing on what people with dementia can *still do*, it felt appropriate to choose a methodology for this study that could respect this. Indeed, sensory ethnography better apprehended the strengths of participants in real-time during sessions, through consideration of their words, movements, senses, interactions, skills and achievements. The findings subsequently show how a theoretically driven methodology – supportive of 'more-than' geographies and social theory – can contribute to new, in-depth knowledge of dementia bodies and strengths in the assemblage of creative settings (Tan, 2020). Accompanied by visual data, sensory ethnography helped to retain 'in the moment' and emplaced experiences within *Setting the Scene* spaces, contributing to the argument that memory is not an entirely 'internal, psychological archive' but can be constructed as an 'emplaced, embodied, multi-sensory phenomenon' (Stevenson, 2014, p.335). Whilst these concepts are embedded in anthropology and human geography (e.g. Davidson & Milligan, 2004), they do not feature as prominently within dementia-based research, even though they can contribute to enriched, alternative perspectives on what memory means; this has implications not only to theory but also to effectively capturing and engaging people with dementia in data collections. These theoretical concepts were thereby operationalised in this thesis through sensory ethnography, aided in particular by the visual and audio data captured and re-watched. Overall, this aspect of the thesis contributes to research conduct that not only aims to understand the benefits of the arts but helps to demonstrate participant capabilities in the process.

Sensory ethnography and visual data have previously been adapted for the inclusion of people with dementia or for engaging with carers (e.g. Hung et al., 2018). In

Chapter 2's review, visual data collection was shown to be popular within dementia research. However, few studies have applied video elicitation methods to interviews with people living with dementia, with more common application being made to adolescent disability studies (e.g. Kaley, 2017). Although it was not the central method of research enquiry, this thesis demonstrates its potential in re-positioning past experiences within present moment contexts, to overcome barriers faced by people with dementia in conventional reflective tasks. As with previous sections discussing the importance of material stimuli for 'in the moment' interactions, so too can visual and multi-sensory stimulation – whether through photo, video or audio – be used to support contributions to research through collaboration and inclusion.

9.4.3 Methodological Reflections

Reflection 1: Elicitation Methods

The use of video and photo elicitation during interviews and action learning meetings led to positive glimpses of engagement. On numerous occasions, a few participants or the whole room sang along to music from the video clips being watched and listened to. Participants also became more engaged in conversations – either about themselves or other recognisable participants – when they had visual stimuli contextualising the discussion. During interviews, elicitation methods often led to engaged, clarifying observations that had otherwise been difficult to obtain during sessions. This was therefore a valuable communication and reflection tool for people with dementia, as it has shown to be in recent disability studies (Kaley, 2017). This use of visual data was not considered in previous participatory arts-based dementia research and therefore contributes novelty to the field. Nevertheless, some participants with aural or visual impairments were unable to reap the same benefits from its use, meaning advantages emerged on a case-by-case basis.

PAR was originally chosen for its transformative and inclusive ontology, which photo and video elicitation methods aimed to embody. Whilst they aided the responsiveness of people with dementia in reflective tasks, it remained challenging to maintain participants' attention for extended periods of time in highly discursive methods. People with dementia could share about their preferences for props, activities and themes, and often attributed the programme's success to facilitators

Jenn and Rachel, but it was difficult to draw these conversations out beyond short affirmative answers. The few participants who suggested improvements were quick to highlight their minor nature, stating that these were only shared due to the purposes of the meetings. I sensed that people with dementia and their carers both felt pressured to respond, which made me feel uneasy facilitating these discussions.

The benefits of elicitation methods were limited in action learning meetings, where carers or particular members highlighted the challenge of joint discussion where some participants are more vocal or dominant than others. Elicitation benefits were also often over-ridden in interviews where carers spoke over their partners. This was particularly true for carers meeting me for the first time, who spent much of the interview introducing themselves, discussing life experiences and their own adjustments to dementia. Furthermore, the majority of carers often spoke in relation to Amy's Care activities rather than *Setting the Scene* specifically, the latter of which they knew little about if their partner attended with social care. This illustrated the complexities of conducting dyadic interviews in projects with multiple organisations. Overall, carer dominance was difficult to overcome given that the study endeavoured to include both perspectives. In retrospect, more opportunities for independent discussion with people with dementia would have been useful.

Reflection 2: PAR Shortcomings

This thesis aimed to collectively recognise the service needs of Theatre by the Lake, the personal experiences of participants, and my own research ideas, for which PAR was deemed a suitable methodology. In a bid to meet the theatre's service needs and to refine their programme, discussions were often framed around the benefits and shortcomings of *Setting the Scene*. However, minimal new knowledge was gained during action learning meetings and there was difficulty finding topics to kindle discussion. This was, in part, because the programme had been running for over four years before the research commenced, giving facilitators time to refine sessions and continually interweave participants' interests and needs into activities. Whilst the mixed success rate of interviews and action meetings was influenced by the challenge of conducting such tasks with people living with dementia (Tsekeleves

et al., 2020), my insights suggest that PAR would work more effectively if centred on a newly developed programme or co-design/co-creation venture.

This project involved three separate organisations, only two of which were recognised as research partners. While communications between Lancaster University and Theatre by the Lake were consistent throughout the project, it was more difficult to liaise with Amy's Care, who had busy schedules and limited availability. The social care group were a major beneficiary of the programme, having had an unforeseen increase in client numbers over the duration of the research. This provided *Setting the Scene* with a reliable participant group fundamental to the running of sessions, but also led to increased pressure on Amy's Care staff that went beyond the tasks required of family carers during fieldwork. On occasion, Amy's Care accommodated for parts of the research by starting work earlier on select days, sharing their client's contact details, and helping to fill out forms on top of their own paperwork. These responsibilities could have been lessened if Amy's Care had been able to contribute to research discussions, allowing for better communication across all organisations and recognition of the needs of their staff.

Reflection 3: Researcher Positionality

Reflecting on my ethnographic fieldwork experiences, my own positionality during fieldwork was difficult to pre-empt, particularly in a space influenced by an improvisational arts approach and the unpredictable nature of dementia. I had to renegotiate my position on multiple occasions (Dawson, 2010), influenced by three main factors:

a) My physical presence in the room. As lead researcher, I felt that participants were comfortable with my presence and considered me as an additional facilitator, given that they too often displayed note-taking behaviours during sessions. Depending on activities and group sizes, I switched between sitting inside the participant circle or sitting/standing outside of it with a more observational role. This was also normalised by professional carers who often sat on the side-lines to complete client paperwork. My overall positionality in the *Setting the Scene* landscape was therefore normalised and blended with existing actions and responsibilities of others.

b) Non-verbal behaviour and participation in activities. Similar to physical presence, my participation in activities often depended on the activity type or practical limitations impacted by group turnout. However, I occasionally experienced sessions where I actively participated in activities and helped to facilitate small group work. On these occasions, I had less opportunity to take notes and observe the room as a whole, but benefited from intimate encounters with nearby participants. Advanced planning was, however, difficult and such decisions were made 'in the moment', meaning that I often had to make compromises on research conduct due to *Setting the Scene*'s limited time frame and space.

c) Verbal behaviour and relationships with participants. I limited my verbal communication during activities to enable participants to respond or initiate conversation. This was testing, given that interactions varied depending on participants' personalities and abilities. Researching an intimate group of people with dementia and accompanying carers inevitably led to the forming of relationships throughout the fieldwork, mirroring those built by facilitators. Experiences of loss and death were common throughout the research, particularly during Phase Four/COVID-19 pandemic. I found this psychologically challenging, particularly at a time when I was close to participant data and vignettes.

Reflection 4: COVID-19 Pandemic Implications

The COVID-19 pandemic impacted this project's final PAR phase, including cutting short my research departure plan, cancelling a pre-planned deliberative panel for March-April 2020, delaying the toolkit development, and postponing an Autumn exhibition at Theatre by the Lake. In particular, the deliberative panel intended to build on the action learning groups from Phases Two and Three, inviting a larger cohort of theatre staff, programme members, research supervisors, and local health and social care professionals. This would originally have given more responsibility to participants in shaping research interpretations and the toolkit development. Furthermore, the national lockdowns associated with the pandemic led to the closure of Theatre by the Lake, including *Setting the Scene*, with significant job losses and furloughed staff. This was a testing time to work from home with emotive, personal data, knowing the ongoing circumstances for those staff and participants.

9.5 Research Limitations

9.5.1 Participant Sample

Recruitment for this research project was limited to recruiting from existing and newly arriving members of *Setting the Scene*, who had existing connections with Theatre by the Lake and invested interest in the programme. This male-dominant participant sample (men = 10; women = 4) is not representative of the general population, given that women living with dementia typically outnumber men by a ratio of 2 to 1. The sample was White British, with one member having dual British and Australian citizenship. This lacks racial and ethnic diversity but is reflective of the Cumbria County Council Census (2011), which highlights the area as being 99.3% White compared to England's national average of 90.9%.

9.5.2 Carer Presence

Some of the carers involved in the research were only occasionally in attendance, leading to limited data. Furthermore, four interviewed carers had never attended a session alongside their partner, due to Amy's Care involvement. Consequently, their understanding of *Setting the Scene* was limited, with more reference made to the services and staff of Amy's Care than of Theatre by the Lake.

9.5.3 COVID-19 Pandemic

As previously mentioned, the COVID-19 pandemic had an impact on the final phase of the PAR project. The cancelled activities would have further involved people with dementia, carers, and other relevant stakeholders, but these were permanently cancelled due to the ongoing pandemic. This impacted the overall intentions of adopting PAR and limited participant voices in the research analysis stages.

9.6 Concluding Thoughts

Setting the Scene participatory arts have been exemplified for their creative, social, personal, material and wellbeing benefits towards living well with dementia. The empirical, theoretical and methodological contributions of this thesis have been explored for how they expand understandings of the 'in the moment' wellbeing benefits of engaging in participatory multi-arts for people living with dementia and their carers. Looking broadly at the overall research project, the findings relay new

insights regarding ‘voice’ and communication; self-identity and participant heterogeneity; materiality and non-human actants; social and relational landscapes; relational wellbeing; and the relevance of more-than-representational perspectives for the advancement of dementia research. Participatory arts activities can empower participants with dementia and their carers to communicate verbally and non-verbally, pertaining to the importance of expressing sense of self, communicating through or with non-human actants, and communicating relationships with other people to strengthen selfhood, personhood and relational wellbeing. ‘Voice’ had implications beyond empirical findings, suggesting that inclusive, process-oriented methodologies like PAR and ethnography can be made accessible to people with dementia when combined with empowering, multi-sensory multi-methods.

Theoretically, this thesis contributes to the integration of therapeutic landscapes and more-than-representational perspectives – such as assemblage theory and human–non-human interactions – in shaping how we attend to the roles of socio-spatial–material encounters in dementia and community-based arts contexts. Through place-based experiences, atmospheres, and the multi-sensory material world, the ‘voices’ of people with dementia – be it through body, face, or conventional verbal voice – could be sought, supported and responded to. The impact of art-based contributions and the overall affective assemblage of creative arts and wellbeing could be better attended to through human and social geographical standpoints. This thesis demonstrates the potential of viewing wellbeing as holistically relational and processual in the everyday routines and arts-based experiences of people living with dementia, rather than entirely individualistic or outcome-oriented.

Chapter 10: *Curtain Call: The Relational Wellbeing of People with Dementia and their Carers during Participatory Arts*

'Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits' (Article 27, Universal Declaration of Human Rights; cited in Ullán et al., 2013).

10.1 Project Overview and Summary of Findings

The worldwide prevalence of dementia is ever-growing, along with the emphasis on moving beyond a symptom-centric biomedical approach to find new and accessible ways of 'living well with dementia' (Oyebode & Parveen, 2019). For ageing populations and areas of higher dementia prevalence – like Cumbria (Cumbria County Council, 2017) – it is necessary to ensure dementia-friendly approaches and services are made available to support people living at home with dementia or indeed caring for their relatives. Responding to local demand and audience needs, Theatre by the Lake's *Setting the Scene* participatory multi-arts programme was developed to enhance social connections and invite creative expression for all those impacted by dementia (Theatre by the Lake, 2020). A noticeable trend has been identified of using arts-based activities for wellbeing in dementia, expanding into cultural and community settings like Theatre by the Lake (e.g. Milligan & Mossabir, 2018) as opposed to purely therapy-based, nursing or clinical settings (e.g. Beard, 2012). Research has begun to untangle the social, relational, psychological/cognitive and emotional wellbeing benefits associated with participating in arts whilst living with dementia (Castora-Binkley et al., 2010; Zeilig et al., 2014; Young et al., 2016; Dowlen et al., 2018). Yet, the existing literature and evidence base lacks the 'voices' of people with dementia and their participation within the research. There also remains an opportunity to expand on dementia and arts research by using complementary, 'in the moment', multi-sensory forms of enquiry that better encapsulate what participatory arts provide to participants.

Through a participatory action research [PAR] approach and sensory ethnographic methods of enquiry, this thesis worked alongside people with dementia, carers, and facilitators to reconsider, words, bodies, movements, and social engagements as ways of eliciting knowledge about the impact of *Setting the Scene*. A detailed look into social, emotional, relational and material tenets of the participatory arts programme was benefited by a combined human geography theoretical framework of more-than-representational concepts, relationality, assemblage, and therapeutic landscapes. I argue that the wellbeing potential of participatory arts extends beyond the intrinsic value of the art itself, relying also on complex assemblage and entanglements of arts-based human and non-human actants; self-identity and expression; meaning and culture; new and existing relationships; the multiplicity of communication and ‘voice’; sensory engagement; socio-spatial-material facets; familiarity and novelty; and collective atmospheres of acceptance and wellness.

The person-centred, ‘in the moment’, and strength-based perspectives guiding participatory arts facilitation not only uphold what participants can still *do* physically and cognitively, but more so who they still *are* individually. Throughout vignettes and events addressed in this thesis, the heterogeneities of participants were expressed and attended to through active and passive participation. Participatory art-making in group-based community settings was shown to contribute to participants’ ‘identities-in process’ (Rose et al., 2020) and their experiences of ‘relational self’ (Andrews et al., 2014), whilst retaining a sense of social belonging, creative stimulation and relational wellbeing. The findings of this thesis reinforce the notion that it is not necessarily the intrinsic quality of an art form or activity that retains benefits, but that it is the *underlying* mechanisms, facilitation processes, social setting, the diversity of people involved, and the materiality of objects that assemble to aid self in dementia and the emergence of relational wellbeing.

10.2 Policy and Practice Implications

Building on practical contributions discussed in Chapter 9, this thesis demonstrates that participatory and collaborative research with external organisations can bring more immediate and informed developments to services or programmes. In the application of PAR to CASE partner Theatre by the Lake, the opportunity to take

action was possible through the fieldwork, due to the proactive and conscious PAR approach guiding emerging findings. Reciprocally, the Theatre by the Lake facilitators involved in this research project demonstrated their value as PAR members, whose insight and experiential expertise in participatory arts offered solutions to research conduct and ways of communicating with participants (Scholar et al., 2021). Yet, elements of the PAR approach were also recognised for their challenges – such as the action learning groups and balance of voices – which is, in part, due to the length of time the programme had been running prior to the research starting. Overall, collaborative PAR research, as exemplified in this CASE project, can build a bridge between arts and research practice, where one can inform the other in developing richer knowledge and development in dementia approaches. The production of user-friendly and accessibly formatted reports, such as this project's toolkit, make research findings more approachable and actionable for non-academic audiences and external organisations, further strengthening the implications of collaborative PAR practice. It should, however, be noted in future projects that the knowledge transfer may become limited as a service or programme ages.

In working alongside Theatre by the Lake, the findings of this thesis offer insight into how participatory arts practice can be used to develop dementia-friendly programmes encapsulating the 'living well with dementia' strategy (Castora-Binkley et al., 2010). Specifically, practices comprising multi-arts focus, multi-modal set-ups, and multi-thematic contents – with underlying community-based, person-centred, 'in the moment', narrative-driven, and strength-based approaches – were impactful for participants. Collectively, these approaches to arts and creative practice promote the enduring skills, strengths, and identities of people living with dementia and their carers, taking attention away from the dementia diagnosis and towards the person. These considerations have transferability to informing practices of other arts-based settings aiming to develop their own dementia-friendly initiatives.

Public campaigning strategies in recent years have been effective in bringing awareness to Alzheimer's Disease and other dementias, which often retain a focus on being 'still me' and skilled (e.g. Public Health Agency, 2016). However, information can remain symptom-centric and from the perspective of carers. Whilst

these perspectives – also illustrated in this thesis – are important when considering all those impacted by dementia, they often lack the ‘voices’ and narrative citizenship of people with dementia, which this thesis worked to promote. The individual accounts captured during fieldwork, creative activity, storytelling and conversations demonstrate participants’ heterogeneities – comprising their interests, past and present experiences, careers, personality traits, and values – which could provide positive information for portraying the realities of living with dementia to wider society. Recent research has been calling for ways to ensure that ‘voices and stories [of people with dementia] can be amplified and heard in society’ (Synnes et al., 2020, p.1029), and participatory arts offer a potential route to do this.

Lastly, in light of the COVID-19 pandemic and national lockdowns that impacted the social and community experiences available to people with dementia (and the support provided to informal carers) there is a heightened need for research demonstrating the significance of arts for relational wellbeing. This thesis can make contributions to national public health strategies for promoting relational reconsiderations of wellbeing, with emphasis placed on arts-based, creative and social interventions, moving beyond a biomedical/pharmacological focus. Revisiting Ullán et al. (2013) from Chapter 2, their research maintained that person-centred participatory arts help to achieve Article 27 of the Universal Declaration of Human Rights, whereby people have a right ‘to participate in the cultural life of a community’ and ‘enjoy the arts’ (Ullán et al., 2013, p.443). Indeed, this statement is particularly apt in light of the impact of the COVID-19 pandemic and its effect on the accessibility of arts and culture to all. With decreasing funding for arts in healthcare, this thesis can contribute to an evidence base of research promoting increased arts interventions for maintaining daily wellbeing, framing them as a human right and wellness-related phenomenon, not simply as something for pleasure.

10.3 Ideas for Future Research

The already well-established *Setting the Scene* programme, and the knock-on effect of the pandemic, both brought limitations to how effectively PAR could be employed in this thesis. Nevertheless, indications of the programme’s benefits were still well

grasped and captured during various forms of the data collection. Future participatory arts research is therefore encouraged to adopt complementary participative, action-based methodologies, with potential to empower participants with dementia to contribute throughout the life cycle of a project, which could not be fulfilled to its utmost potential on this occasion.

Secondly, and inspired by the sensory, more-than-representational lens adopted in this project, careful deliberation should be given to reconfiguring the voices and identities of people with dementia within everyday contexts and research practices. In this thesis, more-than-verbal communication was shown to be supported through arts-based activities whilst 'in the moment', leading to senses of accomplishment, self-identity and wellbeing. Additional studies could more broadly explore the in-depth narratives and lived experiences of people with dementia through accessible, more-than-textual and artistic means. The thesis also suggests that creative, practice-led and 'in the moment' interactions have potential to be used in other studies, not only as the subject of investigation but also as tools to access the creative perspectives of people with dementia. This calls for more than just a future research concept, but rather an overall awareness and acceptance of the validity of unconventional research methods, that can be inclusive of participants with additional needs. Connected to this, future studies interested in investigating the wellbeing benefits of arts or social activities for people with dementia could benefit from a relational conceptualisation of wellbeing, which opened up insights in this thesis into the importance of assemblage, human and non-human relationships, self-expression and identity in 'being well' (Andrews et al., 2014).

When evaluating participatory arts programmes, there is a pronounced need for research to extend investigations beyond the rudimentary, intrinsic, or comparative benefits of art forms, to broader design-based features of participatory arts and their physical, material and atmospheric assemblage. This thesis argues for further examination of the facilitation approaches and design elements that enable interactions and wellbeing potential (this includes but is not limited to person-centred approaches, 'in the moment' techniques, strength-based attitudes, thematic

designs and activity multi-modality). Facilitator perspectives were of benefit to this thesis, but their research involvement could be increased for future studies.

Engagement with therapeutic landscapes concepts and sensory literature can supplement how dementia experiences are considered. To further verify and strengthen the contributions of this thesis, additional insights into the importance of emplaced and relational experiences within participatory arts settings could be extended across different locations and programmes external to *Setting the Scene*, including those within cityscapes or urban spaces. Additionally, this thesis illustrates the centrality of objects for initiating, stimulating and contextualising participant experiences of group-based arts. Being limited to Theatre by the Lake, other questions regarding how materiality and relationality can apply and support people with dementia in everyday contexts were outside of the scope of this thesis. Future investigations could therefore cover this area, to look at how multi-sensory, socio-spatial-material interactions may provide new channels of communication between people with dementia and their families or carers in home contexts.

Lastly, this thesis conducted research between 2018-2019, prior to the COVID-19 pandemic. Since the resulting national lockdown led to the closure of all community, social and group-based activities for an extended time, regular attendees of social support groups and participatory arts programmes became limited to their homes, and isolated from any group-based social or creative contact. Indeed, emerging statistics highlight that people with dementia have been disproportionately impacted by the pandemic (Alzheimer's Society, 2020). Given the emphasis of this thesis on the integrated creative and social benefits of arts groups, future research could revisit participants, such as those from *Setting the Scene*, to examine the COVID-19 impacts on holistic health and wellbeing since participatory arts closures.

10.4 Concluding Statement

This project has illustrated the nuances of relational wellbeing experiences enabled by participatory arts engagements, for both people living with dementia and their accompanying family or professional carers. Methodologically, the project has illustrated the potential of researching participatory arts settings with

complementary sensory and participatory research approaches, that better support the voices and perspectives of participants. Theoretical contributions were made to the study of dementia and arts using more-than-representational, relational wellbeing, assemblage theory, and therapeutic landscapes concepts, to delve deeper into the multi-sensory and more-than-verbal ways of expressing and communicating. Overall, this thesis exemplifies ways of adopting empowering and accessible research designs and philosophical underpinnings, whilst benefiting from capturing richer and personal accounts of creative dementia experiences. The research contemplates the importance of going beyond the participatory arts, observing the other socio-spatial-material features that have potential to advance creative, social, emotional, and relational wellbeing in the bid to live well with dementia; whether as a carer or a person with a dementia diagnosis. Ultimately, this thesis has captured the multiplicity of 'voice' and the heterogeneity of people impacted by dementia, showing the ways that they can continue living authentic, meaningful, and connected lives of wellness through participatory arts.

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12. Appendices

12.1 Appendix 1

TBTL Block 18

Session 5: 070219

Theme: Country&Western

Lead Practitioner – Jenn Supporting: Rachel

Aim: Social time $\frac{1}{2}$ hour – Activity time, 1 hour

Time	Activity	Resources	Notes / Eval
11.00	Music and Welcome	Paper and Pens – Name stickers Wagon Wheels	
11.10	Greetings game	So each person turns to the person on their right and says: "Howdie hawh" the person next to them says "Yeehaw" back then turns to their neighbour to the right and says "Howdie hawh". Then when we have the hang of this we add in a tip of the imaginary hat for "Howdie hawh" and a big thigh slap for "yeehaw".	
11.20	Profile Shots: If you were on a wanted poster... - What would your name be? - What would you be wanted for? What would your 'pose' look like? etc	Help the group come up with examples for each participant if needed Example of a wanted poster...	
11.40	Cowboy spittoon story game	Brown paper and words	
12.05	Dancing Achy Breaky Heart Wagon wheel Freestyle dancing.....	Line Dance: Right heel tap and in x 4, left heel tap and in x 4 (Right foot) Step forward one and back Step to side one and back (repeat) (Left foot) Step forward one and back Step to side one and back (repeat) (Walk forward) Step 1, 2, 3 Clap And back 2,3, Clap (repeat) Lassoo round in a circle Repeat	
12.20	Sing Song	Hey Good Looking Annie's Song Country Roads, Take me Home	
	Back up Balloon with some nice country songs		

12.2 Appendix 2

Participant Information Sheet – Accessible Version

Project: The Use of Participatory Arts Activities for People with Dementia and Their Carers

My name is Meghánn Ward. I am a PhD student at Lancaster University and I am interested in the use of arts activities for people with dementia and their family or carers.

What is the study about?

We want to learn more about Theatre by the Lake's arts activities, in particular how they might help people living with dementia, as well as any family or carers that attend the sessions. We want to learn more about different individual arts activities, such as music, singing, dancing, drama, storytelling, and arts + crafts. We would like to continually improve the activities at Theatre by the Lake for current participants, so that similar sessions may be made available to other groups of people with dementia living elsewhere in the UK.

Why have I been approached?

You are being invited to take part in this project because the study includes people living with early to mid-stage dementia, those who care for them or stakeholders who have a concern for dementia in the United Kingdom.

Do I have to take part?

No. It is your choice whether you want to take part or not. If you agree to take part but later want to withdraw from the study before it ends, it is your right to do so. In these cases, as much information as possible about you will be removed and destroyed from the project.

What will I be asked to do if I take part?

If you would like to take part, and you are a person living with dementia or caring for someone with dementia, you will attend Theatre by the Lake's arts activity sessions once a week throughout the year. You don't have to attend all of the sessions if you are unable to. The weekly sessions will be based on different themes and use drama, storytelling, movement, music and sound, group-based crafts and reminiscence.

You will occasionally be asked to fill out questionnaires during the study. A carer can help complete these forms alongside those they care for. These questionnaires will take place at the start, middle and end of the study (approximately month 1, month 6 and month 12) and will take between 15-20 minutes to do.

While you attend the arts sessions, the researcher Meg will observe and participate in the group, using audio recorders, photography, video recordings and note-taking to capture what happens.

You may be invited to occasional meetings to discuss how you feel about the activities, but these are optional. Participants will be invited to take part in an interview with their carer near the end of the project. These interviews will last for 30-60 minutes and will help the researcher get a better idea of how you felt about your time at Theatre by the Lake's sessions.

Will my data be Identifiable?

The information you provide is confidential. All data collected for this study will be stored securely and only the researchers conducting this study will have access to this data. All interviews or conversations will be kept anonymous. The photography and video data will include facial identification, but your name will not be included; if you have any questions about this or would like to opt out of photographs and video, please let the researcher know. You are free to take part in Theatre by the Lake's arts sessions without taking part in the research study if you choose to do so.

What will happen to the results?

The results will be written in a report. Some results may be published in academic journals. We aim to present the results at an exhibition based at Theatre by the Lake, which all participants will be invited to attend alongside members of the public. A summary of the results will be sent to you and your family.

Are there any risks?

There are no risks anticipated with this study. However, if you experience any distress during or following participation, carers and helpers will be at hand to assist you.

Are there any benefits to taking part?

It is hoped that Theatre by the Lake's carefully chosen arts activities will improve social inclusion, health and wellbeing for both people living with dementia and their carers. The activities aim to connect people and give

people a space to be creative and have fun. For stakeholders, it offers an opportunity to collaborate with local practitioners.

Where can I obtain further information about the study if I need it?
If you have any questions about the study, please contact the principal researcher:

Researcher contact details:

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Or contact Mary Elliott – House Manager at Theatre by the Lake, Keswick
Tel no: 017687 72282

Email: Mary.Elliott@theatrebythelake.com

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Prof. Catherine Walshe
Tel: +44 (0)1524 510124
Email: c.walshe@lancaster.ac.uk
Faculty of Health and Medicine
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Division of Health Research, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster

LA1 4YG

Thank you for taking the time to read this information sheet.

Resources in the event of distress

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of help to you. Please speak to your carer or a member of the Theatre by the Lake team, who will offer you support and advice.

Alzheimer's Society -

https://www.alzheimers.org.uk/info/20011/find_support_near_you#!/search

Local Contact Details:

Alzheimer's Society - Eden and Keswick

32 Tynefield Drive,

Penrith,

Cumbria,

CA11 8HZ

Tel: (01768) 899633

Age UK West Cumbria -

<https://www.ageuk.org.uk/westcumbria/>

Local Contact Details:

Age UK Office / Health and Wellbeing Hub

Cottage Hospital

Crosthwaite Road

Keswick

CA12 5PH

Business Tel: 01768 245698

Client Helpline: 08443 843 843

Email: info@ageukwestcumbria.org.uk

For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection

12.3 Appendix 3

Consent Form

Project: The Use of Participatory Arts Activities for People with Dementia and Their Carers

We are asking if you (or your family member) would like to take part in a research project that will explore the benefits of attending Theatre by the Lake's creative sessions. Before you offer your consent to take part in the project, we are asking that you have read the participant information sheet. After reading the information, please read through this consent form and tick each of the boxes if you agree with the statements. If you have any questions, please contact the principal researcher Meg before signing the consent form.

Please tick the box on the left-hand side if you agree with each statement.



- I have read or been read the information sheet and fully understand what will be involved in the project.
- I have been able to ask questions about the project and they have been answered in a satisfactory way.
- I understand that my discussion at Theatre by the Lake will be recorded and then anonymised, which will be stored securely at Lancaster University.
- I understand that any audio or visual recordings will be securely stored at Lancaster University for 10 years after the written report has been submitted.
- I know that I can request not to be in photographs or videos at any given time; and I can request for images to be deleted.

- I understand that I am not obliged to take part in the study and can withdraw at any point during the project.
- I understand that the information recorded during the project will be anonymised and may be published.
- I agree to anonymised quotations from Theatre by the Lake sessions and interviews to be used in reports, conferences and other presentation events.
- I understand that any information I give will remain strictly confidential and anonymous, unless the researchers believe I am at risk of harm to myself or others.
- I consent to Lancaster University archiving audio, visual and written data about me after the study has finished.
- I consent to take part in this project.

Name of participant: _____

Your Signature (this may be on behalf of the participant): _____

Date: _____

Contact details (tel. no or email address): _____

Name of researcher: _____

Signature: _____

Thank you for agreeing
to take part in our study.

Accessible Demographic Information

Questions 1 and 2 are about your/the participant's age and gender. Questions 3 and 4 are about life and activities outside of Theatre by the Lake.

1. Please draw a circle around your/the participant's age category:

40 or below 41-50 51-60 61-70 71-80 81 or above

OR Prefer not to say

2. Please draw a circle around your/the participant's gender:

Male Female Prefer not to say

3. Who do you/does the participant live with?

- I live by myself
- I live with a spouse or partner
- I live with a son/daughter or other family member
- I live in residential, nursing or specialist care

4. What other activities, social groups or hobbies do you/they like to take part in during the week? Please list a few examples below.

12.4 Appendix 4

Photo Release Form

**Project: The Use of Participatory Arts Activities for People with Dementia
and Their Carers**

I grant permission to Meg (Meghánn Ward) from Lancaster University to use any photographs or video recordings taken of me during her research at Theatre by the Lake (2018-2019). I understand that these photographs and video recordings may be used in publications, research articles, exhibitions or conference presentations in the future.

Tick this box if you are happy for your photographs to be released

OR

Tick this box if you do not want your photographs to be released

Tick this box if you are happy for your video recordings to be released

OR

Tick this box if you do not want your video recordings to be released

Participant Signature: _____

Date: _____

12.5 Appendix 5



Applicant: Meghann Ward
Supervisors: Christine Milligan and Emma Rose
Department: Health Research
FHMREC Reference: FHMREC17093

26 June 2018

Dear Meghann

Re: Exploring the health and wellbeing benefits of engagement in participatory arts activities for older people living with dementia and their carers.

Thank you for submitting your research ethics amendment application for the above project for review by the **Faculty of Health and Medicine Research Ethics Committee (FHMREC)**. The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for the amendment to this research project.

As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses and approvals have been obtained;
- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress);
- submitting details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,

A handwritten signature in black ink that reads "Diane Hopkins".

Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

12.6 Appendix 6. A Visual Step-by-Step Guide from Coding to Theme Development in Multi-Methods Data Analysis

1. All interview transcripts were coded in detail before action learning meetings and arts sessions. This was due to the individual nature of topics discussed within interviews, compared to the more repetitive nature of sessions and meetings. Familiarisation with transcripts, notes and reflections took place before and during coding.



2. Each interview transcript was coded in detail, independently from each other, leading to a large coding bank of 500+ codes. The bank was sorted before coding the remaining sessions and meeting transcripts, ensuring similar codes or duplicates were merged e.g. 'scenic' and 'scenery'.
3. Once the coding bank was condensed, the remaining transcripts of sessions and action learning group meetings were coded, working from the existing coding bank and adding to it where required. Functional codes were added to the transcripts to highlight areas of ambiguity, that needed visual data to further support or illuminate them. This created connections between data forms e.g. 'video elicitation' or 'visual support'.

Jenn: -aww [laughs] so you lost your way. Ah, well we'll find our way again J2.

J2: No we know where we're at now-

Jenn: -/good.

J2: But we came a different way, therefore we're going to be lost for the rest of the day.

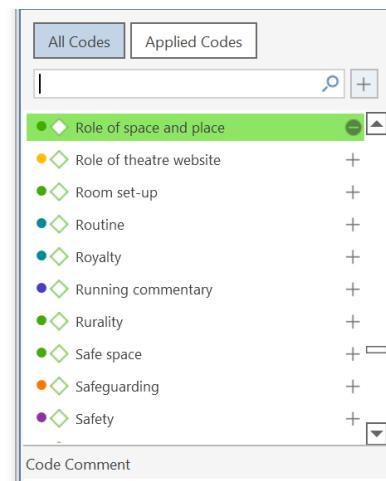
[Some group laughter]

O
Jenn: But you're safe now. You know where you are now.

J2: Keswick.

Jenn: Yeah.

J2: Yes.



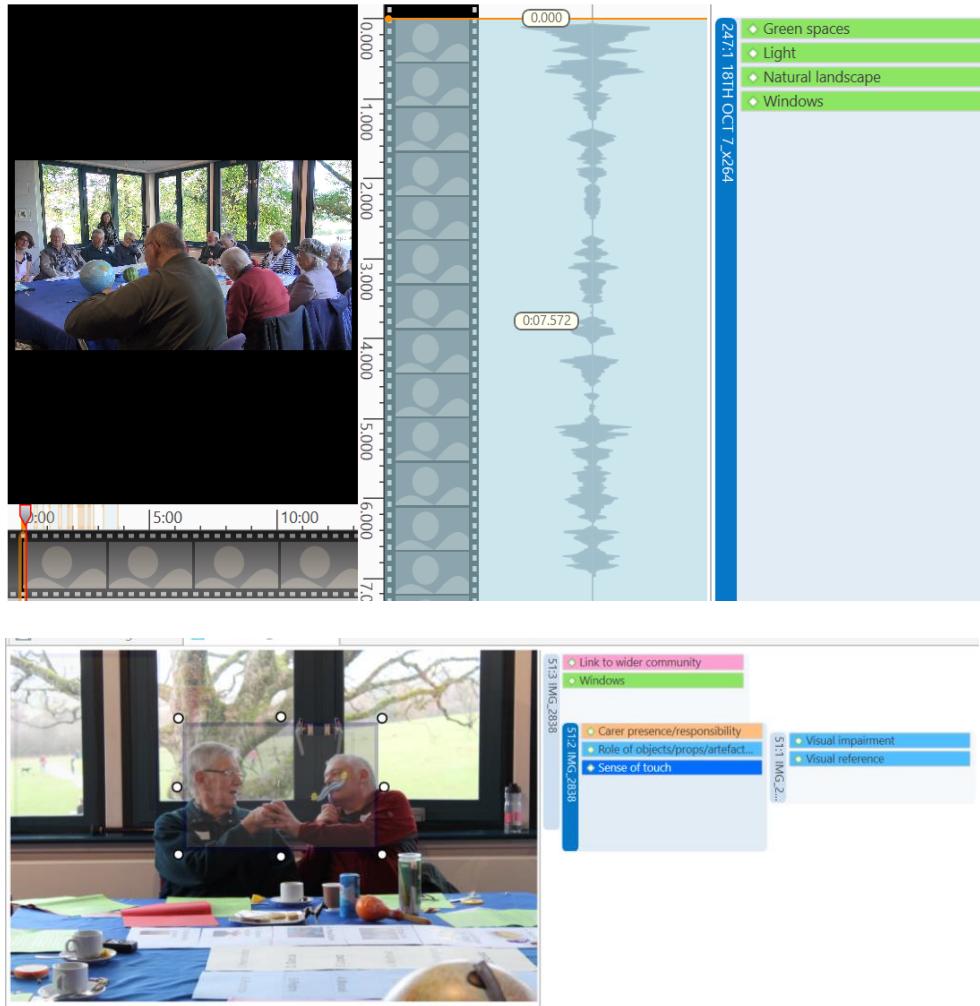
4. After completion of textual transcripts, the coding bank was filtered and condensed again, ensuring that it would be easier to work with for the visual data stage of analysis. Small sample sections of the list, and the number of times each was coded, is shown below.

Name	Grounded	Name	Grounded
Sense of touch	393	Television	7
Sense of understanding	15	Texture	19
Sensitivity	3	The body	275
Separation anxiety	17	Theatre	23
Set design	6	Theatre background	15
Setting	13	Theatre by the Lake	21
Setting the Scene	93	Theatre facilities	17
Setting the Scene mo...	96	Theatre productions	22
Shared activities	4	Theatre setting	20
Shared experiences	11	Theatre staff	7
Sharing	7	Therapeutic landscapes	17
Sharing with others	84	Thinking vs doing/spe...	27
Significance of numbers	40	Time apart	39
Significance of words	272	Time together	14
Simile	10	Tired	13
Simplicity	11	Togetherness	45
Sing-along	93	Transport	14

5. To aid the potential 'messiness' of analysing large quantities of visual data, it was necessary for visual contents to be reviewed and smaller sections chosen for analysis. This familiarisation and sorting process was tracked in two separate Microsoft Excel spreadsheets, as exemplified below, listing their characteristics and reasons for choice.

B	C	IDENTIFICATION	D	E	F	G	H	I	J	K	L	M	CHOSEN
Video-name	Folder-Date		Exclusion?		Positive experience	Negative experience	Arts and crafts	Singing/music	Dance/movement	Storytelling/drama	Games	Individual vs group-based participation	
MLI_2446	2ND AUGUST PILOT-2	ALL OF VIDEO	YES - R & M		X								
MLI_2447	2ND AUGUST PILOT-2	ALL OF VIDEO	YES - R & M		X								
VIDE-O_00010	9TH AUGUST PILOT-3	00:06:54 TO END	NO	X									
VIDE-O_00019	9TH AUGUST PILOT-3	ALL OF VIDEO	YES - M + R & M	X	X	X							
VIDE-O_00020	9TH AUGUST PILOT-3	ALL OF VIDEO	YES - M + R & M	X	X	X							
VIDE-O_00024	9TH AUGUST PILOT-3	ALL OF VIDEO	NO	X									
VIDE-O_00036	9TH AUGUST PILOT-3	ALL OF VIDEO	NO	X									
VIDE-O_00037	9TH AUGUST PILOT-3	ALL OF VIDEO	NO	X									
VIDE-O_00039	9TH AUGUST PILOT-3	ALL OF VIDEO	NO	X									
VIDE-O_00040	9TH AUGUST PILOT-3	ALL OF VIDEO	NO	X									
VIDE-O_00044	2ND AUGUST PILOT-4	ALL OF VIDEO	NO	X									
VIDE-O_00095	2ND AUGUST PILOT-4	00:00:13 TO 00:09:15	NO	X									
VIDE-O_00096	2ND AUGUST PILOT-4	00:04:17 TO 00:06:12	YES - ALG 10TH	X									
VIDE-O_00097 (2)	2ND AUGUST PILOT-4	00:07:40 TO END	YES - M + G	X									
VIDE-O_00098	6TH DEC DAY-2	ALL OF VIDEO	YES - S	X									
MLI_2622	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00099	6TH DEC DAY-2	START TO 00:11:30	NO	X									
MLI_2623	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00100	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00101	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00102	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00103	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00104	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00105	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00106	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00107	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00108	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00109	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00110	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00111	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00112	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00113	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00114	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00115	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00116	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00117	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00118	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00119	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00120	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00121	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00122	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00123	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00124	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00125	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00126	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00127	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00128	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00129	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00130	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00131	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00132	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00133	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00134	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00135	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00136	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00137	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00138	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00139	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00140	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00141	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00142	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00143	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00144	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00145	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00146	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00147	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00148	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00149	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00150	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00151	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00152	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00153	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00154	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00155	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00156	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00157	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00158	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00159	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00160	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00161	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00162	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00163	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00164	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00165	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00166	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00167	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00168	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00169	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00170	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00171	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00172	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00173	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00174	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00175	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00176	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00177	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00178	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00179	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00180	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00181	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00182	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00183	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00184	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00185	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00186	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00187	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00188	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00189	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00190	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00191	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00192	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00193	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00194	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00195	6TH DEC DAY-2	ALL OF VIDEO	NO	X									
VIDE-O_00196	6TH DEC DAY-2	ALL OF VIDEO	NO	X					</				

6. Once video clips and photographs were chosen in the spreadsheets, coding began by highlighting particular seconds of video or areas of photographs, the equivalent of coding sections of text in transcripts.



7. After completing all visual data analysis, codes were read and reviewed in each document/video/photograph and were condensed for a final time to help manage theme development.

Search		
13 1 7 in 4th August transcription		4 Codings
B - ah, and we climbed Fleetwith Pike, went over to Dubs Hut [dictaphone slides and falls off table making a banging noise] then down to the top of Honister.		Cumbrian landsc., Outdoors
1:38 1 117 in 4th August transcription		2 Codings
M.G.: and then we spent our honeymoon here.		Cumbrian landsc., Locality
1:46 1 148 in 4th August transcription		2 Codings
J1: -yeah, it's, in between where we live and Carlisle, out in the country-		Cumbrian landsc., Place names
2:11 1 20 - 34 in 4th Dec 2018 R+M transcript		1 Coding
. It is a beautiful place you live in as well, even if you just stayed here during the day-		Cumbrian landsc.
M: -hm hmn, yes.		
Meg: -you've got such a lovely place.		
2:95 1 387 - 395 in 4th Dec 2018 R+M transcript		2 Codings
R: I like going around eh... N takes us on some runs, around eh, /mountains-		Cumbrian landsc., Natural landscape
Meg: -hm hmn-		

8. Once succinct and condensed, codes were organised into coding groups/sub-themes in an extended iterative process involving different stages and tactics. Each code was given consideration and was placed within one or more sub-themes, depending on its function and meaning. Time was dedicated to reviewing the placement of different codes.

Explore

Code Group Manager

Search

Setting the Scene Theme De

- Documents (257)
- Codes (547)
 - Memos (0)
- Networks (24)
- Document Groups (0)
- Code Groups (43)
 - Memo Groups (0)
 - Network Groups (0)
 - Multimedia Transcripts (0)

Select a single item to show its comment

Name	Created by	Created
'Setting the Scene' Model	66 xxmeg	10/09/2020 07:48
The Social Landscape	60 xxmeg	10/09/2020 17:27
Identity and Individuality	44 xxmeg	09/09/2020 17:56
Living Well With Dementia	42 xxmeg	10/09/2020 09:31
The Built Landscape	31 xxmeg	09/09/2020 16:13
Positive Emotions and Responses	29 xxmeg	09/09/2020 18:01
Negative Emotions and Responses	28 xxmeg	09/09/2020 18:03
Verbal 'Voice'	27 xxmeg	09/09/2020 16:35
Material Culture	25 xxmeg	09/09/2020 16:06
Body and Embodiment	22 xxmeg	09/09/2020 16:09
Family Relationships	21 xxmeg	09/09/2020 16:27
The Senses	21 xxmeg	09/09/2020 15:27
The Natural Landscape	20 xxmeg	09/09/2020 16:12
Physical health	16 xxmeg	10/09/2020 09:23
Temporality	16 xxmeg	09/09/2020 16:49
Types of Participation	15 xxmeg	10/09/2020 09:36
Skills	15 xxmeg	10/09/2020 09:15
Music-Based Activity	14 xxmeg	09/09/2020 16:41
Visual Arts and Craft Activity	13 xxmeg	10/09/2020 09:40
Mental Health and Wellbeing	12 xxmeg	10/09/2020 09:25
...		

9. When a sub-theme was generated, subsequent lists, networks and/or Excel spreadsheets could be exported from Atlas.ti to help visualise the sub-theme data in different ways. This process was also aided by a more embodied process of using post-its and a wall to test code positions. Below is the example of the sub-theme 'Natural Landscapes' and the codes included within it in a list, network and spreadsheet (the colours were added to codes later in the analytical process).

The Natural Landscape

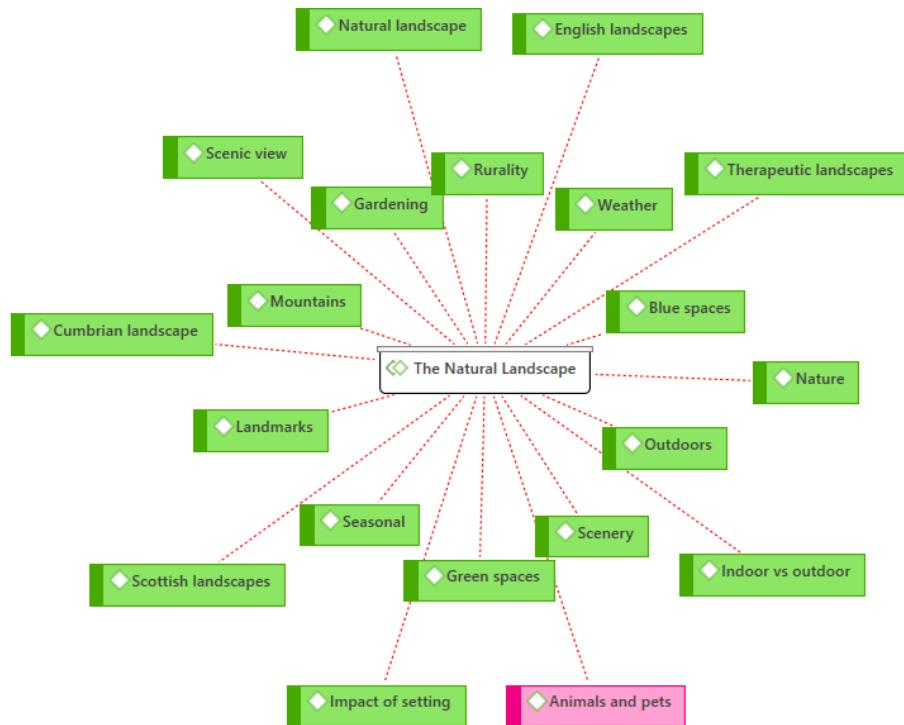
20 xxmeg 09/09/2020 16:12 xxmeg 09/09/2020 16:12

Codes in group:

Name
Blue spaces
Cumbrian landscape
English landscapes
Gardening
Green spaces
Impact of setting
Indoor vs outdoor
Landmarks
Mountains
Natural landscape
Nature
Outdoors
Rurality
Scenery
Scenic view
Scottish landscapes
Seasonal

Codes not in group:

Name
Acceptance
Accessibility
Accidents
Active participation
Activity effectiveness
Actor-audience interaction
Adaptability
Advance planning
Advertisement
Ageing
Aims and goals
Amateur theatre
Amy's Care
Amy's Care report
Anxiety
Apologising
Art background



A	B	C
Document Group The Natural Landscape	Code Animals and pets Blue spaces Cumbrian landscape English landscapes Gardening Green spaces Impact of setting Indoor vs outdoor Landmarks Mountains Natural landscape Nature Outdoors Rurality Scenery Scenic view Scottish landscapes Seasonal Therapeutic landscapes Weather	
Visual Arts and Craft Activity	Art background Art classes	

10. When sub-theme development was completed – with all codes being included in the process – 42 sub-themes were finalised (plus one sub-theme that comprised functional codes). Each sub-theme was written on post-it notes and tested in different potential groupings for larger overarching themes that would inform chapter contents. This practical form of analysis was more accessible than software. This led to the creation of four main themes (see Page 109, Table 4.7) and led to removing three sub-themes that did not fit into the project scope (Money and Finances; Changes; Additional dementia activities outside of *Setting the Scene*).