THE ‘IN THE MOMENT’ MUSICAL EXPERIENCES OF PEOPLE WITH DEMENTIA: A MULTIPLE-CASE STUDY APPROACH

A thesis submitted to The University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health

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ABSTRACT

Background: Music is the most commonly accessed arts-based activity for people living with dementia, but the evidence-base for the use of music is currently lacking. This is because much of the research in this area uses a biomedical lens to understand musical experience, placing a focus on how music might alleviate the ‘behavioural and psychological symptoms of dementia’ rather than exploring the role of music as meaningful and stimulating activity through which a person with living dementia can flourish. Qualitative research suggests that the main benefits of music lie ‘in the moment’ with music providing a platform for multisensory experiences that are embodied and relational. To date, there are no research studies which have sought to understand the ‘in the moment’ musical experiences of people living with dementia where the focus is on embodied and sensory experiences.

Aims: This thesis used a multiple-case study design to develop a thematic description of the ‘in the moment’ embodied and sensory experiences of people living with dementia when they engage with music. The setting for this study was Manchester Camerata’s Music in Mind: an innovative improvisation-based music programme for people living with dementia. Six people living with dementia were recruited into the study, along with four family carers and two Music in Mind practitioners. Each case study presented the individual ‘in the moment’ experiences of each person living with dementia, while a cross-case analysis of the data examined the elements of experience which were translatable across participants.

Findings: A range of embodied and sensory experiences were observed ‘in the moment’ during the Music in Mind sessions. The six individual case studies narrated the experiences of each person living with dementia across the Music in Mind programme, and presented a number of key observations which focussed on embodied and sensory experiences. The thematic description of ‘in the moment’ experience presented in the cross-case analysis of data presented three interacting master themes: Living a Life Story through Music; Being ‘In the Moment’ with Music; and Musical Ripples into Everyday Life. Each of these themes was dynamic and contextualised the ‘in the moment’ experiences of each person living with dementia. The cross-case analysis also presented measurable qualities of experience which were observable across the people living with dementia. Such measurable qualities were directly observable, providing a tangible means by which to examine core features of ‘in the moment’ musical experience.

Conclusions: The study contributes to knowledge by presenting a thematic description of ‘in the moment’ musical experience combined with measurable qualities of the sensory and embodied experiences. This thematic description will form the basis of a new music assessment framework (In the Moment Profiles) which will enable the recording of individual musical stories as well as measurable qualities of experience which can be compared across individuals. This framework places emphasis on music and creativity, which is in direct contrast to the current methods of evaluation that are used to measure the benefits of music for people living with dementia.
DECLARATION

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification at this or any other university or other institute of learning.

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DEDICATION

This thesis is dedicated to the people living with dementia, their family carers and Music in Mind project practitioners who took part in this study. Thank you for sharing your experiences with me, and welcoming me into sessions with open arms.

ACKNOWLEDGEMENTS

I would like to thank the ESRC and Manchester Camerata for funding the three year full-time CASE studentship. I would also like to thank my supervisors, Professor John Keady, Dr Caroline Swarbrick, Professor Christine Milligan, Nick Ponsillo, Lucy Geddes and Bob Riley for their expert support and guidance throughout the duration of this project. I have learned so much from everyone involved, and I am very grateful for all of the hard work and dedication from your side in guiding me and providing feedback throughout the PhD process.

I would like to thank the Manchester Camerata team for their support and investment over the duration of the PhD. I feel very privileged to have worked with such an exciting and innovative organisation and I am in awe of the passion for working with people living with dementia using music and creative arts. I was able to observe first-hand the benefits of the Music in Mind programme in the lives of people living with dementia and their family members. Thank you for letting me a part of such an amazing body of work.

I would like to thank the members of the Dementia and Ageing Research Team for their support across the duration of the PhD. I would especially like to thank Sara Yearsley, Sarah Campbell, Verity Longley and Rita Newton, whose wisdom and encouragement saw me through the process with a smile on my face. I am also grateful to Vivian Attipoe for helping me prepare and for reading through this thesis.

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BACKGROUND TO THE THESIS

The Personal Context

I first held a musical instrument when I was six years old. I was very lucky that my primary school offered every child the opportunity to learn to play a musical instrument. I was also encouraged by my mum (a musician herself) to choose a musical instrument to learn – and I chose the violin. Though I learned to play the violin to the Associated Board of the Royal Schools of Music Grade 8 standard by aged 18, my first musical love was singing. In my childhood, I was a member of the City of Birmingham Symphony Orchestra, which exposed me to exciting choral opportunities all over the world. In my teenage years I performed in a number of school musicals and competed in local singing competitions.

My academic background is in psychology, having completed a BSc in Psychology at Cardiff University in 2014, followed by a Psychology MRes at The University of Manchester in 2015. During my undergraduate degree I had the opportunity to spend a year in industry at the Cerebra Centre for Neurodevelopmental Disorders at the University of Birmingham, working with children with neurodevelopmental conditions and their families. In my role as an Honorary Research Assistant I worked with two PhD students (now Dr Hayley Crawford and Dr Victoria Johnson) whose research focussed on executive functions, decision making and social anxiety in Fragile X syndrome, Rubinstein-Taybi Syndrome, Cornelia de Lange Syndrome and Autism Spectrum Condition. Both Hayley and Victoria made use of visual (quantitative) methods to enhance their understanding of the challenges that were faced by these children, in order to improve their everyday functioning. My placement year really sparked my interest in research and with it my aspiration to undertake a PhD.

I have always had an interest in how the arts can impact on health and wellbeing. During my MRes I volunteered on Manchester Camerata’s Songlines project, a project aimed at bringing together children with autism and their peers through creative ventures such as song composition, art and drama. During this project I was able to observe first-hand the benefits that engaging with the arts had for children with autism and their peers. The creative activities provided a platform for the children to express themselves through the mediums of art, music and drama, with the transformations in the children being very powerful to observe. I was also involved in the evaluation of the programme, led by Dr John Habron (Head of Music Education, Royal Northern College of Music). John used creative methods, such as drawing and photo-elicitation, to facilitate conversations about the project with the children living with autism spectrum condition and their peers. These creative methods enabled a more detailed account of the children’s experiences that were not as easily captured through questionnaire measures.
I was first exposed to dementia when I was 15 years old. My grandmother developed dementia and subsequently went to live in a care home. Granny Lilian had always been a glamorous woman, with her nails always painted and never having a hair out of place. Although I did not know much about dementia at the time of her diagnosis, I remember feeling distressed when she confused me with my cousin on one visit to see her. I also remember visiting one Sunday and seeing her hair had been cut short and dyed a dark purple colour. This was such a contrast to her usual appearance that it took me by surprise. Her sense of identity, held through her clothing and appearance, seemed to disintegrate within the context of the care home which saddened me. Shortly after this incident she passed away and I began to become interested in how a sense of self can be maintained throughout the progression of dementia, wishing I had known more while she was still alive.

Later down the line, I developed an interest in the impacts of music on people living with dementia after watching the documentary *Alive Inside* (Rossato-Bennett, 2014). Within the documentary there was a particularly powerful moment for a person living with dementia when they were given an iPod with their favourite music on it. Henry, before music, was unresponsive to what was going on around him, and spent a lot of his time slumped over in his wheelchair. After he was given ‘his music’ he became alert and sang along, with the widest eyes imaginable. When asked questions about ‘his music’ he said:

[Music] gives me the feeling of love, romance. I figure right now the world needs to come into music, singing you’ve got beautiful music here. Beautiful, oh lovely and I feel a band of love of dreams.

This documentary really opened my eyes to the power of music for people living with dementia, and soon after watching it I came across the advert for the PhD opportunity which incorporated my most significant interests: music - psychology - and dementia.

**Background to the CASE Partnership**

The research programme presented within this thesis is a competitively won Economic and Social Research Council (ESRC) CASE¹ PhD which was held as a three-way award between the University of Manchester (with Professor John Keady as lead), Lancaster University and Manchester Camerata. The collaboration between these institutions was initiated at a NHS North West Research and Development Catalyst day on the 22nd January 2014. The discussions held regarding dementia-related outcome measures, and their suitability in measuring the impact of

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¹ A CASE studentship involves a student working in partnership with an organisation in order to undertake research that is designed to promote interdisciplinary conversation, bridging academic and professional research concerns.
programmes, such as *Music in Mind*, highlighted opportunities for a collaboration between the academic institutions and Manchester Camerata.

The CASE studentship was pre-designed by the supervisory team, with there being scope for the successful candidate to adapt the methods of study in order to make the research their own. I was awarded the studentship in January 2015, to begin the full-time research programme in September 2015. The following section will outline the PhD study and how the research design changed from the pre-designed methods, outlined by my supervisory team, to alternative methods based on the experiences I had with the research literature, and navigating the ethical demands of the study.

**Introduction to the Study**

The focus of this study was to explore the ‘in the moment’ embodied and sensory musical experiences of people living with dementia in the context of Manchester Camerata’s *Music in Mind* programme. The research adopted a multiple-case study design, in which I situated myself as a participant-observer within a community-based *Music in Mind* group.

The initial aim of the research, as developed by my supervision prior to my enrolment on the PhD programme, was to develop a new music assessment tool as an outcome for the PhD. However, it became clear very early on in the research process that the tool could not be a ‘pen and paper’ measure, as the use of video and audio proved essential in the collection of ‘in the moment’ sensory and embodied experiences. It was therefore decided, in discussion with my supervisory team, that the aim of the PhD would be to develop an underlying knowledge-base which could then underpin a new multisensory music assessment tool, which was not possible within the three year timeframe, and funding, of the PhD. The aims of the PhD therefore shifted in order to allow for the development of a thematic description of ‘in the moment’ experience.

As I will describe in the **Methods of Study** chapter (p.63), the original overarching design that was pre-designed by my supervisory team was Participatory Action Research (Reason & Bradbury, 2007), with six planned cycles of action and reflection. However, on examining the research literature, it became evident that a more in-depth and flexible approach to research was needed in order to truly begin to understand the complexities of ‘in the moment’ musical experience. Therefore, as will be explained further in Chapter 3, a multiple-case study design (Stake, 1995, 2013) was selected as a means of allowing for an in-depth and holistic approach to understanding the experiences of the participants recruited into the *Music in Mind* programme. The research focus was therefore shifted onto the 15-week *Music in Mind* programme rather than on the later stages of development for a music assessment tool. For example, I received ethical approval to seek feedback on a completed tool from both those recruited into the *Music in Mind* programme and industry experts (e.g. programme evaluators; music therapists etc.), but did not enact
these phases of the research due to the in-depth nature of data collection and analysis processes.

Due to the nature of the research methods that I used within the context of my PhD research (namely visual research methods), there have been a number of decisions that I had to make regarding the presentation of this thesis. I have thus presented the video data as anonymised stills in order to maintain the anonymity of participants involved in the study as a requirement by the ethics committee. I have presented complementary data (namely participant interviews, diaries and detailed case notes) which provide evidence for what was observed within the video data without the need to present the video itself.

**Organisation of Thesis**

This thesis consists of six chapters:

**Chapter 1** outlines the context for the research study, including key definitions of dementia, the policy context and an introduction to the use of music with people living with dementia. This chapter also critically appraises the current methods for evaluating the impacts of music on people living with dementia, examining the limitations of such approaches in understanding musical experience.

**Chapter 2** outlines a thematic synthesis of qualitative literature surrounding the use of music for people living with dementia, with the aim of the literature review being to understand what the personal benefits of taking part in music are for the person living with dementia. It also explores the current involvement of people living with dementia in the qualitative literature to date.

**Chapter 3** outlines the overarching methodology and methods used to examine the ‘in the moment’ embodied and sensory musical experiences of people living with dementia. This chapter provides an overview of Manchester Camerata’s *Music in Mind* programme, which was the context for the study. The chapter will provide the rationale for using a range of creative and visual research methods within the multiple-case study design, and discuss the ethical considerations that needed to be addressed to ensure the ethical inclusion of people living with dementia in the research. The chapter will end by providing the approach taken in analysing the multisensory research data, which combined sensory and thematic analysis processes in order to develop individual case studies, as well as a cross-case analysis.

**Chapter 4** presents six case studies of people living with dementia who engaged with *Music in Mind*. Within each case study I present the contextual information about each person living with dementia, including their past musical experiences, and explore the key observations derived from the video data, as well as participant interviews.
Chapter 5 presents a cross-case analysis of the study data, examining the features of ‘in the moment’ musical experience which were observed across cases. A thematic description of the ‘in the moment’ embodied and sensory experiences of people living with dementia is presented alongside measurable qualities of experience.

Chapter 6 highlights the key findings of the research and explores how these relate to the current music and dementia literature, as well the wider dementia studies literature. This chapter will reflect on the methods used within the context of the research, and considers the implications of the research for developing new theoretical frameworks for understanding the role of music in the lives of people living with dementia. The chapter concludes with a summary of recommendations for practice, policy, research and education.

Definition of Terms and Writing Conventions

The following terms and conventions have been used:

- The thesis has been written in first person to allow for an exploration of my role as a participant-observer within the data collection, analysis and interpretation.
- With a few exceptions, numbers from one to nine are written within the text in full, with numbers 10 and above written in numerical form.
- I have used the American Psychological Association style of referencing throughout the thesis. Where there are three authors these are cited and when there is four or more authors ‘et al.’ has been used. Authors are presented in alphabetical order in the text and bibliography.
- Direct quotes that are more than 30 words have been indented and italicised within the text. However, shorter quotes are also indented and italicised in the text when an emphasis on a participant contribution needs to be made; this is especially found in the Findings chapters. Otherwise, in the main, shorter quotes are embedded in the text in italicised font and with double quotation marks. When multiple shorter quotes are presented, they are presented indented and italicised within the text.
- I have used the terms ‘people/person living with dementia’ and ‘family carer(s)’ consistently throughout the thesis, unless the terms have been presented differently in quotes taken from published material.
- When I refer to the couples where one person has dementia I position the person living with dementia first and their family carer second when their names appear together e.g. Scott (person living with dementia) and Julie (family carer).
- Within presented quotes I have used ‘[…]’ to indicate where I have shortened quotes for clarity. I have used ‘…’ to indicate pauses taken by the participants.
List of Abbreviations

BME - Black and Minority Ethnic
ESRC – Economic and Social Research Council
CASP – Critical Appraisal Skills Programme
COREQ - Consolidated criteria for reporting qualitative research
MeSH – Medical Subject Headings
MiDAS – Music in Dementia Assessment Scales
NHS – National Health Service
NICE – National Institute for Health and Clinical Excellence
NIHR – National Institute for Health Research
UK – United Kingdom
## Glossary of Musical Terms

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Arpeggio</strong></td>
<td>The notes of a chord broken into a sequence of notes which are played one after the other rather than at the same time.</td>
</tr>
<tr>
<td><strong>Atonal</strong></td>
<td>Music in which the notes are not organised in accordance to harmonic conventions of traditional European musical styles.</td>
</tr>
<tr>
<td><strong>Beater (Percussive)</strong></td>
<td>A hand-held object used to strike a percussive instrument in order for it to produce sound. The beater typically has a long handle with a round head, with the material depending on the type of percussive instrument being played.</td>
</tr>
<tr>
<td><strong>Call and Response</strong></td>
<td>A series of melodies/rhythms played or sung by two or more different musicians. It mimics how people might take it in turns during a vocal conversation, with one person asking a question and the other providing an answer.</td>
</tr>
<tr>
<td><strong>Chord</strong></td>
<td>A group of notes which when played together create a pleasing harmonic sound.</td>
</tr>
<tr>
<td><strong>Chord Progression</strong></td>
<td>A series of two or more chords used in a piece of music.</td>
</tr>
<tr>
<td><strong>Harmony</strong></td>
<td>A combination of notes which is aesthetically pleasing within musical conventions.</td>
</tr>
<tr>
<td><strong>Innate Musical Skills</strong></td>
<td>Musical skills held by a person who has not had any formal musical training.</td>
</tr>
<tr>
<td><strong>Melody</strong></td>
<td>The arrangement of a combination of notes to make a satisfying sequence.</td>
</tr>
<tr>
<td><strong>Music Therapy</strong></td>
<td>A music intervention delivered by a qualified music therapist who seeks to address key clinical outcomes relating to physical and mental health.</td>
</tr>
<tr>
<td><strong>Musical Accompaniment</strong></td>
<td>A musical support for improvisation which provides strong rhythmic and/or melodic structure to a piece of music.</td>
</tr>
<tr>
<td><strong>Musical Beat</strong></td>
<td>The regular pulse which underlies a piece of music.</td>
</tr>
<tr>
<td><strong>Musical Cohesiveness</strong></td>
<td>The coming together of musical sounds so that no one sound is dominating the musical sound. Each musical contribution is equal, resulting in parts that fit together well and form a united whole.</td>
</tr>
<tr>
<td><strong>Musical Conversation/s</strong></td>
<td>The use of instruments in order to mimic language, often within a Call and Response format. It requires listening to other players, and responding with musical phrases that repeat or build on what has been ‘said’ before.</td>
</tr>
<tr>
<td>Term</td>
<td>Definition</td>
</tr>
<tr>
<td>--------------------------</td>
<td>---------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Musical Ear</td>
<td>A propensity for playing, learning or appreciating music.</td>
</tr>
<tr>
<td>Musical Entrainment</td>
<td>The synchronisation of the human body to an external perceived musical rhythm.</td>
</tr>
<tr>
<td>Musical Improvisation</td>
<td>The creative activity of creating new music ‘in the moment’ in a spontaneous fashion, creating new melodies, rhythms and/or harmonies.</td>
</tr>
<tr>
<td>Musical Phrasing</td>
<td>The way in which a musician will shape the notes or rhythms produced in order to convey expression. This is achieved through altering tone, tempo and inflection within the music.</td>
</tr>
<tr>
<td>Musical Repertoire</td>
<td>Collection of music known by each individual which may have been accumulated across their life.</td>
</tr>
<tr>
<td>Musical Skill</td>
<td>The musical abilities held by an individual for rhythm and melody, as well as using creative flair to bring a piece of music to life.</td>
</tr>
<tr>
<td>Musical Solo</td>
<td>A piece of music played or sung by a single performer.</td>
</tr>
<tr>
<td>Musical Stories</td>
<td>The conveying of emotion or a narrative through music, combining melody/rhythm, performance and/or dance.</td>
</tr>
<tr>
<td>Musical Style</td>
<td>The classification of music into a particular genre (e.g. classical, reggae, gospel etc.)</td>
</tr>
<tr>
<td>Musical Tempo</td>
<td>The pace or speed at which music is played.</td>
</tr>
<tr>
<td>Musical Vocalisations</td>
<td>The use of the voice to produce melodies or rhythms using vowel sounds or syllables.</td>
</tr>
<tr>
<td>Musicianship</td>
<td>An overarching term which encompasses musical skill and performative abilities which enable an individual to both contribute musically and bring their performance to life</td>
</tr>
<tr>
<td>Musicking</td>
<td>This term modifies the meaning of the word ‘music’ from that of a noun to a verb, meaning to engage with music (Small, 1998). Accordingly, musicking can be used as an umbrella term for any musical activity from listening to music on one’s own through to performing opera on stage.</td>
</tr>
<tr>
<td>Musicking Space</td>
<td>The physical environment in which the music-making takes place (i.e. a room in a community centre).</td>
</tr>
<tr>
<td>Music-Making</td>
<td>The creation of music through active participation (e.g. improvising melodies, contributing novel rhythms)</td>
</tr>
<tr>
<td><strong>Music-Therapeutic Techniques</strong></td>
<td>Techniques used by music therapists in order to meet defined outcomes for clients (e.g. call and response, rhythmic speech cuing etc.)</td>
</tr>
<tr>
<td>-------------------------------</td>
<td>----------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Percussive Instruments</strong></td>
<td>Instruments which produce sound when struck with a beater or stick. They can be tuned (such as a glockenspiel) or untuned (such as a snare drum).</td>
</tr>
<tr>
<td><strong>Musical Performance</strong></td>
<td>The act of telling a story to an audience through music with gesture and emotional expression.</td>
</tr>
<tr>
<td><strong>Rhythm</strong></td>
<td>A strong, regular repeated pattern of sound.</td>
</tr>
<tr>
<td><strong>Rhythmic Improvisation</strong></td>
<td>Creating new rhythms within a piece of music, by clapping, striking a percussive rhythm or vocalising.</td>
</tr>
<tr>
<td><strong>Tremolando</strong></td>
<td>Creating a wavering effect within a musical tone.</td>
</tr>
</tbody>
</table>
CHAPTER 1. INTRODUCTION

1.1 Introduction

This opening chapter will provide an overview to the background and context of the study. The chapter will begin by outlining the key definitions of dementia and its prevalence within the United Kingdom (UK) and worldwide. Next, the impact that a diagnosis of dementia may have on a person living with dementia, as well as their family members and wider social contexts, will be presented. Following this, there will be an exploration of the different lenses through which dementia has been viewed, highlighting the important shifts from biomedical models towards more holistic discourses of dementia such as personhood, citizenship and embodied selfhood. The chapter will then consider the role of psychosocial interventions for people living with dementia, with an exploration of the role of arts interventions, and specifically music interventions for people living with dementia. The chapter will end with a critical appraisal of the methods through which the impacts of music for people living with dementia are currently evaluated.

1.2 Definitions, Prevalence and Impacts of Dementia

Dementia is an umbrella term for a number of diseases that affect the brain, leading to challenges relating to short- and long-term memory, language, problem solving and sensory perception (NHS Choices, 2018). There are over 100 different types of dementia, the most common of which being Alzheimer’s disease, with rarer forms including frontotemporal dementia and Posterior Cortical Atrophy (World Health Organisation, 2012). Most recent estimates suggest that there are approximately 850,000 people living with dementia in the UK today, with this number projected to increase to over two million by 2051 (Alzheimer’s Society, 2015). Worldwide it is estimated that there is a new diagnosis of dementia every four seconds, equating to a worldwide prevalence of approximately 35.6 million people (World Health Organisation, 2012). Dementia, therefore, has many potential societal impacts, with it estimated that the costs associated with dementia in the UK being approximately £26.3 billion per year in both health and social care costs, as well as the costs associated with the contributions of unpaid carers (Alzheimer’s Society, 2015).
The combined impact of the prevalence of dementia and the societal costs of the condition has led to increased attention and societal concern both nationally and internationally. In 2009, the UK government published a five-year National Dementia Strategy for England (Department of Health, 2009), which outlined the government’s recommendations for the improvement of dementia care within England. The recommendations fell under three key themes: raising awareness and understanding; early diagnosis and support; and living well with dementia. Following on from these recommendations the UK Prime Minister, David Cameron, put forward the Prime Minister’s Challenge on Dementia 2015 (Department of Health, 2012) which proposed recommendations for dementia care and research, highlighting the need for improved early diagnosis of dementia, the creation of dementia-friendly communities, and a necessity for higher quality research. The document also stressed the necessity to centralise the voices of people living with dementia within policy and research, advocating the active inclusion of people living with dementia and family carers within research studies, as well as in the development and implementation of dementia-related policy and practice. This document was followed up in 2015 with the Prime Minister’s Challenge on Dementia 2020 (Department of Health, 2015), which developed these recommendations further and outlined aspirations for England regarding dementia care and research. Such policy has led to an increased public awareness of dementia, especially through initiatives such as ‘Dementia Friends’, an Alzheimer's Society and Public Health England (2015) joint initiative aimed at challenging the stigma associated with the condition, and creating a narrative that demonstrates how a person can ‘live well’ with their dementia.

There are a number of impacts that a diagnosis of dementia can bring both for the person living with dementia, their family members, as well as broader impacts on the provision of health and social care (Banerjee, 2010). With a decline in memory and decision making skills, a person living with dementia may lose their sense of autonomy and sense of purpose with their diagnosis, becoming increasingly dependent on family carers, or those supporting them in a professional capacity (van Vliet et al., 2017). This may, in some cases, lead to a negative impact on self-esteem, increased anxiety, and feelings of restriction being felt by the person living with dementia (Kindell, Wilkinson & Keady, 2018). A diagnosis of dementia may also
impact the relationships between the person living with dementia and their family members, with the possible change in roles to that of ‘caregiver’ being associated with feelings of stress and loss (O'Shaughnessy, Lee, & Lintern, 2010).

Although there is a tendency for there to be a discourse of ‘tragedy’ and ‘loss’ after a diagnosis of dementia (Reed, Carson, & Gibb, 2017), the recent developments in challenging the stigma associated with dementia through initiatives such as the Prime Minsters’ Challenges (Department of Health, 2012, 2015) and ‘Dementia Friends’ (2015) have begun to change the public discourse of what it means to live with dementia. Furthermore, in the dementia studies literature, there has been a shift in perspective in the way in which the experience of living with dementia is framed, moving away from a purely biomedical stance to more holistic accounts of experience. The following section will outline the ‘paradigm shift’ that has occurred in the dementia studies literature over the past 20 years which has changed the perception of dementia as a purely pathological condition towards definitions that strive for the inclusion of people living with dementia as active citizens within society.

1.3 Dementia: A Paradigm Shift

Until relatively recently, the definitions of dementia centred predominantly on biomedical models of disease and illness (Kitwood, 1997). After the discovery that Alzheimer’s disease was a neurodegenerative condition, rather than an inevitable part of aging, dementia was treated as a purely pathological condition with debilitating symptoms and a poor prognosis (Bruens, 2014). As Alzheimer’s disease, and dementia more generally, was acknowledged as having a neurological cause the focus of research and care became the ‘treatment’ or ‘cure’ of the dementia ‘patient’. Under this lens, dementia was defined purely by the symptoms that were displayed by a person living with dementia, such as difficulties with short- and long-term memory, planning ahead, and changes in sensory perception. This perspective thus neglected the wider context and individual circumstances of each person living with dementia (Behuniak, 2010).

The definition of the symptoms of dementia was later expanded to include ‘behavioural and psychological symptoms of dementia’, which is an umbrella term
that encapsulates a number of non-cognitive symptoms associated with the condition such as agitation, anxiety and ‘wandering’ behaviour (Cerejeira, Lagarto, & Mukaetova-Ladinska, 2012). However, although these behaviours were viewed as ‘symptoms’ under a biomedical model, there were alternative explanations being provided for such behaviour, which classified the ‘behavioural and psychological symptoms of dementia’ as being the result of unmet needs rather than being symptoms caused by diseases underlying the different types of dementia (Kovach, Noonan, Schlidt, & Wells, 2005). Such interpretations of behaviours were underpinned by a new means of framing dementia: through a lens of personhood (Kitwood, 1997).

Personhood is defined as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood, 1997, p. 8). Kitwood (1997), who first proposed the notion of personhood, suggested that it was the behaviours and preconceptions of others which undermined the personhood and sense of wellbeing in people living with dementia, which he termed “malignant social psychology” (p. 4). Personhood, therefore, was an attempt to shift the definition of dementia away from its biomedical roots, to one providing a more balanced account which included psychological and social processes. Kitwood (1997) developed an ontological orientation to dementia care that centred around the person living with dementia (and not the person with dementia) (p.7), promoting the importance of maintaining personhood throughout the progression of dementia by meeting psychosocial needs such as “attachment”, “inclusion”, “comfort”, “identity”, “occupation” and “love” (p. 82).

The notion of personhood has been very influential within the dementia studies literature and has led to many positive outcomes in the lives of people living with dementia, including the wide implementation of person-centred dementia-care principles (Kim & Park, 2017) and the development of person-centred outcome measures such as Dementia Care Mapping (Bradford Dementia Group, 2005). However, although personhood is a more widely accepted lens through which dementia can be viewed, there are a number of limitations associated with the approach (Bartlett & O’Connor, 2010; Bruens, 2014). A lens of personhood is most
commonly applied to a care setting, where the person living with dementia is a ‘care recipient’ with needs that need to be met, which places them as a passive recipient of care with no active agency (Nolan, Ryan, Enderby, & Reid, 2002). This means that it is the actions of those supporting the person living with dementia which are believed to bring about change. Consequently, there have been a number of researchers who have sought to expand upon Kitwood’s (1997) work in order to ensure that people living with dementia are viewed as active agents rather than passive recipients of care (Bartlett & O’Connor, 2007, 2010; Kontos, 2004, 2005; Kontos, Miller, & Kontos, 2017). The following paragraphs will explore the discourses of citizenship (Bartlett & O’Connor, 2007, 2010), embodied selfhood (Kontos, 2004, 2005) and relational citizenship (Kontos, Miller, & Kontos, 2017), which have built on the notion of personhood to create discourses in which a person living with dementia is seen as a person with agency.

Citizenship models of dementia seek to politicise the dementia agenda by acknowledging people living with dementia as active social agents within the societies in which they live. There are a number of ways in which citizenship has been defined both generally, and within the dementia studies literature. More traditional definitions of citizenship emphasise the role of active political participation, such as voting, which allows an individual to be an active member of their community or society (see for example: Marshall, 1950). However, such definitions view only those who are cognisant as being citizens, which disregards the possibility of being an active citizen while living with dementia (Lister, 2007). Bartlett and O’Connor (2010) therefore adopt the term social citizenship to encompass the ways in which people living with dementia can remain active citizens even with a diagnosis of dementia. Bartlett and O’Connor’s (2010) definition of social citizenship is therefore reflective of this notion to ensure the rights of people living with dementia throughout the progression of their condition:

*Social citizenship can be defined as a relationship, practice or status, in which a person with dementia is entitled to experience freedom from discrimination, and to have opportunities to grow and participate in life to the fullest extent possible. It involves justice, recognition of social positions,*
rights and a fluid degree of responsibility for shaping events at a personal and societal level. (p. 37).

Citizenship approaches to dementia also stress the importance of understanding dementia beyond the measurement of outcomes relating to wellbeing and quality of life, and instead suggest that the emphasis should be placed on understanding the ways in which the rights of people living with dementia can be ensured through challenging public perception, fighting for equality, and acknowledging the rights of each person living with dementia, even in the face of diminished capacity (Behuniak, 2010). Citizenship, therefore, is viewed as a lens that is “rights-based” rather than “needs-based” (Bartlett & O’Connor, 2010, p.35), acknowledging that people living with dementia have agency and can contribute to society through a myriad of actions. Furthermore, citizenship approaches also emphasize the necessity for growth within models of understanding for dementia. They state that enabling growth for people living with dementia through meaningful occupation can enable people to do more than ‘live well’ with their dementia and to contribute to the societies in which they live, fulfilling a sense of purpose and connectedness. As such, a citizenship discourse takes the lens of understanding dementia beyond the realm of care alone, and allows active exploration of how people living with dementia are able to be active citizens, or what factors prevent the active citizenship of those living with dementia.

An alternative lens through which to understand the experiences of those living with dementia is embodiment (Kontos, 2004, 2005; Millett, 2011; Twigg & Buse, 2013), and more specifically embodied selfhood (Kontos, 2004, 2005). An embodiment lens offers an opportunity to understand dementia through the body, and how a sense of agency can be maintained for the person living with dementia through their actions, gestures and sounds (Kontos & Martin, 2013). Kontos (2005) proposes that people living with dementia are able to demonstrate embodied selfhood, the notion that the body is central in the outwards expression of self-identity, throughout the progression of their dementia. For example, people living with dementia will still demonstrate preferences for certain foods through bodily reactions, even after their capacity to verbally communicate these preferences has diminished (Kontos & Martin, 2013; Kontos, Mitchell, Mistry, & Ballon, 2010). This would suggest that
dementia is not a “death that leaves the body behind” as people living with dementia are able to maintain their sense of self through their bodies (Kontos, 2005, p.567). This allows dementia to be placed in a macro-level context, rather than the micro-level stance of personhood (Bartlett & O'Connor, 2010). This school of thought has provided a platform for understanding the experiences of people living with dementia through their bodily expressions, and how these embodied expressions connect the person to other people and the environments in which they live.

Although the notion of embodiment and embodied selfhood provide a means of understanding the experiences of people living with dementia, it does not consider the possibility of the connections between people living with dementia and their communities through their embodied actions. More recently, Kontos, Miller, and Kontos (2017) have proposed the notion of ‘relational citizenship’ which expands on the notion of social citizenship proposed by Bartlett and O’Connor (2010) to incorporate the body into models of dementia citizenship. What differentiates this model from the previously proposed models of social citizenship is that it recognises the role of the self beyond ‘cognition’ and proposes that embodied selfhood, and the relationships between bodies, can enable those even with more severe cognitive impairments to connect with society through their embodied actions. Although this lens is in its infancy, it provides an opportunity to understand how people living with dementia might remain active citizens through the progression of their dementia, allowing a more inclusive lens than previous descriptions of citizenship allow for.

Overall, in recent years, there has been a shift from a biomedical discourse of dementia towards an agenda that promotes the individual rights of people living with dementia, viewing them as active contributors to the research agenda and to the societies in which they live. The shift away from the biomedical stance has led to an increase in the development and use of non-pharmacological, or psychosocial, interventions for people living with dementia (British Psychological Society, 2014). Psychosocial interventions encapsulate interventions which do not use medications, but instead seek to enable a person living with dementia, as well as family carers, to ‘live well’ after a diagnosis of dementia (McDermott et al., 2018). There are a number of interventions which fall under the umbrella term of psychosocial interventions for people living with dementia, which Patel, Perera, Pendleton,
Richman, and Majumdar (2014) have categorised into five key groups: sensory interventions (such as aromatherapy and multisensory rooms); activity-based interventions (such as exercise programmes); psychological interventions (such as doll therapy and reminiscence therapy); environmental interventions (such as adapting the home living environment); and creative interventions (such as music and art therapy). The focus of this study is on music as a creative intervention for people living with dementia. Thus, the following sections will first provide an overview of the arts, health and wellbeing movement, and then present the different music interventions available to people living with dementia, and the strength of the current evidence-base to date.

1.4 The Arts, Health and Wellbeing

There is a growing recognition, both nationally and internationally, that the arts can foster improved health and wellbeing in the general population (Cayton, 2007; Stickley et al., 2017), as well as for those living with dementia (Beard, 2012; de Medeiros & Basting, 2014). The ‘arts’ include visual arts (e.g. painting, photography and sculpture), performing arts (e.g. music, theatre and dance) and literary arts (e.g. creative writing and poetry) to name but a few approaches. The intersection between the arts, health and wellbeing is a phenomenon which has a long history in human culture (Fancourt, 2017). However, it was not until the 20th Century that the potential of the arts for therapeutic and healthcare gains began to be researched from the perspectives of different academic disciplines (Clift & Camic, 2016). The growth in outputs relating to research with an arts and health focus has increased rapidly in the past 15 years, with there now being two dedicated journals to the publishing of arts and health focussed research (Arts and Health: An International Journal for Research, Policy and Practice; and The Journal of Applied Arts and Health).

The arts, health and wellbeing movement promotes a ‘wellness agenda’ focusing on psychological wellbeing rather than on mental ‘illness’ or ‘distress’ (Clift, 2012). This is in line with the World Health Organisation’s definition of health, which focuses not only on the absence of ill-health but the experience of “complete physical, mental and social wellbeing” (World Health Organisation, 2006, p.1). The arts have been proposed provide a platform for self-expression and creativity, which
in turn has been shown to have influences on physical (see for example: Keogh, Kilding, Pidgeon, Ashley, & Gillis, 2009; Paul & Ramsey, 2000), psychological (see for example: Fancourt & Perkins, 2017; McCormack & Henry, 2017) and social wellbeing (see for example: Redmond, Sumner, Crone, & Hughes, 2018; Tischler, 2018). However, although the World Health Organisation’s definition of health is used within the context of arts and health research to define outcomes (namely physical, psychological and social wellbeing) there have been a number of critiques of this definition which may influence how we categorize arts and health programmes in the future. For example, it has been suggested that this definition of health is too broad, with it being proposed that it is impossible to meet the extensive criteria for ‘complete’ health and wellbeing (Bickenbach, 2015). Furthermore, such definitions operate at a macro-level of experience, thus neglecting micro-level signifiers of wellbeing, such as embodied and relational experiences.

This research area has brought together a number of disciplines in order to answer questions relating to the use of the arts to promote health and wellbeing (Stickley et al., 2017). This means that there is a prominent multidisciplinary focus to much of the research being conducted in the broad arts and health area (Camic, 2008). In recent years, policy makers have also begun to recognise the value of the arts in relation to public health, and the value of multidisciplinary perspectives (Fancourt, 2017). In 2017, an All-Party Parliamentary Group report Creative Health: The Arts for Health and Wellbeing (All-Party Parliamentary Group on Arts Health and Wellbeing, 2017) was launched within the Houses of Parliament. The report sought to collate information regarding practice and research in the area of arts for health and social care, in order to make recommendations which could feed into policy and practice. The report took a life course approach, seeking to understand how the arts can foster improved wellbeing from childhood through to end of life care, and made 10 key recommendations, including:

i. The development of a national strategic centre for arts, health and wellbeing.

ii. The development of a cross-governmental strategy for arts, health and wellbeing.
iii. The development of a role within NHS England which focuses on institutional policy for arts, health and wellbeing.

iv. The incorporation of social prescribing of the arts within commissioning plans and care pathways.

v. The education of clinicians and health care professionals in the arts and health evidence and practice through accredited modules.

vi. The consideration of multidisciplinary approaches to the arts, health and wellbeing evidence-base.

These recent developments in policy recommendations show how the arts, health and wellbeing agenda is beginning to become part of mainstream narratives within society. However, although the report described many significant benefits of the arts for health and social care, it acknowledged that the movement was deterred from making bigger influences due to pressures to contribute to an evidence-base which is highly reliant on biomedical approaches. For example, there was an expectation that the arts needed to be evaluated using the same means of investigation as pharmacological interventions using standardised outcome measures, randomised controlled designs and strict inclusion/exclusion criteria (All-Party Parliamentary Group on Arts Health and Wellbeing, 2017).

Overall, there has been increased attention in recent years on the value of the arts within health and social care. A significant body of arts and health work seeks to understand the benefits of the arts for those living with dementia. The following section will provide an overview of the role of the arts for people living with dementia, and then consider the role of music as a psychosocial intervention.

1.5 The Arts, Music, and Dementia

In the past 15 years, there has been a substantial increase in the use of arts-based interventions in the context of dementia care. There are a wide range of arts programmes which have been reported in the literature, including creating visual art (see for example: Camic, Tischler, & Pearman, 2014), theatrical productions (see for example: Basting, 2006) and improvised music-making (see for example: Campbell, et al., 2017). Arts-based interventions are typically facilitated by qualified arts therapists (i.e. music therapists, art therapists, drama therapists), but there is a
growing movement of artist-led projects which explore the benefits of such activities without the term ‘therapy’ attached to practice. Such programmes place an emphasis on understanding the benefits of arts activities on people living with dementia from a personal, community and societal level, rather than focusing purely on improving clinical outcomes (see for example: Windle et al., 2016).

Music is the most commonly accessed arts-based intervention for people living with dementia (Beard, 2012). Music-based interventions are primarily observed within residential settings, with very few music-interventions focusing on people living with dementia residing within the community (Elliott & Gardner, 2018). Within care homes, music is often a structured activity, with many care homes incorporating music listening and group-based music therapy into residents’ weekly activities. In community settings, music is typically engaged with in a group setting within a community centre or similar. There are many different types of music intervention for people living with dementia and the following section will examine the key differences between music therapy, and musician led programmes.

There are a number of different music-based interventions that have been implemented with people living with dementia, ranging from formalised music therapy (see for example: Chu et al., 2014), to singing groups (see for example: Unadkat, Camic, & Vella-Burrows, 2017), through to music composition programmes (see for example: Campbell et al., 2017; McCabe, Greasley-Adams, & Goodson, 2015) (see Table 1, p.29). There is an important distinction to be made between music therapy and musician-led programmes for people living with dementia. Music therapy interventions are delivered by qualified music therapists, who are registered with the Health and Care Professionals Council. Music therapists assess the physical, social and psychological needs of clients, and use music as a means of improving outcomes in these key domains (MacDonald, 2013). Musician-led programmes, on the other hand, are delivered by musicians who do not have the qualifications of a music therapist, but have musical expertise and knowledge which can facilitate musical communication and support for people living with dementia. The term music therapy is often misused within this research area, with many researchers ascribing the term to programmes of intervention which are not led by a qualified music therapist (Hsu et al., 2015).
The majority of published work that focuses on the use of music with people living with dementia comes from the music therapy discipline, with the focus placed on how music therapy interventions influence pre-determined clinical outcomes, such as anxiety, agitation, ‘wandering’ behaviour. However, similar to the wider arts and dementia literature, there are an increasing number of programmes which are led by musicians, who are not qualified music therapists. For example, *Singing for the Brain*, an Alzheimer's Society (2018) initiative, is a group-based singing activity, facilitated by trained singing leaders, in which people living with dementia sing familiar, biographically significant songs together with family carers and/or friends. It provides a platform for people living with dementia to take part in an enjoyable activity in a supportive environment, as well as connect with memories that are associated with the biographically significant pieces of music (Osman et al., 2016).

Over the years, there have been a number of research studies which have sought to quantify the benefits of music for people living with dementia. There have been a number of published reviews (see for example: Koger, Chapin, & Brotons, 1999; McDermott et al., 2013; Sherratt, Thornton, & Hatton, 2004), which have attempted to bring together research studies in a systematic way in order to build an evidence-base for the use of music with people living with dementia. There have also been three Cochrane reviews which have sought to review the current evidence for the use of music with people living with dementia. The first two reviews (Vink, Bruinsma, & Scholten, 2003, 2011), focussed on music therapy alone and concluded that the methodological quality of the included studies was too poor to be able to draw meaningful conclusions, highlighting limited definitions of music interventions and lack of transparency regarding reporting of methods and analysis procedures.

The most recent Cochrane review (van der Steen et al., 2017) broadened the inclusion criteria to include music programmes that were not led by music therapists. Although this resulted in the increase in the number of studies able to be included in the review, the findings still reflected poor methodological reporting within studies, with the only conclusion being that music ‘might’ reduce symptoms of depression. van der Steen et al. (2017) also highlighted the lack of dementia and music specific outcome measures, with many studies using generic outcome measures to understand changes in ‘behavioural and psychological symptoms of dementia’ over time. These
Cochrane reviews highlight a number of current failings within the music and dementia literature, demonstrating the need for more rigorous methodology and more appropriate outcome measures. The following section will critically appraise the most commonly used outcome measures within this research area, highlighting the current shortcomings of such methods in understanding the musical experiences of people living with dementia.
<table>
<thead>
<tr>
<th>Music Programme</th>
<th>Description</th>
</tr>
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<tbody>
<tr>
<td><strong>Music Therapy</strong></td>
<td>A music intervention delivered by a qualified music therapist who seeks to address key clinical outcomes relating to physical and mental health. There are many different types of music therapy, including Nordoff-Robbins Music Therapy (Guerrero, Marcus, &amp; Turry, 2015); and Dalcroze eurhythmics (Habron, 2014). Music therapy can be an individual or group intervention, depending on the needs of the client group. See for example: Raglio et al. (2015).</td>
</tr>
<tr>
<td><strong>Personalized Listening</strong></td>
<td>Listening to pre-recorded familiar repertoire that has been suggested by the person living with dementia themselves, or a family member. This can be done as an individual or group intervention. See for example: Baker (2012); Playlist for Life (2018).</td>
</tr>
<tr>
<td><strong>Music in Caring Contexts</strong></td>
<td>Music is used during care situations, such as bathing or dressing, in order to reduce anxiety and stress for the person living with dementia. This can be achieved through pre-recorded music or through caregiver singing. See for example: Göttell, Brown, and Ekman (2002); Hammar, Emami, Engström, and Göttell (2010).</td>
</tr>
<tr>
<td><strong>Singing Groups</strong></td>
<td>Singing groups, typically facilitated by a musician, follow a ‘sing-along’ style where group members will sing familiar repertoire with an accompaniment, which can be live or pre-recorded. See for example: Alzheimer's Society (2018); Osman et al. (2016).</td>
</tr>
<tr>
<td><strong>Music Performance</strong></td>
<td>Musicians perform to an audience of people living with dementia. Repertoire that is familiar to those in the setting it is being performed in will often be performed, such as classical music or contemporary popular music. See for example: Holmes et al. (2006).</td>
</tr>
<tr>
<td><strong>Composition Programmes</strong></td>
<td>People living with dementia are supported to create new pieces of music. These interventions are typically facilitated by arts organisations. In some cases, the people living with dementia will perform the piece of composed music to an audience. See for example: Campbell et al. (2017); McCabe et al. (2015).</td>
</tr>
<tr>
<td><strong>Attending Music Venues</strong></td>
<td>People living with dementia attend live music performances in music venues. See for example: Shibazaki and Marshall (2017).</td>
</tr>
</tbody>
</table>
1.5.1 Measuring the Impacts of Music on People Living with Dementia

To develop an evidence-base it is necessary for psychosocial interventions to go through rigorous research programmes in order to demonstrate efficacy and cost-effectiveness (McDermott et al., 2018). Arts interventions for people living with dementia have a tendency to be evaluated in the same way that a pharmacological intervention would be assessed, by comparing a control group and an ‘intervention’ group using a range of standardised outcome measures as part of a randomised controlled trial. On the one hand, there are some who argue that it is not realistic to measure the individual nature of experience for people when engaging in arts-based activities (de Medeiros & Basting, 2014). On the other hand, it still remains important to understand these experiences in a tangible way so that a stronger evidence-base for the use of music, and other arts-based interventions, can be established and implemented within practice guidelines as recommended by National Institute for Health and Care Excellence (NICE, 2018), for example.

Further developing the point above, the Medical Research Council (Craig et al., 2013) has developed guidance on the implementation and evaluation of complex interventions, with the aim of ensuring methodologically rigorous research, which can help to build an evidence-base for the use of complex interventions with clinical populations. Interventions involving music are categorised as ‘complex interventions’ as there are a number of outcomes that can be observed, and interactional components that have to be considered. However, the Medical Research Council’s guidelines (Craig et al., 2013) are still very much in line with biomedical approaches to illness, with the guidance on evaluating complex interventions appearing to favour the use of standardised psychiatric measures as part of randomised controlled trials.

However, in recent years, there has been a movement to use qualitative methods to evaluate arts-based interventions, with the argument being made that they can provide more insight into the experiences of people when they engage with arts-based interventions, due to the ability to learn about individual’s subjective experiences. For example, the *Arts for Health and Wellbeing: an Evaluation Framework* report (Public Health England, 2016) recommends that qualitative
approaches to the evaluation of arts-based interventions be used to explore the in-depth experiences of people engaging with arts programmes. Furthermore, the Public Health England (2016) report recommends the use of participatory research, case studies and creative and arts-based methods in order to provide a platform for the people engaging with the interventions to have a voice in the process. Although there is guidance which suggests the use of qualitative and participatory approaches to arts evaluation, the current methods for measuring the impact of music on people living with dementia rely heavily on behavioural and emotional outcomes (Phinney, Chaudhury, & O’Connor, 2007), often measured through the use of standardised outcome measures. The following section will critically appraise the current methods that are being used to evaluate the impact of music on people living with dementia, and identify the potential strengths and limitations in measuring impacts of music using such methods.

There are a number of methods by which the impacts of music on the person living with dementia are currently measured, ranging from non-specific standardised outcome measures (e.g. Cohen Mansfield Agitation Inventory, Cohen-Mansfield, Marx, & Rosenthal, 1989), to dementia-specific standardised outcome measures (e.g. Cornell Scale for Depression in Dementia, Alexopoulos et al., 1988), through to dementia specific music therapy assessment tools (e.g. Music in Dementia Assessment Scales, McDermott, 2014). There have also been a number of qualitative research methods used to investigate the experiences of people living with dementia when engaging with music, but these will be focussed on in Chapter 2 (see p.41). The following section will discuss the use of standardised outcome measures as a means of measuring the impacts of music on people living with dementia.

There are a number of non-specific outcome measures that have been used in the measurement of the impact of music on people living with dementia (Table 2). These measurements are frequently used as outcome measures within randomised controlled trials, in which characteristics of people living with dementia are measured at baseline, at the end of an intervention, and post-intervention (follow-up). For example, Chu et al. (2014) used a randomised controlled trial to investigate the impact of group music therapy on depression and cognition, and used a number of psychiatric outcome measures including the Mini-Mental State Examination
and the Chinese Version of the Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988). Participants received a six-week music-therapy programme, and measurements were taken prior to the engagement with the music therapy intervention, at the end of the six weeks and one month after the intervention. This research design is fairly typical for examining changes in ‘behavioural and psychological symptoms of dementia’ as a result of a music programme.

Table 2: Non-specific outcome measures

<table>
<thead>
<tr>
<th>Tool</th>
<th>Focus</th>
<th>Structure</th>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mini Mental State Examination (Folstein et al., 1975)</td>
<td>Cognitive Impairment</td>
<td>30-Point Questionnaire</td>
<td>Clinician/Researcher</td>
</tr>
<tr>
<td>Cohen Mansfield Agitation Inventory (Cohen-Mansfield et al., 1989)</td>
<td>Agitation</td>
<td>29-Point Questionnaire</td>
<td>Family Carer/Researcher</td>
</tr>
<tr>
<td>Geriatric Depression Scale (Yesavage et al., 1982)</td>
<td>Depression</td>
<td>30-Point Questionnaire</td>
<td>Clinician/Researcher</td>
</tr>
<tr>
<td>Neuropsychiatric Inventory (Cummings, 1997)</td>
<td>Neuropsychiatric Symptoms</td>
<td>10-Item Interview</td>
<td>Family Carer/Clinician/Researcher</td>
</tr>
<tr>
<td>Neuropsychiatric Inventory – Questionnaire (Kaufer et al., 2000)</td>
<td>Neuropsychiatric Symptoms</td>
<td>10-Item Questionnaire</td>
<td>Family Carer/Clinician/Researcher</td>
</tr>
</tbody>
</table>

As well as non-specific outcome measures, there are also dementia-specific outcome measures. These are outlined in Table 3 and include the Cornell Scale for Depression in Dementia (Alexopoulos et al., 1988) and the Rating of Anxiety in Dementia Scale (Shankar et al., 1999). These outcome measures are not as frequently used within the music and dementia literature, but they also aim to measure presence and severity of a given ‘behavioural and psychological symptom of dementia’, such as depression or anxiety. For example, Cooke et al. (2010) used the Rating of Anxiety in Dementia Scale, along with a number of non-specific standardised outcome measures, to explore how taking part in a live group music programme, including singing and listening to music, impacted on anxiety and agitated behaviours in people living with dementia.
dementia. Their pre-and post-intervention measurements revealed no significant differences between the two time scales, with it being concluded that “the study proved unsuccessful in isolating the unique therapeutic value of the music program in ameliorating agitation and anxiety” (p. 913).

Table 3: Dementia-specific outcome measures

<table>
<thead>
<tr>
<th>Tool</th>
<th>Focus</th>
<th>Structure</th>
<th>Respondent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cornell Scale for Depression in Dementia</td>
<td>Depression</td>
<td>19-Item Interview</td>
<td>Family Caret/ Researcher/ Person Living with Dementia</td>
</tr>
<tr>
<td>(Alexopoulos et al., 1988)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rating of Anxiety in Dementia</td>
<td>Anxiety</td>
<td>20-Item Clinical Rating Scale</td>
<td>Clinician/ Researcher</td>
</tr>
<tr>
<td>(Shankar et al., 1999)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia Quality of Life</td>
<td>Quality of Life</td>
<td>29-item instrument</td>
<td>Person Living with dementia</td>
</tr>
<tr>
<td>(Brod et al., 1999)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dementia Care Mapping</td>
<td>Processes and outcomes of care/</td>
<td>Observational tool mapping 24 behaviours</td>
<td>Clinician/ Researcher</td>
</tr>
<tr>
<td>(Bradford Dementia Group, 2005)</td>
<td>Quality of Life</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Research that implements these non-specific and dementia-specific tools has resulted in mixed findings on the impact of music on people living with dementia (Ueda et al., 2013), and brings into question whether these standardised measures are truly capturing the essence of experience held by people living with dementia when they engage with music. Even more concerning is the prospect that the majority of the measures in Tables 2 and 3 rely on proxy reporters to provide accounts on the behalf of the person living with dementia. Considering that studies which use these standardised outcome measures as part of their research designs dominate the literature, it suggests that the views of people living with dementia are currently underrepresented, as well as undervalued in the current evidence-base. It therefore seems imperative that research should incorporate the voices of people living with dementia in order to achieve a more person-centred account where individual experience is placed centrally, rather than on the periphery.

Less frequently encountered within the music and dementia literature is the use of tools which are specific to music, or music therapy, outcomes. There are a number of
clinical tools which are used by music therapists in order to assess changes in clinical outcomes as a result of a music therapy intervention. The majority of these tools assess the musical competencies of people living with dementia, as well as specific clinical outcomes (Cripps, Tsiris, & Spiro, 2016). On examining the literature there appears to be only one dementia and music therapy specific tool designed for use within research studies rather than clinical assessment: *Music in Dementia Assessment Scales* (MiDAS). These scales were developed by Dr Orii McDermott as part of her doctoral work (McDermott, 2014) in order to design a clinically relevant music therapy assessment tool that was based on the experiences of people living with dementia (McDermott, Orrell, & Ridder, 2014). The final version of the MiDAS tool included Visual Analogue Scales, where music therapists and staff carers would rate the existence of certain responses to music on a scale of 0 to 100 (McDermott, Orgeta, et al., 2014). The five components of the Music in Dementia Assessment Scales are displayed in Table 4.

Table 4: The five components of Music in Dementia Assessment Scales

<table>
<thead>
<tr>
<th>Item</th>
<th>Example</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Interest</strong></td>
<td>▪ Did he/she show his/her interest in an activity or other people around him/her?</td>
</tr>
<tr>
<td></td>
<td>▪ Did his/her posture or facial expression change if activities or music catch his/her attention?</td>
</tr>
<tr>
<td></td>
<td>▪ Did he/she become animated if activities or music catch his/her attention?</td>
</tr>
<tr>
<td><strong>Response</strong></td>
<td>▪ Did his/her facial expression or body movements indicate his/her awareness of staff or therapists?</td>
</tr>
<tr>
<td></td>
<td>▪ Did he/she make eye contact with staff, therapist, or other group members?</td>
</tr>
<tr>
<td></td>
<td>▪ Did he/she join in conversation, music-making, or make vocal sound?</td>
</tr>
<tr>
<td><strong>Initiation</strong></td>
<td>▪ Did he/she try to communicate with staff, therapist, or other group members?</td>
</tr>
<tr>
<td></td>
<td>▪ Did he/she start conversation, start music-making, or initiate vocalization?</td>
</tr>
<tr>
<td></td>
<td>▪ Did he/she talk about his/her life experiences (reminiscence), or mention music was meaningful to them?</td>
</tr>
<tr>
<td><strong>Involvement</strong></td>
<td>▪ Did he/she become engaged in conversation, music-making, or any forms of communication?</td>
</tr>
<tr>
<td></td>
<td>▪ Did he/she show his/her enthusiasm in activities that interest him/her?</td>
</tr>
<tr>
<td><strong>Enjoyment</strong></td>
<td>▪ Smiling, laughing, brighter mood, playfulness, sense of humour, relaxed mood.</td>
</tr>
</tbody>
</table>
These components were developed through interviewing people living with dementia, as well as staff carers, family carers and music therapists (McDermott, Orrell, et al., 2014). Although McDermott, Orrell, et al. (2014) looked to understand what music meant to people living with dementia through interviews and focus groups, the questions that were asked to people living with dementia and family carers/music therapists differed in their angle. For example, people living with dementia were asked:

i. What does music mean to you?
ii. What do you think of your music therapy/music activities?
iii. In what way is music important to you?

Whereas families, staff and music therapists were asked:

i. What changes and responses do you observe in your families/clients following music therapy or music activities?
ii. How do you know if music is meaningful to the person?

The framing of these questions suggests that the observation scale is based more upon what was said by those caring for people living with dementia, rather than the people living with dementia themselves.

Furthermore, the MiDAS tool is predominately focussed on the behaviours of the person living with dementia and does not seek to understand the interpersonal or environmental benefits that may be experienced when engaging with music. It is interesting to note that although the MiDAS is a music therapy tool, it does not consider the musical skills of people living with dementia. This observation was made by Dr Jacqueline Kindell who used the MiDAS tool as part of her doctoral work. Kindell (2016) reported that the MiDAS:

[…] lacked the ability to analyse the unique aspects of performance and interaction within the quantification of engagement […] rather surprisingly [the MiDAS was] lacking any particular detailed exploration of reaction to music. (p 272).
Therefore, although the MiDAS used a number of research strategies to ensure the inclusion of the voices of people living with dementia within the development of a music assessment tool, there are a number of limitations associated with these scales.

Overall, the current methods of evaluating the benefits of music for people living with dementia rely heavily on biomedical lenses with the focus being placed on examining changes in ‘behavioural and psychological symptoms of dementia’ across a music intervention. This reliance on ‘before and after’ approaches neglects the individual experiences of people living with dementia enrolled in such music programmes. What is also evident from these current methods of evaluation, is the lack of possibility for the contributions of the person living with dementia themselves to the reporting of their own experiences. Relying on proxy accounts of experience foregoes the work of more recent theoretical developments surrounding the notions of personhood (Kitwood, 1997), social citizenship (Bartlett & O’Connor, 2007, 2010) and relational citizenship (Kontos, Miller, & Kontos, 2017). Thus, there appear to be significant limitations associated with the current ways in which the benefits of music for people living with dementia are measured and understood.

1.6 Summary

This chapter has presented the contextual background to the research study, highlighting the current policy context which the study was conducted, as well as exploring the different discourses used within dementia studies literature. The chapter also considered the role of arts, and more specifically music interventions for people living with dementia, and explored the ways in which the impacts of music are currently evaluated. It is evident that there is a need to develop new music assessment tools which move beyond the biomedical model, and examine the lived experiences of people living with dementia when they engage with music. The voices of people living with dementia should be central in the development of such tools, given the currently literature is dominated by proxy reporting of experience. The next chapter will provide an overview of the qualitative literature that has been published to date, as a means of exploring the personal benefits of musicking for the person living with dementia, as well as exploring the level of involvement of people living with dementia in the qualitative and mixed-methods research to date.
CHAPTER 2. LITERATURE REVIEW

2.1 Introduction

This chapter will present the methods and findings of a systematic review of the qualitative literature surrounding the use of music with people living with dementia using a thematic synthesis approach. Published reviews have so far failed to identify the personal benefits of engaging with music for people living with dementia, focusing instead on how music might reduce ‘behavioural and psychological symptoms of dementia’. The exploration of such factors may lead to a greater understanding of why music has positive effects on the quality of life and wellbeing of people living with dementia. Exploring this phenomenon through a systematic process forms the primary focus of this review. The undertaking of the review allowed for the exploration of the qualitative literature to date, as well as understanding the level of involvement of people living with dementia within this research area. The chapter begins by describing the aims and methods of the review, as well as the methods for the quality appraisal of included studies. The thematic synthesis of the literature then follows, detailing both the synthesis findings and the level of involvement by people living with dementia in extant studies. The findings section will outline the four themes that were developed as part of the thematic synthesis: Taking Part; Feeling Connected; Affirming Identity; and Immersion ‘In the Moment’. The chapter concludes with a summary of the key findings and the implications of these findings for the research study.

This review was first published in the peer reviewed journal Arts & Health: An International Journal for Research, Policy and Practice in September 2017 (Dowlen et al., 2017 and see Appendix 1) and this chapter will present an updated review having searched the literature for any new studies that have been published since the publication of the review (between September 2017 and April 2018).
2.2 Aims

The overarching aim of this review is to explore the personal benefits of musicking for people living with dementia by systematically reviewing the qualitative literature in order to understand its emotional, psychological and social impacts.

The secondary aim is to report upon the involvement of people living with dementia within the research studies as, to date, much of the literature in this area has relied on proxy accounts to understand and represent lived experience.

2.3 Review Methods

2.3.1 Definitions

The term musicking modifies the meaning of the word ‘music’ from that of a noun to a verb, meaning to engage with music (Small, 1998). Accordingly, musicking can be used as an umbrella term for any musical activity from listening to music on one’s own through to performing opera on stage. Levels of engagement can differ between musicking activities, with the use of instruments and the human voice being viewed as ‘active participation’, and listening to music deemed as ‘passive participation’. It is also possible to combine active and passive approaches within a single musicking activity (Guettin et al., 2013). By adopting the term musicking as a key operational definition for this review, I view musicking as a creative activity rather than solely aligning music to therapy. This subtle shift of emphasis allows all levels of engagement with music to be reported in the review.

2.3.2 Search Terms

The search terms were pre-planned and combined terms from MeSH headings with terms observed frequently in the literature (see Table 5). Key terms relating to the topic area were combined with key terms associated with qualitative methods to increase the likelihood of identifying qualitative research studies.
Table 5: Search Terms

<table>
<thead>
<tr>
<th>Population</th>
<th>Intervention</th>
<th>Methodology/Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>dementia OR</td>
<td>music OR musicking OR music therapy* OR</td>
<td>qualitative OR mixed method* OR</td>
</tr>
<tr>
<td>Alzheimer’s</td>
<td>singing OR preferred listening</td>
<td>interview OR focus group OR</td>
</tr>
<tr>
<td></td>
<td></td>
<td>observation</td>
</tr>
</tbody>
</table>

### 2.3.3 Inclusion/Exclusion Criteria

Studies were eligible for inclusion if they were written in English, used a qualitative or mixed-methods design, included individuals with a diagnosis of a dementia, and focussed on outcomes relating to the impact of music on people living with dementia.

Studies were excluded if the focus was solely on caregiver experiences, if music was combined with another activity (e.g. music and exercise programmes) or where it was not possible to disentangle the results of the participants with dementia from other participants (e.g. in mixed populations of participants with dementia and older people without a diagnosis of dementia). Non-primary research articles were also excluded.

### 2.3.4 Search Strategy

Searches were originally conducted in February 2016 and updated in April 2018 using PsycINFO (via Ovid search platform), Cumulative Index to Nursing & Allied Health Literature (via Ebsco) and Web of Science (Arts and Humanities Citation Index and Social Sciences Citation Index). No date restrictions were placed on the database searches.

Hand-searches of relevant journals and reference lists were conducted to ensure all relevant qualitative research had been identified. Unpublished theses were identified using Open Grey and Proquest Theses and Dissertations: American and International databases.
2.3.5 Quality Appraisal

The consolidated criteria for reporting qualitative research (COREQ; Tong, Sainsbury, & Craig, 2007) were used in order to critically appraise the identified literature. COREQ is a 32-item checklist that covers items indicative of quality including: researcher reflexivity; relationship with participants; study design; participant selection; study setting; analysis and findings. Although COREQ was not designed as a critical appraisal tool, but as a checklist for researchers reporting qualitative research, it provides a comprehensive account of what should be included within the reporting of qualitative research in order for it to be deemed high quality (Tong et al., 2007). However, the COREQ checklist does not appraise research based on ethical considerations, which is essential within research involving people living with dementia (Dewing, 2002). Therefore, the Critical Appraisal Skills Programme qualitative tool (CASP, 2018) was chosen to complement the COREQ checklist (Tong et al., 2007) as it includes good ethical practice as an indicator of quality.

Studies were not excluded on the basis of their score, but studies of lower quality were given less weighting in the synthesis of studies (Aveyard, 2014). This was in order to include as many studies as possible considering the limited qualitative research in this area. There is no set method for the weighting of studies within qualitative synthesis, however there are suggestions that the use of weighting is important in ensuring the findings of higher quality studies are well represented within the analysis and reporting of findings (Borije, van Wesel & Alsic, 2011). In order to weight the studies, I categorised studies as ‘low’ quality if they scored less than 12, ‘medium’ if they scored less than 24, and ‘high’ if they scored 25 or above. All studies were coded no matter the quality score (see Analysis), but those with lower scores were given less weighting within the synthesis and reporting of themes so as to ensure research of the highest quality was represented most centrally.

2.4 Analysis

Analysis was conducted in three phases, in accordance with Thomas and Harden’s (2008) guidance on thematic synthesis. Firstly, each line of text was examined in its entirety. Following this, each line of data was coded by hand using free line-by-line coding. Newly emerging codes were added to a coding bank which was used
iteratively when analysing successive literature. Secondly, I formulated descriptive themes and refined these through several meetings (led by myself) with my supervisory team. Finally, analytical themes were developed in order to ‘go beyond’ what was said in the primary research, which was achieved through understanding the themes in the context of the aims of the review. I presented the generated themes within supervision meetings in order to ensure the authenticity and representativeness of the final set of generated themes.

2.5 Findings

2.5.1 Search Results

A total of 195 articles and six theses were identified through database and hand searches (see Figure 1). Duplicate articles were removed, and the remaining 144 texts were subject to title and abstract review. After title and abstract review, 21 articles were fully screened having met the inclusion criteria for the review. Following full text screening, three studies were removed as on closer inspection they did not meet the inclusion criteria for the review. This resulted in a total of 18 studies being included within the original thematic synthesis. In searches during April 2018 a further three studies were identified as meeting the inclusion criteria for the review (Campbell et al., 2017; Daykin et al., 2017; Shibazaki & Marshall, 2017), taking the total studies to 21.

2.5.2 Characteristics of Included Studies

The characteristics of included studies are presented in Table 6. The majority of studies were from a music therapy discipline, with other studies being from nursing or social science disciplines. Musicking activities varied substantially, but the majority required active participation through singing or playing instruments.

The majority of studies chose to explore the impacts of musicking through proxy accounts provided by caregivers; with only nine studies collecting first-hand accounts from people living with dementia (Camic, Williams, & Meeten, 2013; Daykin et al., 2017; Hara, 2013; McCabe et al., 2015; McDermott, Orrell, et al.,
2014; Osman et al., 2016; Shibazaki & Marshall, 2017; Sixsmith & Gibson, 2007; Unadkat et al., 2017).

Figure 1: Flow diagram of database and grey literature searching
Table 6: Included Studies

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Country</th>
<th>Participants</th>
<th>Musicking Activity</th>
<th>Methodology</th>
<th>Data collection methods</th>
<th>Analysis</th>
<th>Research questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Baker</td>
<td>2012</td>
<td>Australia</td>
<td>5 spousal caregivers</td>
<td>Listening to pre-recorded music</td>
<td>Mixed-method</td>
<td>Semi-structured interviews; Diary entries</td>
<td>Thematic Analysis</td>
<td>To understand the benefits of music on the wellbeing of the person with dementia, from the perspective of the spousal caregiver.</td>
</tr>
<tr>
<td>Camic et al.</td>
<td>2013</td>
<td>UK</td>
<td>10 people with dementia; 10 family caregivers</td>
<td>Group singing</td>
<td>Mixed-method</td>
<td>Semi-structured interviews</td>
<td>Thematic Analysis</td>
<td>To examine whether participation in group singing impacted on the quality of life of both people with dementia and their family caregivers.</td>
</tr>
<tr>
<td>Campbell et al.</td>
<td>2017</td>
<td>UK</td>
<td>1 music therapist; 4 orchestral musicians; 2 organisational staff; 3 activity workers; 1 care home manager</td>
<td>Improvisation-based group music therapy</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>Thematic Analysis</td>
<td>To conduct an exploratory evaluation of Manchester Camerata’s <em>Music in Mind</em> program.</td>
</tr>
<tr>
<td>Dassa &amp; Amir</td>
<td>2014</td>
<td>Israel</td>
<td>6 people with dementia</td>
<td>Group listening to pre-recorded music</td>
<td>Qualitative</td>
<td>Observation</td>
<td>Qualitative content analysis</td>
<td>To explore the role of music in stimulating communication in people with dementia.</td>
</tr>
<tr>
<td>Daykin et al.</td>
<td>2017</td>
<td>UK</td>
<td>38 people with dementia; 12 Staff members</td>
<td>Participatory music-making</td>
<td>Mixed-Methods</td>
<td>Observation; Semi-structured interviews</td>
<td>Analytic induction</td>
<td>To investigate the effects of music in a hospital based intervention for people with dementia, including impacts on patients and staff.</td>
</tr>
<tr>
<td>Gardner* 1999</td>
<td></td>
<td>USA</td>
<td>2 people with dementia; 2 family caregivers</td>
<td>Individual music therapy</td>
<td>Qualitative</td>
<td>Interviews with family carers; Observation</td>
<td>“Inductive data analysis” (p.21)</td>
<td>To explore the impacts of long-term music therapy on the relationships between the person with dementia, their family caregiver and the music therapist.</td>
</tr>
<tr>
<td>Götell et al.</td>
<td>2002</td>
<td>Sweden</td>
<td>9 people with dementia; 5 nurse caregivers</td>
<td>Caregiver singing; Background pre-recorded music</td>
<td>Qualitative</td>
<td>Interviews with staff carers; Observation</td>
<td>Phenomenologic-Hemeneutic method</td>
<td>To explore the use of background music versus caregiver singing during caregiving activities.</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Participants</td>
<td>Intervention</td>
<td>Design</td>
<td>Methodology</td>
<td>Analysis Method</td>
<td>Objective</td>
<td></td>
</tr>
<tr>
<td>-----------------------------</td>
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<td>--------------</td>
<td>--------------</td>
<td>--------</td>
<td>------------------------------------------------------------------------------</td>
<td>-----------------</td>
<td>------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Göttel et al. (2009)</td>
<td>Sweden</td>
<td>9 people with dementia; 5 nurse caregivers</td>
<td>Caregiver singing; Background music</td>
<td>Qualitative</td>
<td>Observation Qualitative content analysis</td>
<td>To examine the effects of background music versus caregiver singing on the emotions and moods of people with severe dementia.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hammar et al. (2010)</td>
<td>Sweden</td>
<td>6 staff caregivers</td>
<td>Music Therapeutic Caregiving</td>
<td>Qualitative</td>
<td>Group interviews Qualitative content analysis</td>
<td>To explore the reaction of people with dementia to Music Therapeutic Caregiving during morning care situations.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hammar et al. (2011a)</td>
<td>Sweden</td>
<td>10 people with dementia; 6 staff caregivers</td>
<td>Music Therapeutic Caregiving</td>
<td>Qualitative</td>
<td>Video observation Qualitative content analysis</td>
<td>To explore verbal and non-verbal communication of people with dementia during morning care routines with Music Therapeutic Caregiving.</td>
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<tr>
<td>Hammar et al. (2011b)</td>
<td>Sweden</td>
<td>6 staff caregivers</td>
<td>Music Therapeutic Caregiving</td>
<td>Qualitative</td>
<td>Group interviews Qualitative content analysis</td>
<td>To explore the differences in staff caregiver experiences with and without Music Therapeutic Caregiving during morning care situations.</td>
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<tr>
<td>Hara* (2013)</td>
<td>UK</td>
<td>People with dementia*, family carers*, volunteers*; 1 singing group facilitator</td>
<td>Group singing</td>
<td>Qualitative</td>
<td>Interviews Observations Grounded Theory analysis</td>
<td>To use ethnographic study to explore how musicking benefits people with dementia and their caregivers.</td>
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<tr>
<td>McCabe et al. (2015)</td>
<td>UK</td>
<td>9 people with dementia; 3 family caregivers</td>
<td>Creative musical project</td>
<td>Qualitative</td>
<td>Semi-structured interviews Thematic analysis</td>
<td>To explore the experiences of people with dementia involved in a creative music project, and how the benefits of involvement evolve over time.</td>
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<tr>
<td>McDermott, Orrell, et al. (2014)</td>
<td>UK</td>
<td>15 people with dementia; 15 family carers; 14 staff carers; 8 music therapists</td>
<td>Group music therapy</td>
<td>Qualitative</td>
<td>Focus groups; Interviews General inductive approach</td>
<td>To understand the meaning and value of music for people living with dementia.</td>
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<tr>
<td>Osman et al. (2014)</td>
<td>UK</td>
<td>10 people with dementia; 10 family carers</td>
<td>Group singing</td>
<td>Qualitative</td>
<td>Semi-structured interviews Thematic Analysis</td>
<td>To explore the experiences of people with dementia and their carers attending a group singing activity.</td>
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<td>Study</td>
<td>Country</td>
<td>Participants</td>
<td>Setting</td>
<td>Methodology</td>
<td>Analysis Methodology</td>
<td>Method Details</td>
<td>Purpose</td>
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<td>Pavlecevic et al. (2015)</td>
<td>UK</td>
<td>6 music therapists</td>
<td>Music Therapy</td>
<td>Qualitative</td>
<td>Focus group</td>
<td>Interpretative Phenomenological Analysis</td>
<td>To reflect on the experiences of music therapists using music for the therapeutic benefit of people with dementia within care home settings.</td>
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<tr>
<td>Shibazaki et al. (2017)</td>
<td>UK/Japan</td>
<td>27 people with dementia; 13 family carers; 9 staff carers</td>
<td>Concert attendance</td>
<td>Qualitative</td>
<td>Semi-structured interviews; Observations</td>
<td>Not reported</td>
<td>To understand the benefits of attending a care facility based concert.</td>
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<tr>
<td>Sissmith &amp; Gibson (2007)</td>
<td>UK</td>
<td>26 people with dementia; Family/staff caregivers**</td>
<td>Music in everyday life</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>Analysis guided by “conceptual model of wellbeing” (p.129) template</td>
<td>To explore the role of music and music-related activities in the everyday lives of people with dementia.</td>
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<tr>
<td>Tomaino* (1998)</td>
<td>USA</td>
<td>4 people with dementia</td>
<td>Individual music therapy</td>
<td>Qualitative</td>
<td>Video observation; Reflexive journal</td>
<td>Not reported</td>
<td>To explore the experiences of people with dementia when they engage with familiar music.</td>
<td></td>
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<tr>
<td>Tuckett et al. (2015)</td>
<td>Australia</td>
<td>7 family caregivers; 23 staff caregivers</td>
<td>Group music therapy</td>
<td>Qualitative</td>
<td>Focus groups</td>
<td>Qualitative content analysis</td>
<td>To examine the benefit of music in reducing ‘behaviours that challenge’.</td>
<td></td>
</tr>
<tr>
<td>Unadkat et al. (2016)</td>
<td>UK</td>
<td>17 people with dementia; 17 family caregivers</td>
<td>Singing group</td>
<td>Qualitative</td>
<td>Couple interviews</td>
<td>Grounded Theory Analysis</td>
<td>To understand the benefits of group singing for people with dementia.</td>
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* Thesis
** Unable to determine precise participant numbers
2.5.3 Quality of Included Studies

The quality of the identified literature, which was assessed using a combination of COREQ and CASP criteria, ranged between nine (Dassa & Amir, 2014) and 21 (Hammar et al., 2011b) out of 35, with a mean of 14.2 (see Appendix 2). Studies with lower scores did not provide enough information regarding sampling, data collection or provide information disclosing the relationship between the researcher and participants. There was very little evidence of reflexive practice in the vast majority of papers, with only one thesis (Tomaino, 2005) displaying evidence of meeting all five criteria identified in COREQ. Out of the 21 included studies, few discussed the methodological or epistemological positioning of the research, with only two studies providing detail concerning their methodological stances (Hara, 2013; Unadkat et al., 2017).

Overall, the CASP and COREQ quality appraisal tools revealed that the methodological quality of many of the research studies was poor, with many studies lacking sufficient detail to ensure transparent methodological approaches and analysis strategies.

2.6 Thematic Synthesis

Overall, the thematic synthesis of qualitative literature resulted in four themes:

i. Taking Part.
ii. Being Connected.
iii. Affirming Identity.
iv. Immersion ‘In the Moment’.

These themes were interpreted as overlapping, rather than distinct, but provided an emergent understanding about the personal benefits of musicking for people living with dementia. The following section will outline each theme in turn, supported by quotations taken from the research studies included in the review.
2.6.1 Theme 1: Taking Part

Music was viewed as an accessible medium where the ability to take part was not
determined by cognitive abilities or any previous music training. Musicking was
enjoyed on an “emotional and sensory level rather than an intellectual level”
(Sixsmith & Gibson, 2007, p.134), with people at all ‘stages’ of dementia (mild,
moderate, advanced) enjoying the soothing and motivating nature of music, as seen
in the following quote:

All participants discussed the stimulating effect of music and how playing
instruments or listening to music instantly caught the attention of many
residents who often appeared less aware or disinterested in other people or
activities around them. (McDermott, Orrell, et al., 2014, p.710).

People living with dementia expressed pride and a sense of accomplishment at
having taken part in a musicking activity (Camic et al., 2013; Hara, 2013; Osman et
al., 2016; Shibazaki & Marshall, 2017; Tomaino, 2005). Through this encounter,
people living with dementia were also able to refresh skills that may have been lost
over the progression of their condition and ‘learn something new’ through exposure
to music that may not have been in their personal repertoire (Camic et al., 2013;
Hara, 2013; McCabe et al., 2015; McDermott, Orrell, et al., 2014; Unadkat et al.,
2017). In turn, this exposure facilitated increased confidence and self-esteem, which
was further heightened by the immediate, sensory feedback participants received
through musicking.

Moreover, through musicking, people living with dementia were able to share in the
experience as equals to those who did not live with the condition (Gardner, 1999;
Götell et al., 2009; Hammar et al., 2010; Hara, 2013; McCabe et al., 2015; Shibazaki
& Marshall, 2017; Unadkat et al., 2017). This appeared to draw attention away from
‘the dementia’ and onto ‘the person’. For example, care staff and family carers often
appeared surprised that people living with dementia were able to engage with music
even after their abilities to verbally communicate had been significantly
compromised (Campbell et al., 2017; Gardner, 1999; Hammar et al., 2010; Hammar
et al., 2011b; McDermott, Orrell, et al., 2014; Osman et al., 2016; Sixsmith &
Gibson, 2007; Unadkat et al., 2017). Being perceived as an equal may have
enhanced the person living with dementia’s sense of identity through the acknowledgement that they were still able to make a meaningful contribution within a shared activity, as in this exchange:

Spouse: Well, I can’t sing, you always sang didn’t you?

Person living with dementia: Yes, I have to teach you! I didn’t half laugh at your efforts, it’s very funny, you are getting better though. (Unadkat et al., 2016, p.9).

Although musicking was seen as accessible, there were a number of barriers to taking part, with the most frequent being access to music. People living with dementia may not have been able to bring to mind their enjoyment of music nor had choice in the way in which they engaged with music. For example, within care home environments, music was often engaged with through media such as the radio or CD players, or, alternatively, via pre-determined activity schedules. People living with dementia in these situations had little control over when or how they engaged with music, or had to rely on others to make the decisions for them, as this illustration suggests:

For some people the problem lay in articulating their musical wishes and preferences to others. As a result, people with dementia tended to become increasingly dependent upon others in order to gain access to music or musical activity. Because of limits on their time and personal resources, carers were not always able to provide regular access to music. (Sixsmith & Gibson, 2007, p.137).

Overall, although this theme highlights that music is universally accessible to everyone in the musicking space there appear to be barriers to taking part for people living with dementia, especially within care home environments.

### 2.6.2 Theme 2: Being Connected

Musicking facilitated enhanced connection between people living with dementia and their spouses, other family members, care staff, musicking facilitators (i.e. music therapists) and the environment in which the activity took place. The majority of
studies in the review explored the use of music within a group setting and as a shared activity between people living with dementia and their support networks (Camic et al., 2013; Campbell et al., 2017; Dassa & Amir, 2014; Daykin et al., 2017; Hara, 2013; McCabe et al., 2015; McDermott, Orrell, et al., 2014; Shibazaki & Marshall, 2017; Unadkat et al., 2017). These music groups were viewed primarily as a social activity in which, over time, a supportive group culture could be developed whatever the encountered environment:

*Music Therapist:* When you see one of those care-home rooms with 20-30 chairs in a huge circle – generally speaking, I feel that that is the worst sort of setup for any socialising any communication anything going on at all. But then this focus of the music, and what music enables, changed that. (Pavlicevic et al., 2015, p.670).

This group culture, created through musicking, provided people living with dementia with a sense of belonging and a sense of security (Camic et al., 2013; Dassa & Amir, 2014; Hammar et al., 2010; Hara, 2013; Osman et al., 2016; Pavlicevic et al., 2014; Tomaino, 2005; Unadkat et al., 2017). Moreover, such an initiative, and the shared enjoyment of musicking, also created a sense of togetherness between those with dementia and those supporting them. Furthermore, musicking provided a space in which the person living with dementia was not dependent on others. In turn, this enhanced the quality of existing relationships with carers and facilitated positive interactions across a number of social and relational networks as these two extracts reveal:

*The caregivers described the elements in the caring situation as uninterrupted and this time was described as a nice moment they shared with the [people living with dementia], which made them feel close to them.* (Hammar et al. 2011b, p.105).

*Person living with dementia:* Wherever you go and whatever group of people you’re in, singing seems to break down barriers and to open up sort of, not only companionship, but a sense of belonging, and that’s great (Osman et al., 2014, p.5).
This sense of being connected was heightened by musicking as it helped people living with dementia to connect with family members, music therapists and care staff on a level that did not require words (Baker, 2012; Campbell et al., 2017; Gardner, 1999; McDermott, Orrell, et al., 2014; Sixsmith & Gibson, 2007; Unadkat et al., 2017). Furthermore, musicking facilitated enhanced eye contact and touch between the person living with dementia and others, thus making connections across the musicking space (Gardner, 1999; Hammar et al., 2010; Hammar et al., 2011a, 2011b; McDermott, Orrell, et al., 2014; Pavlicevic et al., 2014; Tomaino, 2005). Musicking also promoted non-verbal communication and this created a space in which new ways of meaningful communication could be explored, as below:

Spouse of person living with dementia: ...just being able to be together and enjoy and listen to something we both love is a benefit. [...] There were no words or anything...We didn’t need to talk. The music did enough. (Baker, 2012, p.14).

Overall, musicking provided an opportunity for people living with dementia to connect to others and the environment around them, without the need for words. This connection enabled people living with dementia to feel part of a group culture, which enhanced a sense of togetherness and a sense of security.

2.6.3 Theme 3: Affirming Identity

Within each study in the review, it was evident that each person living with dementia had a musical identity and musical history. Personal preferences for certain pieces, or genres, of music were expressed both verbally and non-verbally, for example by foot tapping, conducting and smiling. Music was also bound to cultural and spiritual identities with many people living with dementia connecting to religious music that was significant in their life. The expression of musical preferences, in combination with the memories that musicking evoked, resulted in care staff and music therapists actively seeking to understand the life history of the person living with dementia (Campbell et al., 2017; Hara, 2013; Tomaino, 2005). In turn, this enabled people living with dementia to strengthen their sense of identity and promoted an understanding of the person that went far beyond a diagnostic label.
This strong affiliation between a person’s life history and their musical preferences resulted in the awakening of memories in people living with dementia. For example, people living with dementia were able to remember past events that were coupled with music, remember lyrics to songs and, in some cases, develop new memories of the musicking activities from week to week. All but two studies (Campbell et al., 2017; McCabe et al., 2015) drew on biographically relevant songs within group musicking activities. The use of familiar, biographically significant songs was twofold: firstly, people living with dementia were able to reminisce about memories associated with these songs and affirm a sense of past-present identity; and secondly, the person’s confidence in their abilities was enhanced through an ability to remember lyrics and melodies.

The shared musical history of many group members allowed people to identify with others who had grown up in the same era. Musicking was therefore able to stimulate memories of times gone by, which people living with dementia shared with others in the same space. This ability to reminisce as a group affirmed a collective identity as this quotation attests:

*Person living with dementia: ... music and singing especially, brings people together, if you are singing then you are sharing in something no matter who you are beforehand because you are all going for it together.*  (Unadkat et al., 2016, p.8).

Furthermore, people living with dementia were able to develop new musical tastes throughout the engagement with music activities. This would suggest that although musicking can be used as a tool to reminisce with a person living with dementia, it is also important to understand that musical preferences evolve over time. Therefore, as the literature reveals, new musical experiences should be explored in order to expose the person living with dementia to new and interesting musical experiences and consequently a new and changing identity as seen in the illustration below:

* [...] one of the popular waltz tunes, “Irish eyes are smiling” started to be known as Arnold’s [person living with dementia] favourite song. I observed the process of how it went from being ‘a song’ to being ‘Arnold’s Song’*  (Hara, 2013, p.155).
Overall, this theme highlights that music enables the person to connect with their past through personal musical preferences and a shared musical history with others. This enabled shared reminiscence, which affirmed a sense of personal and collective identity.

2.6.4 Theme 4: Immersion ‘In the Moment’

People living with dementia appeared absorbed in musicking to the extent that they were “lost in its hearing” (Sixsmith & Gibson, 2007, p.132), appearing happier, more ‘alive’ and less agitated. Although these observable changes in wellbeing were described as immediate, doubts were expressed from care staff and family members about the lasting effects of musicking outside of the musicking space (McDermott, Orrell, et al., 2014; Sixsmith & Gibson, 2007; Tuckett et al., 2015). However, the positive impact that musicking had on the person living with dementia ‘in the moment’ was seen as being as important as any long-term effects on sociability and mood, for example, as these two slices of data attest:

*Many therapists acknowledged they did not know how much staff or family carers noticed sustained communicability following music therapy sessions. Therapists generally seemed to regard meaningful connection with others and normal togetherness that happened during a session more crucial for the well-being of people with dementia than potential long-term effects of therapy* (McDermott, Orrell, et al., 2014, p.712).

*The nature of dementia means that, for those with the condition, the benefit of the sessions is somewhat short-lived as the activity is forgotten in some cases; therefore, the intrinsic value of the sessions becomes most important* (Osman et al., 2014, p.7).

As well as improved mood and communication, music facilitated many embodied reactions which allowed people living with dementia to express themselves and take part in the activity without the need for words. This embodied musical participation resulted in people living with dementia being able to express musical preferences through their bodily movements, such as dancing and/or reaching out for instruments. It also empowered the person living with dementia to express their
enjoyment of musicking, whether this was expressed outwardly, such as by actively engaging with the music therapist, or more subtly, such as through foot tapping and swaying in time to the music (Gardner, 1999; Götell et al., 2002; Hammar et al., 2011a; Hara, 2013; Sixsmith & Gibson, 2007; Tomaino, 2005; Tuckett et al., 2015). Such actions enabled the person living with dementia to enhance their sense of self and strengthen their relationships with others, as well as to perform embodied memories from the past. Two further examples of the bodily responses by people living with dementia to in the moment experiences are shared below:

There were several sessions when Carmen [person living with dementia] was very tired and displayed almost no response. On closer observation, however, I could see that her breathing was synchronised with the rhythm of the music. (Tomaino, 1998, p.60).

The memory exercises, through singing familiar songs, were supported by the rhythm of the songs […] these rhythms entrained their bodies, enabling an almost automatic participation with others. (Hara, 2013, p.223).

[A person living with dementia] requested her favourite piece of music and when it was played, her whole body reacted as she leant back, stretched her neck and closed her eyes. She was completely absorbed in the music and there were tears from her eyes […]. In the interview she explained that the music transported her to another time and place and it made her wish she could fly. (Daykin et al., 2017, p.9).

Overall, this theme highlights the benefits of musicking for the person living with dementia ‘in the moment’ allowing for a multi-sensory experience that enabled an exploration of sound and self.

2.7 Discussion

In recent years, there has been a move away from the view that music is a ‘curative’ intervention for symptoms associated with dementia, and towards a view that music can enhance the wellbeing and quality of life of people living with dementia (Sixsmith & Gibson, 2007). For this review, a comprehensive search of the qualitative literature surrounding the use of musicking with people living with
dementia was conducted. Overall, 21 studies were identified and a thematic synthesis of the qualitative findings revealed a number of emotional, psychological and social benefits for the person living with dementia when engaging with music. These personal benefits were presented under four themes: Taking Part; Being Connected; Affirming Identity; and Immersion ‘In the Moment’.

The first theme, Taking Part, was a common thread running through the literature, emphasising that musicking enables people living with dementia to take part without having to rely solely on cognitive and/or linguistic capabilities. The accessibility of music also enabled people living with dementia to take part in an activity that was failure-free, meaning they were viewed as equals within the musical space. This democratisation of the musicking space enabled the stigma associated with dementia to be challenged, with others involved in the activity able to see beyond the diagnostic ‘label’ of dementia and to the person living with the condition (Batsch & Mittelman, 2012).

This theme also highlighted a number of barriers to musicking, such as control over when and how musicking was engaged with by the person living with dementia. Many people living with dementia, particularly when they enter a care home setting, may not have control over when and how they engage with music or other arts activities. Such activities may be viewed predominantly as entertainment, with care staff and residents anticipating scheduled activities at a set time on a certain day of the week (Basting, Towey, & Rose, 2016). Perhaps thinking beyond music as a scheduled activity, and beginning to explore how musicking can become an integral part of people living with dementia’s day-to-day lives and linked to the person’s biography, the barriers to taking part in musicking can be reduced. Seeking the views of people living with dementia in the design of products which enhance access to music would further enhance the usability and acceptability of such technology (Brankaert, 2016).

The second theme Being Connected highlighted that musicking provided a space for the person living with dementia to be connected: both to themselves, to other people and to the sensory environment. This sense of being connected enabled the person living with dementia to feel a sense of security and a sense of belonging, thus providing an opportunity for them to feel part of a community through the
meaningful social interactions that musicking afforded (Nolan, Brown, Davies, Nolan, & Keady, 2006). As everyone was able to take part as equals, this enabled the person living with dementia to “connect with themselves, to music and then, perhaps...to another person” (Pavlicevic et al., 2015, p.668).

The third theme, Affirming Identity, explored the idea that musicking strengthened the sense of identity held by a person living with dementia. People living with dementia were able to express musical preferences, either verbally or non-verbally, but also developed new musical tastes and preferences across time. The singing of biographically significant music acted as a catalyst for memories for the person living with dementia, allowing them to remember key life events that were interwoven with different pieces, or genres, of music. However, it was the sense of strengthening a sense of identity and creating a meaningful connection with others that appeared more important than the remembrance of particular life events.

The fourth theme, Immersion ‘In the Moment’, highlights the value of embodied musical experiences within the present moment. Although the personal benefits of musicking may not have lasted outside of the musicking space, the immersive, multisensory experience of the moment was still valued greatly by family members, care staff and music therapists. In recent years, there has been a growing body of work that is seeking to understand the benefits of meaningful activity for people living with dementia ‘in the moment’ (Gridley, Brooks, Birks, Baxter, & Parker, 2016). Understanding of ‘in the moment’ experiences, specifically ‘flow’, are also closely linked to the positive psychology movement (Csikszentmihalyi, 1997, 2014a) in which emphasis is placed not only past experiences, but also on the present moment and the future (Hefferon & Boniwell, 2011).

By placing the focus on music for reminiscence purposes alone, the importance of embodied, ‘in the moment’ responses, can be overlooked (Killick, 2016). Musicking can, therefore be seen as a platform for ‘embodied selfhood’ enabling the person living with dementia to strengthen their sense of identity through their bodily agency (Kontos, Hydén, Brockmeier, & Lindemann, 2014). Only by shifting the focus of enquiry towards understanding ‘in the moment’ experiences can we begin to understand the possibilities for music outside the remit of cognitive enhancement or as ‘symptom’ reduction. Through further exploration of the musical bodies of people
living with dementia, we can begin to learn more about how music enables a person living with dementia to connect with those around them, and to interact with the world around them (Phinney, Hyden, Lindemann, & Brockmeier, 2014).

This review has revealed that many music engagement programmes for people living with dementia place a significant emphasis on the shared musical histories of people living with dementia, but there are very few instances of the creation of new music with people living with dementia. Of 21 studies, only two studies explored improvisation and composition with people living with dementia (Campbell et al., 2017; McCabe et al., 2015). Although reminiscence-based singing groups appear beneficial, it is also important to consider how gaining creative control over a musicking project may facilitate enhanced engagement and a sense of agency for people living with dementia. As one person living with dementia in Unadkat et al’s (2016) study expressed:

   All that looking back, it can be a bit mindless maybe, possibly if we were being active and creating something it would be more beneficial, like a sort of new learning for us. (p.8).

Going forward it would seem necessary that, in practice, it is important to explore the use of music beyond simply being a tool for reminiscence purposes. By shifting the focus away from reminiscence and towards the ‘in the moment’ experiences and the creative musical output of people living with dementia, the field may begin to understand the benefits of musicking further. Highlighting the importance of ‘in the moment’ creative engagement to those funding, facilitating and taking part in musicking programmes may also lead to more nuanced and participatory approaches to evaluation.

The second objective of this review was to understand the involvement of people living with dementia in the research surrounding their musicking experiences. Within the identified studies there were relatively few examples of active participation in research by people living with dementia. Many of the studies relied on observation, or reports from family members, care staff, and music therapists meaning the voices of people living with dementia are largely absent from this research area. The drive to involve people living with dementia in research has
significantly increased in recent years, with it no longer seen as being acceptable to rely on proxy accounts (McKeown, Clarke, Ingleton, & Repper, 2010). The qualitative literature surrounding the use of musicking in dementia studies needs to make a similar move towards enhanced inclusion of people living with dementia in the conduct and presentation of future research (Gridley et al., 2016).

2.8 Summary and Implications for this Study

The qualitative literature surrounding the personal benefits of musicking for people living with dementia has revealed that the benefits of musicking go far beyond the reduction of the ‘behavioural and psychological symptoms of dementia’ and enable a person living with dementia to take part in meaningful and stimulating activity. However, there is still a dearth of research which seeks to actively involve people living with dementia in reporting their own subjective experiences when musicking. This means that this research area is still dominated by proxy accounts and so it is essential that new methods are explored which seek to actively include the voices of people living with dementia in this area of research.

What is also evident from the literature is the idea of ‘in the moment’ experience and how valuable music programmes are seen to be, even if the benefits do not extend past the end of a musicking activity. To date, there has been little research conducted into ‘in the moment’ experiences, and it is therefore important to consider how we might understand what the ‘in the moment’ benefits of music are, in order to build more appropriate methods of assessment which can capture a more holistic account of experience than ‘before and after’ approaches allow for. Furthermore, the evidence to date has yet to consider the role of the body in the experience of musicking, creating a general disembodiment of experience for people living with dementia.

This review, therefore, indicates a gap in the literature surrounding the ‘in the moment’ sensory and embodied experiences of people living with dementia when they engage with music. Furthermore, the review highlights that many qualitative studies seek proxy accounts of experience, rather than hearing the experiences of people living with dementia first-hand. This highlights the importance of considering methods which do not rely purely on verbal communicative abilities, which may
allow people living with dementia to have more voice within this research area. In the next chapter I will show how this literature has informed the development of the methodology and methods of study adopted for this study.
CHAPTER 3. METHODS OF STUDY

3.1 Introduction

The purpose of this chapter is to provide information about the methods of study that were adopted in order to understand the ‘in the moment’ embodied and sensory experiences of people living with dementia who were engaging in Manchester Camerata’s *Music in Mind* programme. This chapter will begin by presenting the theoretical rationale for the study, presenting the positive psychological principles which underpin this study. Next, the *Music in Mind* programme which is the context for the research will be outlined, highlighting the key principles and features of the programme. Following this, the study aims and objectives will be defined, and an overview of the decision to change from a participatory action research project to a multiple-case study design will be discussed. The chapter will then detail the multi-method approach to data collection within a multiple-case study design, with a particular focus on the use of video-methods in the context of dementia studies. The chapter will then describe the working methods of the research, presenting the characteristics of the recruited participants and the way in which the methods were used and adapted when in the field. The practical elements of collecting the video data and conducting the video-elicitation interviews will also be discussed, including the consenting procedures used throughout the research. Finally, the chapter will outline the approaches to data analysis that were used to develop individual case studies as well as a cross-case analysis of the data.

3.2 Theoretical Rationale for the Study

The findings of the literature review presented in Chapter 2 suggest that the benefits of musicking go beyond simply reducing ‘behavioural and psychological symptoms of dementia’, for example, and can promote an environment where people living with dementia have an opportunity to connect to themselves and to other people whilst taking part in meaningful activity (Dowlen et al., 2017). These experiences are not easily explained using a biomedical discourse, which suggests that music benefits the person living with dementia in more ways than reducing ‘symptoms’. It is therefore necessary to consider alternative theoretical frameworks in which the
person living with dementia, and their experiences, relationships and environment contribute to a positive musical experience.

This study was underpinned by a positive psychological approach (Seligman, 2011; Seligman & Csikszentmihalyi, 2000), placing emphasis on how music can contribute to a meaningful and fulfilling environment for a person living with dementia rather than focusing on the amelioration of the ‘behavioural and psychological symptoms of dementia’. Positive psychology has been defined by Seligman and Csikszentmihalyi (2000) as:

*A science of positive subjective experience, positive individual traits, and positive institutions [which] promises to improve quality of life and prevent the pathologies that arise when life is barren and meaningless.* (p. 5)

The positive psychology movement does not seek to undermine what is known about different conditions and pathologies, but rather seeks to complement this work by providing understanding of how individuals can live well, and even flourish, in the face of adversity. Flourishing has been defined as “[living] within an optimal range of human functioning, one that connotes goodness, generativity, growth and resilience” (Fredrickson & Losada, 2005, p. 678. In the context of the lived experience of dementia, a focus is often placed upon what is ‘lost’ as a consequence of the condition, and there is very little work that seeks to understand the ways in which positive personal, social, relational and societal factors may influence the wellbeing and flourishing of people living with dementia (Dupuis, Kontos, Mitchell, Jonas-Simpson, & Gray, 2016; Reed et al., 2017).

Recently, Clarke and Wolverson’s (2016) edited text *Positive Psychology Approaches to Dementia* acted as a catalyst in this context, with chapters covering a range of positive psychological attributes and emotions such as humour (Clarke & Irwin, 2016), resilience (Harris & Carroll, 2016), and creativity (Killick, 2016). Whilst this theoretical shift remains in its infancy, this thesis will build on this emerging evidence-base and will seek to explore the experience of living with dementia, and the intersection with musicking, through a positive psychological lens.

There have been a number of models and frameworks that have been developed in order to understand the role of different positive psychological factors on wellbeing.
and flourishing. For example, Seligman’s (2011) PERMA model outlines the interactions between a number of positive psychological factors (i.e. Positive emotions; Engagement; Relationships; Meaning; and Accomplishment) and their relationship to individual and collective wellbeing. Although this model has been applied within a number of different contexts, such as understanding student wellbeing (Kern, Waters, Adler, & White, 2015), as well as music practice and participation in the general population (Croom, 2015), there are some who suggest that the PERMA model neglects the role of the body within the experience of happiness and wellbeing (Hefferon, 2013). It has therefore been proposed that positive psychology needs to shift from being a “neck up focussed discipline” (Hefferon, 2013, p. 176) to one that incorporates the body into its understanding of human happiness and flourishing (Hefferon & Boniwell, 2011).

As has been discussed in Chapter 2, there has been a general disembodiment of experience in the music and dementia field, leaving the body a neglected source of information surrounding subjective experience. Therefore, by combining an understanding about the impacts of music from a positive psychological perspective and as it then intersects with the body in the sensorial experiences of people living with dementia, a new theoretical frame can emerge. Accordingly, it is important to consider the role of the body as an additional factor that should be explored alongside the factors of wellbeing that have been proposed by authors such as Seligman (2011) and Jayawickreme, Forgeard, and Seligman (2012). This thesis will therefore seek to understand the ‘in the moment’ experiences of people living with dementia through a positive psychological lens which incorporates the body into understanding this topic area. The context through which I was able to examine the ‘in the moment’ experiences was Manchester Camerata’s *Music in Mind* programme. The following section will present an overview of Manchester Camerata’s *Music in Mind* programme, introducing the key principles of the programme, and then presenting the specific features related to the 15-week programme which was the context for the study.
3.3 *Music in Mind and the Research Setting*

*Music in Mind* is a music-therapy based programme for people living with dementia and their family carers, or those supporting them in a professional capacity, which is co-facilitated by a music therapist and a Manchester Camerata orchestral musician. The aims of *Music in Mind* are to:

i. Improve the quality of life of people living with dementia.
ii. Develop musical interaction.
iii. Improve the ability to communicate (both verbally and non-verbally).
iv. Reconnect relationships between people living with dementia and their family carers and/or to develop relationships between other people living with dementia or those supporting them in a professional capacity.
v. Develop the skills of family carers and/or those supporting people living with dementia in a professional capacity to use improvisational techniques outside of the *Music in Mind* sessions.

*Music in Mind* was first piloted in Greater Manchester in 2012 in a community setting (Habron, 2013a) and since its inception has engaged with over 1000 people living with dementia in the North West of England. *Music in Mind* has been delivered in community settings, day care centres, care homes and hospital wards. *Music in Mind* began as a 10-week programme, but was extended to a 15-week programme due to requests from the project practitioners, and in response to the early evaluations of the programme (Habron, 2013a) which suggested that a group dynamic was able to be built by week seven of the programme. Practitioners expressed that a 10-week programme appeared to come to an abrupt end, expressing that the programme had only just begun before the idea of ending was being introduced. Thus, by extending the programme to 15-weeks, it provided the optimal opportunity for group dynamics to develop, space for individual growth, and then time to bring the programme to an end.

There are a number of key principles that underpin *Music in Mind*. These principles place the person living with dementia centrally within the programme, enabling active participation through improvisational techniques. The following section will
provide an overview of the key principles of Music in Mind: improvisation and creativity; choice; and co-facilitation.

The first key principle of Music in Mind is the nurturing of musical improvisation and creativity. Music in Mind is based around the principles of improvisational music therapy (Bruscia, 1987) in which the music therapist supports a client using instruments and voice to create unique musical interactions through musical improvisation (see also: Ruud, 1998). The combination of an improvisational approach to musicking and the co-facilitation of sessions by a music therapist and Manchester Camerata musician is what differentiates Music in Mind from other programmes of music currently being delivered with people living with dementia (e.g. Singing for the Brain, Playlist for Life, unstructured musical activity). Whilst there are other programmes which use the principles of improvisation within sessions (see for example: Wigmore Hall, 2018), Music in Mind is the only programme to combine the expertise of a music therapist and an orchestral musician, who bring different skills and experience to the music-making process. The following paragraphs will describe how these principles are enabled within the musicking space.

During each Music in Mind session, people living with dementia have access to an array of tuned and untuned percussive instruments, such as maracas, tambourines and hand bells (see Appendix 3 for an overview of instruments available to group members), which are placed on an instrument table placed at the centre of a circle of chairs. This enables people living with dementia to see the different instruments available to them, but also enables everyone to see one another. This creates an atmosphere of creative equality as it enables each person to be seen and to see the contributions of other members of the group. Instruments are brightly coloured and inviting but are not children’s instruments, so as to give respect to the individuals in the group and the music they make. A number of the instruments are also chosen because they originate from different countries (e.g. castanets; lyre) which can enable exploration and storytelling through supported improvisations. As can be seen in Appendix 3, the instruments on offer to group members promote curiosity and imagination in learning how to use these instruments to contribute within the music.
Project practitioners will use a number of improvisational techniques in order to encourage musical participation by people living with dementia. The improvisational techniques include: musical games; call and response exercises; repeating and building upon musical phrases; and providing musical accompaniment. There are often familiar songs that are sung by the group but these are instigated by participants rather than being predetermined by the project practitioners. Practitioners thus incorporate these songs within sessions but attempt to encourage the participants to improvise around what is familiar to them.

The second key principle of Music in Mind is choice, which enables the opportunity for people living with dementia to make active musical decisions. The person living with dementia has access to a number of instruments that they can choose to play, or not. Project practitioners support the person living with dementia to play but do not force any engagements or interactions. This means that sometimes it takes a number of weeks before a person living dementia is able to feel comfortable with the fact they are in control of the process, perhaps through developing a sense of trust and confidence within the musicking space. Practitioners also support family carers and staff carers in developing strategies that do not rely on manipulating the bodies of the people living with dementia they support, helping to nurture a sense of musical independence and allowing the person living with dementia to develop their own sense of musical and non-musical identity.

The third key principle of Music in Mind is co-facilitation. Music in Mind is co-facilitated by a qualified music therapist and a Manchester Camerata orchestral musician. The combination of the therapeutic skill of the music therapist with the high level musical skill of a professional musician is what sets Music in Mind apart from other music programmes for people living with dementia (Habron, 2013b). It has been proposed that the combined skill set of a music therapist and professional musician may bring about the maximum possible benefits for people living with dementia when they engage in musicking (van der Steen et al., 2017). This principle of co-facilitation therefore enables a musicking space which is defined by creativity rather than specific therapeutic outcomes.

When looking at the broader music for health literature, it appears as if Music in Mind bridges the gap between ‘Music Therapy; and ‘Community Music’
(MacDonald, 2013). MacDonald (2013) suggests that music therapy places emphasis on the therapeutic relationship between therapist and client, focusing on positive outcomes over a set ‘intervention period’; whereas community music emphasises promoting “opportunity for creative expression in informal setting” (p.2), with pre-determined outcomes becoming secondary to creativity and musical expression. The co-facilitation principle thus enables the project practitioners to address the objectives of Music in Mind, while keeping creativity and flexibility central within the delivery of the programme.

Overall, the principles of Music in Mind allow for a space where the person living with dementia is given choice and the opportunity to be creative within the sessions. Improvisation is supported by the project practitioners, enabling the person living with dementia to situate themselves in a supportive musicking environment where their musical contributions are heard and responded to. The following section will provide an overview of the format of a typical Music in Mind session.

Each Music in Mind session follows a flexible format with the improvised music-making being bookended between social time at the beginning and end of a session. The social time, which typically lasts half an hour, provides an opportunity for group members to have refreshments and to socialize with other members of the group. Before group members arrive, the room is set up with a circle of chairs around the central instrument table. The practitioners position themselves within the circle of chairs as a non-verbal means of highlighting musical equality rather than in a position that would suggest it is a musical performance which separates ‘audience’ and ‘performer’. During the social time, group members and project practitioners will take their seats in the circle, with the instrument table and the other group members clearly visible to all in the musicking space.

Project practitioners typically initiate the musicking component of the session by introducing the Hello Song, which is consistently introduced across the duration of the programme to allow for a non-verbal signal that the music-making is beginning. The typical format of the Hello Song is in call and response format, allowing for group members to listen and repeat back the lyrics to the song, enabling the song to be learned without the need for lyric sheets or musical notation. Figure 2, below,
presents the Hello Song which was used in the context of the *Music in Mind* programme that was followed as part of the research study.

Figure 2: The Hello Song

<table>
<thead>
<tr>
<th>Chorus</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Call:</strong> Well Hello</td>
</tr>
<tr>
<td><strong>Response:</strong> Hello</td>
</tr>
<tr>
<td><strong>Call:</strong> Well Hello</td>
</tr>
<tr>
<td><strong>Response:</strong> Hello</td>
</tr>
<tr>
<td><strong>Together:</strong> It’s nice to see you. Hello, Hello, Hello</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Verse</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Call:</strong> Hello [name of group member]</td>
</tr>
<tr>
<td><strong>Response:</strong> I’ve (you’ve) come to sing and play</td>
</tr>
</tbody>
</table>

[Repeat until each member of the group has been welcomed by name]

The Hello Song is then followed by the creative music-making component of the session, which provides an extended time period for people living with dementia to explore the different instruments on offer to them, creating new music through supported improvisation, improvisation games and improvising around familiar repertoire.

The musicking component of the session is brought to a close by the project practitioners using the Goodbye Song. The decision to bring the session to an end is typically driven by the time constraints of the session as taxis may be waiting to pick up group members, or the project practitioners may need to travel to a separate venue to deliver another *Music in Mind* session. The practitioners listen carefully to the contributions of the group members to ensure that no one is cut off in their contributions due to the time constraints of the programme. The Goodbye Song used by the project practitioners within the research context is presented in Figure 3.

. 
In total sessions last approximately 90 minutes, with 60 minutes allocated to the music-making component and 30 minutes allocated to social time before the session.

This section has provided an overview of the key principles of *Music in Mind* and the typical format of a session. This information provides a backdrop to the research study, which used *Music in Mind* as context in which to study the ‘in the moment’ embodied experiences of people living with dementia. The following section will provide an overview of the study aims and objectives, and then will present the methods that were adopted in order to address these.

### 3.4 Study Aims and Objectives

The primary aim of the study was to develop an in-depth understanding of the ‘in the moment’ musical experiences of people living with dementia when engaged with *Music in Mind* as a creative music-making programme.

The objectives of the research were to:

i. Follow one community-based *Music in Mind* programme over 15-weeks in order to develop an understanding of the range of sensory and embodied responses to live music created and experienced by people living with dementia.
ii. Use a range of creative social research methods within a multiple-case study design, including visual research methods, as part of a flexible approach to research that ensures the maximum feasible participation of people living with dementia, their family members and project practitioners.

iii. Define measurable elements of ‘in the moment’ experience which could be used as a basis for a future music assessment tool.

iv. Explore my role as a participant-observer and how this impacted on data collection, interpretation and presentation.

The decision to follow a community-based *Music in Mind* group was twofold:

i. There has been very little exploration of community-based music programmes for people living with dementia, with the majority of research having been conducted within care home settings (Elliott & Gardner, 2018).

ii. It would be possible to control the context in which the video recording took place, ensuring that only those recruited into the study were captured on video. This would have been more difficult to control in a care home or hospital ward environment due to *Music in Mind* typically having to take place in shared spaces.

### 3.5 Methodology and Research Methods

This research study sought to implement a range of creative social research methods within a multiple-case study design in order to explore the ‘in the moment’ embodied and sensory experiences of people living with dementia engaging with a creative music-making programme (*Music in Mind*). The decision to use creative research methods was based around the findings from the literature review presented in Chapter 2, which highlighted a reliance on traditional qualitative research methods (i.e. semi-structured interviews and observations) that were potentially unsuitable to those who had challenges in expressing their experiences verbally (Phillipson & Hammond, 2018). Creative research methods have been defined as: “the physical making of something, leading to some form of communication, expression or revelation” (Gauntlett, 2007, p. 25). This definition highlights the importance of the
non-verbal in communicating elements of experience. Creative research methods do not need to be newly formulated research methods, but can adapt the more traditional research methods to address complex questions, especially in hard to access groups (Kara, 2015). This section will begin by providing an overview of multiple-case study research, and will then present the creative visual research methods that were used within this case study approach.

This study used a multiple-case study design to gain an understanding of the ‘in the moment’ musical experiences of people living with dementia. Multiple-case design research studies seek to explore both the factors that are unique to a case, as well as provide opportunity for cross-case analysis in order to understand common features of experience (Stake, 1995, 2013). It has been proposed that a multiple-case study design enables a researcher to gain a more in-depth understanding of a phenomenon than is possible in a single case study because of the possibility to explore the phenomena across different individuals, contexts or processes (Chmiliar, 2010). This means that a multiple-case study design was well suited to this study, as it allowed for a holistic exploration of ‘in the moment’ experiences, focusing on both the individual people living with dementia, and collective group experiences.

As has been discussed in the Background to the Thesis (p. 13), the methodological approach to the research changed as a result of the demands of the research programme. The original research strategy chosen by my supervisory team to address the research questions was a participatory action research approach to inquiry (Reason & Bradbury, 2007), but this was changed a year into PhD to a multiple-case study design (Stake, 1995, 2013). It became necessary to change the approach to enquiry once I took over and immersed myself in the study as it became obvious quite early on in the study that the context of Music in Mind, combined with the life stories of the group members, needed further exploratory work in order to gain an in-depth understanding about the embodied and sensorial experiences of group members who were living with dementia. This was particularly evident when examining the literature surrounding the use of music with people living with dementia as discussed in Chapter 2. Although the term ‘in the moment’ was discussed within several papers, there had yet to be any studies which sought to directly explore such experiences. Therefore, a multiple-case study design (Stake,
1995, 2013) was chosen due to the shift in focus of the research, allowing for an in-depth holistic approach to understanding the ‘in the moment’ experiences of people living with dementia when they engaged with music to address this gap in knowledge which had been identified through the literature and multidisciplinary discussion with my supervision team.

There are a number of different approaches to case study research, and it is important to distinguish between the different approaches as they have different philosophical positions (Boblin, Ireland, Kirkpatrick, & Robertson, 2013). A researcher should therefore consider the aims of their research and their own worldview when considering the most appropriate approach to case study research (Harrison et al., 2017). There are three widely used approaches to case study research, that of: Yin (2014); Merriam (1988); and Stake (1995, 2013). Each approach has a different philosophical positioning with Yin (2014) most closely aligning with realism; Merriam (1988) with pragmatic constructivism; and Stake (1995, 2013) with constructivist and interpretive orientations. Stake’s (1995, 2013) position most closely aligns itself with purely qualitative case study research, enabling the case study researcher to gather multiple subjective views on a topic area in order to interpret the reality of the case. Stake (1995, 2013) also advocates the use of ‘thick description’ in order to provide in-depth description and interpretation of behaviours, interactions and processes within a given context (Ponterotto, 2006) in order to illuminate the uniqueness of each case. Although this study adopted Stake’s (1995, 2013) approach to studying the case, there are a number of common features of case study research that are consistent across the three most commonly used approaches. The following section will provide an overview of the key features of case study research, and how these were considered in addressing the research aims and objectives.

Case study approaches to research allow for an in-depth exploration of a given unit of interest, whether it is an individual, a group of individuals, an organisation or a programme (Stake, 1995, 2013; Yin, 2014). In case study research, the researcher situates themselves within the real-life context of the case in order to gain an in-depth, holistic understanding of processes, as well as interactions that influence the case. This is achieved through the use of multiple research methods and gaining
multiple perspectives (Simons, 2009). Stake’s (1995) approach to conducting case study research places emphasis on understanding the case within the context it occurs within, allowing for an exploration of processes and contextual factors.

Stake (1995, 2013) also distinguishes between single and multiple-case studies. A single case study considers the in-depth exploration of an individual, context or process whereas a multiple-case study explores a number of such cases (e.g. individual context, or process), providing opportunity for understanding the uniqueness of each case, as well as common features across-cases. A multiple-case study design (Stake, 2013) was implemented within this research study as it enabled both the exploration of the subjective experiences of people living with dementia but also allowed for a cross-case analysis, seeking to understand what factors were translatable across group members. The exploration of both individual experience and experiences that were common across group members was vital for gaining a holistic account of ‘in the moment’ musical experiences, which could be used to develop a new means of measuring such experiences.

It can be particularly challenging, especially for those who have not conducted case study research before, to determine appropriate units of analysis within case study research (Baxter & Jack, 2008). It has been proposed that a unit of analysis can be defined as “a phenomenon of some sort occurring in a bounded context” (Miles & Huberman, 1994, p. 25). The bounded context within this research was predetermined as Music in Mind due to the research study being an ESRC funded CASE studentship. However, even though the context of the case was not sought out based on specific characteristics determined by myself as a researcher, Music in Mind provided a context to understand a programme which differs from the majority of music projects for people living with dementia because of its focus on improvisation and creativity, rather than reminiscence-based music activities.

I spent a great deal of time considering what each ‘case’ would be in the context of this research study. It was important for me to understand the individual subjective experiences of people living with dementia, but also seek to understand the factors that were shared, and could be measured across group members, including the perspectives of family carers and project practitioners. As I wanted to privilege the voices of the people living with dementia in the research, I determined that each
person living with dementia would form a case, but within each case I would explore relational and group factors in order to build a dynamic approach to understanding ‘in the moment’ experiences. This decision was made because it was anticipated that it would be difficult to disentangle the experiences of others from each case study due to *Music in Mind* being a group rather than solo musicking activity.

This section has provided an overview of multiple-case study research methodologies, and the key decisions that I made regarding the approach to case study that was implemented, as well as defining each case. The following section will provide an overview of the multiple research methods which were used within the multiple-case study approach adopted for this study.

### 3.6 Research Methods

An essential component of case study research is the use of multiple data sources which can allow the researcher to gather multiple perspectives on the case that is under investigation (Flyvbjerg, 2006; Merriam, 1988; Stake, 2013; Yin, 2014). The data collected as part of a case study can be purely quantitative, qualitative or use a mixed-methods approach. This study used purely qualitative methods in order to understand the ‘in the moment’ experiences of people living with dementia because the focus of the research was on understanding subjective ‘in the moment’ experiences rather than seeking to quantify changes in ‘symptoms’ over time. Qualitative methods, particularly video methods, provided a platform to explore these experiences from the perspective of the person living with dementia, their family carer and project practitioners. The study utilised three research methods under the multiple-case study framework: video-observation; video-elicitation interviews; and participant diaries.

Another key component of case study research is the understanding of phenomena from multiple perspectives, in order to preserve multiple realities (Stake, 1995). This is important in being able to triangulate the findings across the multiple perspectives held by participants. This study drew on a range of research methods which allowed multiple perspectives to be collected: the perspective of the person living with dementia; the perspective of the family carer; the perspective of the project practitioners; and the perspective of myself as a participant-observer. Owing to the
number of perspectives within this research, it was essential to choose research methods that were accessible to all research participants. Stake (1995, 2013) advocates the use of interviews and observations as the primary means of gathering data within case study research. Although these research methods are well established within case study research, it was also important to consider how more creative research methods could be used in order to ensure the research was as accessible as possible to all group members (Dowlen et al., 2017; Simons, 2009). Thus, this study drew upon a number of creative visual research methods in order to ensure that people living with dementia could actively contribute to the research, even if their capacity for verbal language had diminished.

The next section will begin by presenting an overview of the use of visual methods in the context of dementia research, as well as discussing the ethical concerns that need to be taken into consideration when using video with this population. Following this, the situated research methods (video-observation; video-elicitation interviews and participant diaries) used in this study will be discussed. This section will also present information relating to researcher reflexivity, and how this was examined throughout the duration of the research project.

3.6.1 Visual Research Methods and Dementia

In recent years, the use of visual methods within dementia studies research has increased in prevalence (Keady, Hydén, Johnson, & Swarbrick, 2017). The use of visual methods is considered to be particularly important in the context of dementia studies as they facilitate the opportunity for people living with dementia to actively engage in the research process without the need to rely on verbal communication skills (Cook, 2002). There are a number of research studies that have sought to understand complex social phenomena using visual methods such as photo-elicitation (see for example: Brorsson, Öhman, Lundberg, & Nygård, 2016; Shell, 2014), participatory video (see for example: Capstick, 2011; Ludwin & Capstick, 2015) and video-observation (see for example: Kindell & Wilkinson, 2017).

A number of researchers in the area of dementia studies have begun to use video as a means of examining the lived experiences of people living with dementia (see for example: Cook, 2002; Örulv, 2010). Video provides an opportunity for those even in
the more ‘severe’ stages of dementia to be active research participants, allowing for the exploration of emotional, sensorial and bodily experiences in the context of specific events (Campbell & Ward, 2017) or within the context of everyday life (Kindell & Wilkinson, 2017). Video is effective in recording such experiences as it allows for a multidimensional account of individuals’ lived experience (Spencer, 2010) as the video cameras capture combined audio and the visual. This means that even those whose verbal communication skills have diminished as a result of their dementia can still have a ‘voice’ in the research process.

Of particular importance to this research study were the sensory and embodied experiences of people living with dementia when they engage with music. There have been a number of research studies that have sought to understand the embodied and sensory experiences of people living with dementia using video. Campbell and Ward (2017), for example, used a video ethnographic approach to understand the role of hairdressing in dementia care settings. The use of video within this context enabled the researchers to understand the importance of appearance-related processes (such as hair styling and shaving) in the lives of people living with dementia. Campbell and Ward (2017) proposed that the use of video within their research enabled them to adopt a multi-dimensional approach to data collection, where both the visual narratives of people living with dementia could be shown, as well as their relational interactions and connections to the hair-dressing environment. This meant that those who may have had difficulty expressing their experiences using spoken narratives could still contribute data to the research project, thus enabling the experiences of people living with dementia to be studied through what was shown, rather than having to rely solely on verbal narratives (Kontos, 2004, 2005; Lyman, 1989).

Another key reason for the use of video methods within this study was determined by the desire to understand the ‘in the moment’ benefits of music for people living with dementia. Campbell et al. (2017) suggested in their evaluation of *Music in Mind* that the use of video and multi-media data could be used to measure such ‘in the moment’ experiences. Video is particularly useful in understanding such ‘in the moment’ experiences as it is a permanent, multisensory account of a given situation (Campbell & Ward, 2017). The use of video in the context of the current research
study would therefore allow for the in-depth exploration of ‘in the moment’ experience as it would allow for a permanent record of the music sessions and could be reviewed outside of the field setting (Cook, 2002; Kontos, Miller, Mitchell, & Stirling-Twist, 2017). This is not to say that video data would provide an objective account of the experiences of the people living with dementia in the group, but it allowed for a more holistic exploration of the data compared to traditional observational methods (Algar, Woods, & Windle, 2016).

The current research study adopted two visual research methods within its design: video-observation and video-elicitation interviews. These two methods will now be discussed in more detail.

### 3.6.2 Video-Observation

To date, there have only been a handful of studies within the music and dementia literature that have used video as a means of conducting systematic observations of people living with dementia when they engage with music (see for example: Hammar et al., 2010; Jones, Sung, & Moyle, 2015; Ragneskog, Asplund, Kihlgren, & Norberg, 2001). However, the majority of these studies have used formalised observational tools, such as the Facial Action Coding System (Ekman & Rosenberg, 1997) and Dementia Care Mapping (Bradford Dementia Group, 2005), in order to ‘code’ for the existence (or non-existence) of certain behaviours using a ‘before and after’ music approach. This style of observation limits scope of the research to behaviours that fall into predefined categories, rather than allowing for an in-depth exploration of the individual’s experience (Cook, 2002). This means that only predetermined factors are investigated rather than allowing for a more open exploration of the complex factors that influence experiences during musicking.

Considering one of the primary aims of this research was to understand the ‘in the moment’ experiences of people living with dementia, unstructured video-based observation was used as a means of developing a holistic account of experience within the context of Music in Mind. Video-based observation contributes to a more multisensory account of a given context as it enables the researcher to capture more detail surrounding behaviours, processes, and interactions, particularly when there is more than one individual to observe (Asan & Mantague, 2014). As Music in Mind is
a group-based programme, and I was the only researcher, it seemed that video-based observation would provide a platform from which I could observe the group as a whole rather than having to focus my attentions on one particular individual at a time.

I therefore situated myself with three cameras in the context of the 15-week *Music in Mind* programme as a participant-observer in order to capture the ‘in the moment’ multisensory experiences of people living with dementia when they engaged with the programme. I decided that my role within the group would be that of a participant-observer, meaning I would have a dual role by actively taking part in the *Music in Mind* sessions as well as being responsible for the collection of video data. I believed that situating myself in the group, rather than being an ‘outside’ observer would firstly help me to develop rapport with group members as I would be part of the group culture (Oswald, Sherratt, & Smith, 2014). My positioning in the circle would also enable a deeper understanding of cross-circle dynamics which would not be possible to observe in the footage alone. This facilitated a platform for understanding the complex interactions and experiences had within the musicking space (Labaree, 2002). Furthermore, being present as a participant-observer allowed me to gain an understanding of my own embodied and sensory experiences, and how these experiences influenced my interpretation of the data.

The particulars surrounding working details of this method within the context of the *Music in Mind* programme can be found in the data collection section of this chapter on page 100.

### 3.6.3 Video-Elicitation Interviews

Video-elicitation interviews use video of a given context or interaction to obtain deeper discussion about a given experience than would be granted by a traditional research interview (Henry & Fetters, 2012). Video-elicitation interviews have a number of advantages over traditional interviews, with research demonstrating that video can act as a prompt to remind participants about key elements of experience, or enabling people to re-live their experiences within the context of the research interview. Video-elicitation interviews have also been demonstrated to enable non-verbal responses in the interview setting to be acknowledged and interpreted. For
example, Morris, Clayman, Peters, Leppim, and LeBlanc (2015) used video-elicitation interviews as a means of understanding communication strategies that were preferred by persons with aphasia. They found that persons with aphasia were able to communicate using non-verbal cues within the video-elicitation interviews even though they had language-related impairments and would, for example, point at the video on screen in order to indicate aspects of their experience. Thus, video-elicitation interviews provided a platform for revisiting the musical encounters with people living with dementia, as well as providing an opportunity to explore the non-verbal and embodied reactions to video as a means of understanding experience.

Another advantage of video-elicitation interviews is that they allow for a great deal of control from the participants, as they are instructed to stop the video when there is an element within the scene that they would like to discuss (Flower, 2014). This means that the researcher is not imposing set questions on the participant, rather the participant is completely in control of what they believe is significant in the video. This is important within the context of this study as the majority of research conducted to date involves people living with dementia as passive, rather than active, contributors in the research process in musicking studies (Dowlen et al., 2017). It was also noted, that even if the person living with dementia was unable to stop the video themselves, their embodied responses to the video could be observed and interpreted within the context of the interview setting.

As one of the key objectives of the research was to enable the maximum feasible participation by people living with dementia in the research, it was fundamental that the interpretation of the findings should be through the lens of the Music in Mind participants, rather than relying solely on researcher-led interpretations of the data. Therefore, it was imperative that the video could be used to stimulate discussion with the research participants, so that data analysis could be guided by the experiences of participants rather than simply by my own interpretation of the video (Kristensen, 2018). I therefore sought to conduct two video-elicitation interviews with each participant enrolled on the 15-week Music in Mind programme. Details surrounding the application of the method within the context of the research can be found on page 104.
3.6.4 Participant Diaries

The third method that was used in the research project was the use of participant diaries. Solicited diaries, written for the purpose of research, are argued to be a means of capturing the experiences of thoughts, feelings, emotions and reflections over time (Bartlett & Milligan, 2015). Diaries have also been suggested to be effective in eliciting information regarding bodily and sensorial experiences (Bartlett & Milligan, 2015), especially when participants have the opportunity to review video and audio of a given event (Pink, 2007). Diary methods were therefore used to complement the video-based observation and video-elicitation interviews and elicit further reflection on the multisensory and embodied experiences of the people living with dementia in the group.

There are many examples, particularly in health research, where diaries are used as structured means of logging predetermined ‘symptoms’ (Elliot, 1997), but it is only in recent years that diaries as narrative accounts of experience are becoming more common (Milligan, Bingley, & Gatrell, 2005). As this study sought to understand experience over the existence of particular ‘symptoms’, it was deemed necessary to keep the diaries as broad as possible to enable the participants to record their own personal reflections, which were not guided by any predefined categories. Therefore, diary entries were guided by three broad questions, allowing participants to provide as much or as little detail as they wished:

i. What happened during this Music in Mind session?
ii. What are your reflections on what happened during the session?
iii. Are there any moments that were particularly poignant to you, and if so, why?

In the context of this research study, diaries were used by project practitioners and family carers as a means of reflecting on the programme outside of the session time or video-elicitation interview. The diary method was chosen as the method had been shown to have some success within previous Music in Mind evaluations (New Economy, 2014) and had been shown to provide space for the project practitioners and family carers to reflect on their experiences of the programme. The particular type of diary used within the context of this research study was an unstructured...
event-based diary as participants were asked to complete the diary at their earliest convenience after each *Music in Mind* session. This meant that the diaries were used as a means of writing weekly reflections about the sessions rather than capturing the everyday life experiences outside of the sessions.

The diary was placed in a research pack for the project practitioners and family carers, including a copy of the information sheets and an A5 notebook to record their thoughts. In the front of the notebook there were instructions and the questions to guide diary entries. Diaries were not monitored throughout the duration of the project, but rather collected once the *Music in Mind* programme had finished and participants had taken part in their video-elicitation interviews. This was intended as a means of allowing participants to have a platform for expressing aspects of their experience that they maybe did not feel comfortable sharing during the group or within interviews (Milligan et al., 2005). It also allowed a certain level of control over what family members and project practitioners chose to disclose in person, and what they chose to share when they had control over what they wrote.

### 3.6.5 Researcher Reflexivity

My own reflexivity was a vital part of the research process, enabling me to examine how my own life experiences and biases may have impacted on the data collection, analysis and write-up of the research (Krefting, 1991; Tracy, 2010). The process of reflexivity is vitally important within qualitative research due to the central role of the researcher in interpreting the subjective experiences of others. Reflexivity has been defined as:

*The process of a continual dialogue and critical self-evaluation of the researcher’s positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome.*

(Berger, 2015, p. 220).

Through reflexivity, the researcher acknowledges their centrality throughout the research process by understanding their own preconceptions on the world and how this may have influenced on the data collection and analysis processes (Pillow, 2003). Reflexivity is not an attempt to make research more objective, but allows the
researcher to be aware of and understand their own interpretations and representations of the data as a result of what they bring with them from their own life experiences, values and feelings (Pink, 2013). Researchers should be aware of how their personal characteristics, such as age, gender, ethnicity and class relate to their research (Berger, 2015), and how these factors contribute to the produced meanings and knowledge that is produced as a result of engaging with a specific group of people in a particular context (Pink, 2013).

Reflexivity was deemed as particularly important within this research context as I was a participant-observer taking part in the Music in Mind session as well as making observations about the impacts of the programme on the group members with dementia. I used reflexivity as a means of understanding my role in the collection of the data, as well as in acknowledging how my own biases, beliefs and personal experiences may have influenced my interactions with participants, the knowledge generated and the interpretation of the data (Berger, 2015).

Before entering the field I engaged in a reflexive practice exercise recommended by Simons (2009) in which I thought about how my own personal background and life experience may influence the collection and analysis of the data. I thought about the factors relating to myself and how this might influence the research process and my interaction with the group participants. The following section outlines the key factors which I reflected on during this reflexive practice exercise:

1. I am White-British and middle class.

   Many of the areas in Manchester which participants were drawn from are deprived areas in which there is a lot of poverty. The fact that I am from a middle-class background may influence the rapport that I am able to develop with participants as they may not be as trusting of someone who has not come from the same background as them, or may take more time to warm up to me.

   My White-British ethnicity may also be a barrier to rapport with those of different ethnicities. Group members from different ethnicities may not be as willing to open up about their experiences due to their own life experiences. My interactions with music in my own life may also be significantly different to
those from different cultural backgrounds and so it is important that I do not interpret musical experiences through my own cultural lens.

**ii. I am a trained musician.**

My background as a musician may have an influence in a number of ways. I received formal musical training from the age of four, learning how to play the violin and to sing. I learned violin using the Suzuki method (Mills, 1973), which places emphasis on developing a musical ear rather than learning to read music straight away. This means that my ear is very sensitive to atonal music which does not fit into a typically Western harmonic musical structure.

It is possible that being involved in the group will allow me to experience some of the same sensory experiences as group members, but I also have to consider how my own musical training may influence my own sensory experiences within the *Music in Mind* context.

It is also important to remember that I am a researcher in this context and not a project practitioner. Although I may have the abilities to hold strong rhythms and melodies as part of a musical accompaniment, my role in the group is to take part and observe rather than engage any members of the group using any music-therapeutic techniques I have been exposed to in the past.

**iii. I have an undergraduate and Master’s degree in psychology.**

Both my Undergraduate and Master’s degrees had a focus on quantitative and clinical research. Although I have developed a new way of thinking about how music influences people living with dementia through a positive psychological lens, there may still be a tendency for me to view participants as ‘patients’ who have symptoms.

**iv. I am the granddaughter of someone who lived with dementia.**

My grandmother had dementia, though at the time I was not aware of her diagnosis as I was in my early adolescence. I therefore need to ensure that I am listening to the experiences of the group members rather than interpreting their experience through the lens of the experience I had with my grandmother.
v. I am in my mid-twenties and female.

It is very likely that I will be younger than any of those involved in the programme, including the people living with dementia, family carers and project practitioners. I need to consider whether my age may influence the quality of the data that is collected as it may be that participants might not take me seriously as a researcher, especially if they have children or grandchildren my age.

It is possible that I may encounter some behaviour that is specific to being a female fieldworker. I have, in the past, been overlooked within a research setting when male colleagues have been present. I worry that my previous negative experiences in research will lead to a lack of confidence in building relationships with participants and asking difficult questions, as I am concerned they will not take me seriously.

vi. I am not a clinician and have not worked with people living with dementia in a research context.

I have not worked in any clinical settings and so I need to consider how my lack of clinical knowledge may influence the data collection process. I wondered whether I might feel uncomfortable in asking people about their diagnoses (a condition of ethical recruitment of participants into the study) or not pick up on key language relating to services that were accessed by participants. My experience before the PhD was focussed in research understanding factors associated with Autism Spectrum Condition, with the majority of the projects being with children rather than adults. I do not want to come across as patronising in any way with the people living with dementia involved in the project, but I am concerned that my lack of experience in speaking with those with communication difficulties may impact the rapport I have with research participants living with dementia.

Overall, this reflexive exercise allowed me to understand the potential influence that I might have on the data, as well as highlight the potential preconceptions I may have had when beginning to analyse the data. Reflexivity is not an activity to engage with only before entering the field, but should be a continuous process throughout data collection, analysis and write-up (Simons, 2009). Thus, during the data collection
process I engaged reflexively after every session, considering how the factors above and other factors that had come to light as a result of engaging with the field may have had influence on the data collection. I also recorded reflexive notes after every participant interview. I recorded these reflexive observations using a dictaphone and then transcribed them as soon as possible after they were recorded. During the transcription process I added any additional comments that had come to mind when transcribing the data. This enabled me to be actively reflexive during the data collection process.

I also engaged in reflexive practice exercise during the data analysis process. More information regarding the strategies I used in this process is detailed within the Overarching Approaches to Analysis section (p.119).

3.7 Recruitment

This study recruited people living with dementia, family carers and Music in Mind practitioners into the research. At the outset of the study I aimed to recruit six to eight people living with dementia and their carers into the research study, with a maximum group size of 14. This sample size was selected taking into consideration a number of factors:

i. Case study approaches are most suited to smaller sample sizes, allowing for the in-depth exploration of a given situation or context (Stake, 1995).

ii. A sample size of six to eight case studies was deemed to be manageable in the timeframe of the research. Case study research can be very time consuming (Baxter & Jack, 2008) and I would be working within the time constraints of a doctoral training programme.

iii. Music in Mind programmes are best suited to smaller groups, with 14 group participants (people living with dementia; family carers; and project practitioners) tending to be the maximum number of group participants deemed as suitable in order to allow for the project practitioners to develop the key musical relationships needed within a 15-week time frame (HKD Research, 2018).
The following section will address the approach taken to ensure the ethical recruitment of people living with dementia into the study. The section will first outline the steps taken to ensure the study received ethical approval, and then will present the recruitment strategies for people living with dementia who had capacity, as well as those who were assessed not to have capacity. The section will also present the approach taken to recruit family carers and project practitioners into the study.

3.7.1 Ethical Approval

Ethical approval for this research study was given by the Social Care Research Ethics Committee (Ref: 16/IEC08/0049) on the 24th of January 2017 (See Appendix 4 for approval letter). The Social Care Research Ethics Committee reviews adult social care research study proposals in accordance with the Mental Capacity Act (Department of Health, 2005), including the review of studies involving individuals who may not have capacity to consent for themselves, which was the case for this research study.

The study presented a significant number of ethical challenges which had to be addressed within the research protocol and supporting documentation. The most significant ethical challenge was the use of video data collection methods within the group context of *Music in Mind*. I developed information sheets that were accessible to people living with dementia, whether they had capacity or not, using the Dementia Engagement & Empowerment Project (2018) guidelines for producing dementia-friendly documents for people living with dementia. I worked with the recommendations from the Social Care Research Ethics Committee to develop information sheets further to ensure that all information given was transparent and accessible. This meant that two information sheets were developed, one for those who had capacity to consent, and one for those who did not. Further information on the consenting procedure for people living with dementia can be found in the *Assessing Capacity* (p.90) section of this chapter.
3.7.2 Recruitment of People Living with Dementia

Due to the use of video within the study, consent had to be obtained from all members of the group prior to the initiation of filming within sessions. As a requirement of ethical approval given by the Social Care Research Ethics Committee, it was essential to create a ‘research specific’ Music in Mind group, rather than situating myself within an already established group. By establishing a new group it was possible to recruit those who were both interested in taking part in Music in Mind and the research study. This ensured that filming could take place over the course of the research project as all individuals within the project would have consented, or have had a personal consultee agree to their involvement in the research.

To ensure equity within the research design, it was therefore decided that anyone who expressed an interest in taking part in Music in Mind, but not the research project, would be referred to the Manchester Camerata team in order to see whether there were any opportunities to take part in other ‘non-research’ projects. This ensured that individuals still had the opportunity to engage with Manchester Camerata and would not be excluded from other projects on the basis of not wanting to take part in the research. Although these procedures were in place, there were no individuals who expressed an interest in taking part in Music in Mind but not the research, so no referrals were made.

The research strategy was purposive due to the need to recruit individuals with dementia living in the community who had an interest in taking part in both Music in Mind and the research study (Ritchie et al., 2013). This meant that the recruitment strategy was focussed around sharing information about the study with key groups based in the community (e.g. dementia support groups; local charity groups etc.), as well as advertising the study in community areas (e.g. places of worship, community centres and community notice boards). The project was advertised using recruitment flyers (see Appendix 5) and by sharing information about the project via email or telephone with the key groups. This method of recruitment was adopted as this is the primary method used by Manchester Camerata when recruiting people living with
dementia in the community to *Music in Mind* programmes, which had been a successful strategy for recruitment for past programmes.

Unfortunately, this recruitment strategy was not successful as no one responded to the flyers. This meant that it was not possible to recruit anyone to the group in time for the scheduled first week of the project. This was problematic as the project practitioners had been contracted to work a 15-week project beginning on the 26th April 2017. This session was therefore used as an opportunity for me to talk to the project practitioners about their experience of working on *Music in Mind* programmes and their motives for wanting to be involved in the project. The project practitioners were contracted to work an additional week at the end of the programme to ensure that the project remained a 15-week *Music in Mind* programme.

In order to enhance the possibilities for participants in the next week of the project, I worked with Manchester Camerata team members to identify individuals who had been involved in previous Manchester Camerata projects (not necessarily *Music in Mind*). A Manchester Camerata staff member made first contact with these individuals to see whether they would be both interested in taking part in *Music in Mind* and the research project. Once they had expressed a verbal interest in taking part in the research I made contact with them to discuss the research component of the programme. In the majority of cases, contact was made with the family carers of the people living with dementia who had been involved in previous projects. This gave me an opportunity to discuss the capacity of the people living with dementia with the family carer, which enabled me to adjust my consenting procedure accordingly.

### 3.7.2.1 Assessing Capacity

The study sought to include people living with dementia who had capacity as well as those who lacked capacity. The research methods for the study were thus developed as a means of ensuring the maximum feasible participation of people living with dementia in the project, whether they had capacity or not. It was therefore essential to develop a detailed consenting protocol to ensure the ethical inclusion of people living with dementia across the duration of the study.
The capacity of people living with dementia was monitored by myself throughout the project using a process consent approach (Dewing, 2008). The process consent method acknowledges the fluctuating nature of capacity, and ensures that capacity is measured over time during the research process. The method also acknowledges “that ethical decisions and actions are context specific and centred on interdependence within a caring relationship and acknowledges that capacity is situational” (Dewing, 2008, p.10). This meant that the consent was assessed across the different situational contexts in the research (Music in Mind vs. interview visit at home) and the role of the family carer in the consenting procedure was acknowledged throughout.

Dewing (2008) has proposed a five stage process consent method. These factors will be discussed below with specific examples taken from the consenting procedure of the current study.

i. **Background and preparation**

The first stage in the process consent method is to establish permissions to gain access to communicating with the person living with dementia, through a family carer, staff carer or another named individual (such as a friend or lawyer). Dewing (2008) notes that this stage is not proxy consent but rather recognises the role of gatekeepers in the consenting process for people living with dementia. Therefore, the first stage was to make contact with the family carers who had expressed an interest in taking part in the Music in Mind programme and the research project. During the initial telephone call I explained the research project in detail and asked the family carer whether they thought that their spouse would be interested in taking part, based on their preferences before their diagnosis. We discussed the capacity of the person living with dementia, which provided an initial understanding of whether the person had the capacity to consent or not. I assessed capacity in a more structured way on meeting the person living with dementia in the context of the Music in Mind programme within the private space in the community centre.

ii. **Establishing the basis for consent**

The second stage of the process consent method is to assess capacity formally, in order to document whether a person living with dementia can make an informed
decision about taking part in the research. During this stage, I used a structured capacity assessment tool (Appendix 6) in order to assess capacity to consent with all people living with dementia enrolling into the research study. This capacity assessment was completed during the social time of the session, in a private space in the community centre to ensure privacy. Having established whether a person living with dementia had capacity to consent, or not, I was able to identify the appropriate procedures for enrolling into the study.

iii. Initial consent

The third stage in the process consent method is to provide the participants with information and to establish verbal or written consent to take part from the person who has dementia if they have shown to have capacity to consent. For those who do not have capacity to consent, this process includes providing information to an individual who can act as a personal consultee, who can provide agreement (rather than proxy consent) on behalf of the person living with dementia.

For people living with dementia who were assessed as having the capacity to consent, I gave an information sheet (Appendix 7) and a consent form (Appendix 8) that was designed to provide information in an accessible manner, with information provided in larger text with images used to back up the points of consent in the form. I encouraged the person living with dementia to talk through the information with friends and family in order to help them to make a decision about whether they would like to take part in the research. I therefore gave participants a week to decide whether they would like to take part, and then discussed their decision in the following week’s Music in Mind session. If they had decided to take part, we sat in a private space and worked through the consent form, with the person living with dementia providing written consent by ticking ‘agreement’ statements (e.g. I agree to being filmed while I am taking part in the music sessions). If people living with dementia preferred an alternative to written consent, there was the possibility to video record their agreement to the various consent statements. However, although this process was in place, neither of the individuals with capacity chose to record their consent in this way.
For people living with dementia who did not have capacity to consent, I worked with their family carer in order to provide information and to gain personal consultee agreement. I provided an information sheet for the person living with dementia (see Appendix 9), which detailed what their involvement in the project meant. I felt it was important to provide this information to all people living with dementia involved in the project, even if they did not have the capacity to consent. This was an issue of debate with the ethics board and so there were a number of versions of the consent forms that were developed for the people living with dementia who did not have capacity, before being granted approval for the use of the document. I worked with my supervision team and the comments from the ethics board to ensure that people living with dementia who did not have capacity were provided with information but were not making the decision as to whether they would take part or not, in line with the Mental Capacity Act (Department of Health, 2005).

Family carers of people living with dementia who did not have capacity to consent were also given a personal consultee information sheet (Appendix 10) which provided detailed information regarding the involvement of the person living with dementia who they cared for within the research process. I gave the information sheets to the family carer to consider the information and gave them a week to consider the information. If they decided to provide agreement on the behalf of the person living with dementia, I gave them a personal consultee agreement form (Appendix 11) in order to have this decision documented. This was completed during the social time of the Music in Mind session.

Due to the challenges surrounding recruitment, this process was a lot longer than was anticipated. The changes in the recruitment strategy meant that I was unable to consent all members of the group into the research project until week 5 of the programme. This was because two group members (Carol and Richard) did not join the Music in Mind programme until week 4 and I needed to ensure they had the opportunity to consider the information booklets and sign the consent forms before being able to turn the cameras on. However, this time at the outset of the programme allowed participants time to ‘warm up’ to me as a researcher, and so were less interested in the presence of the cameras once they were introduced into the setting (Cook, 2002).
iv. On-going consent monitoring

The fourth step in the process consent method is to ensure the continued monitoring of consent during each instance of contact with the researcher. The process of monitoring consent throughout the process was less formal than using the structured capacity assessment that had been used to establish initial capacity. In the social time prior to each *Music in Mind* session, I talked to each group member about their continued agreement to take part in the research. Outside of the *Music in Mind* context, when visiting the people living with dementia in their homes, I also made sure to ask the person whether they were still happy to take part in the interview, asking whether they were happy to answer my questions and for our conversation to be audio recorded.

v. Feedback and support

Dewing’s (2008) fifth and final step in the process consent method is the need for feedback and support if there are any issues relating to the wellbeing of the person living with dementia. I developed abuse (Appendix 12) and distress (Appendix 13) protocols in order to ensure systems were in place to ensure the wellbeing of the person living with dementia should any information be revealed to be as a result of the research project. Although there were no instances where these protocols needed to be used, it was important to have them in place especially as the project used video, and as such any instances of abuse or distress could be recorded on camera during the *Music in Mind* sessions.

3.7.3 Recruitment of Family Carers

Family carers were also recruited to take part in the research. Manchester Camerata has always encouraged the participation of family carers or staff carers within *Music in Mind* sessions. This is because enhancing the relationships between people living with dementia and the people who support them is seen as a key objective for *Music in Mind* (Habron, 2013b). Furthermore, the inclusion of family carers in the research was seen as essential as it would allow for the triangulation of data collected with people living with dementia. The following inclusion and exclusion criteria were used in the recruitment of family carers:
Inclusion Criteria

i. Supporting a person living with dementia enrolled in the Music in Mind group.
ii. Ability to attend at least four Music in Mind sessions.
iii. Ability to speak and write in English.

Exclusion Criteria

i. Unable to attend at least four Music in Mind sessions.
ii. Unable to speak and write in English.

3.7.4 Recruitment of Project Practitioners

It was also essential to recruit the project practitioners into the research. Within the music and dementia literature musicians and music therapists seem to be another unheard voice, with only a handful of studies acknowledging the role of practitioners in the context of music programmes (see for example: Pavlicevic et al., 2014). However, these individuals have great skill and expertise when it comes to delivering music programmes and understanding outcomes (Habron, 2013a). It was believed that the recruitment of the project practitioners would allow for an understanding of the music therapeutic techniques used within the context of Music in Mind, as well as musical terminology which would be essential in my understanding of the musical interactions within the sessions. The following inclusion and exclusion criteria were used in the recruitment of the project practitioners:

Inclusion criteria

i. Ability to facilitate at least four Music in Mind Sessions.
ii. Ability to speak and write in English.

Exclusion criteria

i. Unable to facilitate at least four Music in Mind Sessions.
ii. Unable to speak and write in English.
3.8 Group Characteristics

In total, six people living with dementia, four family carers and three project practitioners were recruited into the study. For the purposes of protecting the identities of those involved, all study participants have been given pseudonyms in line with my ethical permission and study protocol. All participants had been involved in previous Manchester Camerata projects with some having taken part in previous Music in Mind sessions (see Table 7). All but one couple (Scott and Julie) had taken part in previous projects together and so had met on a number of occasions before the formation of the Music in Mind research group. Some of the family carers had also been interviewed as part of previous Manchester Camerata projects, so they had experience in talking to researchers about the programmes they had been involved in.

Four of the six people living with dementia attended the group with a family carer (Scott, Phillip, Carol and Henry) and two attended the group without (Mary and Sam). The majority of individuals who were recruited into the project were living with young onset Alzheimer’s disease, with the range of ages being between 59 (Phillip) and 77 (Scott) years old, and had been living with dementia for at least three years at the time of the project. There were a range of diagnoses held by group members, which are reported in Table 7. Only two out of the six people living with dementia had capacity to consent at the time of initial recruitment into the research study. Each group member attended between 11 and 15 sessions (see Table 8) with Scott attending the most sessions (15/15) and Phillip and Carol attending the fewest (11/15).

Three project practitioners (Barbara, Nicola and Anne) were also recruited into the study. Barbara (music therapist) facilitated all 15 sessions, while Nicola (Manchester Camerata musician) was present for 13 sessions, with Anne (Manchester Camerata musician) providing cover for two weeks of the project where Nicola had prior commitments. This meant that Anne consented to be videoed but did not take part in an interview or complete a practitioner diary.

Barbara and Nicola had four years’ experience in facilitating Music in Mind sessions in care homes, community settings and hospital wards. The majority of the sessions
they had facilitated were in a care home environment, and they had recently begun to facilitate *Music in Mind* at a hospital in Greater Manchester. Nicola had attended training led by Manchester Camerata in order to gain training in dementia awareness skills and music therapeutic techniques that could be used within the context of *Music in Mind*. Both practitioners had parents who had lived with dementia, and they stated that this was a motivation for wanting to work with people living with dementia in their professional lives.
<table>
<thead>
<tr>
<th>Participant</th>
<th>Diagnosis</th>
<th>Gender</th>
<th>Age (years)</th>
<th>Capacity to consent?*</th>
<th>Relationship to person with dementia</th>
<th>Previous Manchester Camerata Projects**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scott</td>
<td>Alzheimer’s Disease</td>
<td>M</td>
<td>77</td>
<td>No</td>
<td>-</td>
<td>Music and Drama project</td>
</tr>
<tr>
<td>Julie</td>
<td></td>
<td>F</td>
<td>75</td>
<td>-</td>
<td>Wife</td>
<td></td>
</tr>
<tr>
<td>Henry</td>
<td>Posterior Cortical Atrophy</td>
<td>M</td>
<td>62</td>
<td>No</td>
<td>-</td>
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</tr>
<tr>
<td>Jenny</td>
<td></td>
<td>F</td>
<td>59</td>
<td>-</td>
<td>Wife</td>
<td></td>
</tr>
<tr>
<td>Phillip</td>
<td>Dementia with Lewy Bodies</td>
<td>M</td>
<td>59</td>
<td>No</td>
<td>-</td>
<td>Music and Art project; Music in Mind</td>
</tr>
<tr>
<td>Esther</td>
<td></td>
<td>F</td>
<td>57</td>
<td>-</td>
<td>Wife</td>
<td></td>
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<td>Carol</td>
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<td>Yes</td>
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</tr>
<tr>
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<td></td>
<td>M</td>
<td>70</td>
<td>-</td>
<td>Husband</td>
<td></td>
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<td>-</td>
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</tr>
<tr>
<td>Sam</td>
<td>Young Onset Alzheimer’s Disease</td>
<td>M</td>
<td>60</td>
<td>No</td>
<td>-</td>
<td>Music and Art project; Music in Mind</td>
</tr>
</tbody>
</table>

*At the time of the outset of the programme
**The names of the projects have been kept generic to ensure the anonymity of participants
Table 8: Attendance across the project

<table>
<thead>
<tr>
<th>Group member</th>
<th>W1</th>
<th>W2</th>
<th>W3</th>
<th>W4</th>
<th>W5</th>
<th>W6</th>
<th>W7</th>
<th>W8</th>
<th>W9</th>
<th>W10</th>
<th>W11</th>
<th>W12</th>
<th>W13</th>
<th>W14</th>
<th>W15</th>
<th>Total Sessions</th>
<th>Percentage Attendance</th>
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<tbody>
<tr>
<td>Scott</td>
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<td>Carol</td>
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<td>Phillip</td>
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<td>Sam</td>
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<td></td>
<td>12</td>
<td>80.0</td>
</tr>
</tbody>
</table>

- **Attended**
- **Did not attend**
- **Attended part of the session**
- **Not enrolled on the programme**
3.9 Data Collection

The following section will present the practical elements of data collection. First, I will present information regarding how data was collected within the context of the Music in Mind sessions, discussing how I made decisions surrounding the placement of cameras in the setting, as well as how I situated myself in the group in my role as participant-observer. Following this, the practical details and key observations from the video-elicitation interviews are presented, as well as a discussion surrounding the different styles of diary entries produced by the family carers and project practitioners.

3.9.1 The Field Site

The field site was a community centre within Manchester. The specific location of the community centre will be kept anonymous in order to protect the identities of those involved in the research project. I worked with a Manchester Camerata staff member to choose the location for the Music in Mind project. We visited three community centres in Manchester in order to assess their suitability for the project. Out of the three venues that we visited, the third venue was chosen due to its open and bright space which was a key criterion for enabling good quality video data collection, as well as providing a positive and welcoming atmosphere for the Music in Mind group members.

Furthermore, the space was easily accessible, with a door from the pavement outside leading directly into the space without the need to navigate around other parts of the venue. This meant that it would be easily accessible to people living with dementia and those accompanying them for the project. This private entrance also ensured that only those who had signed up to be research participants would be captured on film, a requirement for the ethical conducting of filming across the duration of the project. The room itself was large enough to fit the 14 group members comfortably around a central table on which the instruments would be placed. The photographs in Figures 4 and 5 were taken by myself in the venue at the beginning of the Music in Mind programme.
Figure 4: View of the musicking circle towards the outside street

Figure 5: View of the musicking circle towards the refreshment area
3.9.2 Using Video in the Field Setting

In preparation for entering the field, I attended The Film Making for Fieldwork summer school (https://filmmakingforfieldwork.co.uk/f4f-summer-school) at Futureworks (Salford, UK) in order to gain practical knowledge of how to collect video and audio data, as well as how to edit footage. The course enabled me the opportunity to have practical experience in operating video cameras and how to situate myself with cameras in the group. This course enabled me to understand the power of the camera in capturing embodied and sensory experiences, but also the subjectivity on the part of the researcher when choosing what to film, and what not to film (Heath, Hindmarsh, & Luff, 2010).

Before entering the field I reflected on how many cameras would be necessary, where the cameras would be placed and how I would record sound. These were all decisions that would have an impact on the data that was collected and so it was important to make note of why these decisions were made and how this may have impacted on the data collection. I decided to use three Sony HDR-PJ410 Handycams® to capture video within the Music in Mind sessions. These particular cameras were chosen because they were small and user friendly meaning they could be placed easily and would not rely on manual operation, enabling me to actively take part in the Music in Mind session. Their size also ensured that they were discreet. However, the built in video camera microphones were not of sufficient quality to capture the audio of the music created within the sessions, therefore I decided to use a ZOOM H5 Handy Recorder to record the audio of the sessions.

Guided by the summer school training, I decided that the cameras would be in a fixed position rather than being roving, as I wanted the cameras to be as unobtrusive as possible so that they would not detract from the sessions. It has been argued that by fixing cameras in a position it is possible for the researcher to take on more of an observer role as compared to a cameraperson (Heath et al., 2010). This meant that I could situate myself within the group rather than being on the perimeter of the circle. I hoped that this would enable me to have a greater understanding of the experiences of the group as I would be part of the music-making rather than an ‘outsider’.
However, on entering the field, it became apparent on reviewing the footage from weeks 5 and 6 that the fixed position cameras were not always able to capture the facial expressions of participants, especially those sitting furthest away from the cameras. I therefore felt it was necessary to introduce an additional camera that I would operate manually in order to gain close-ups of participants’ facial expressions and embodied gesture. Using three cameras, I was able to capture each hemisphere of the musicking circle (see Figure 6) as well as filming close up footage of participants’ faces and body movements from my position in the circle. As I was a solo researcher, it was only possible to focus on individuals or dyads at any one point in time. This resulted in me having to ‘follow the moment’ and focus in on key moments that were happening within sessions. I reflected extensively on my choices to record certain interactions and not others in order to examine whether I had any inherent biases that led me to focus more on certain individuals than others.

Figure 6: Recording frame of the two fixed position video cameras

It was not always possible to capture all group members within the recording frame of the cameras, so I placed the tripods in a way that captured the people living with dementia and their family members. This meant that the actions of the project practitioners and myself were not always captured in the footage. This approach to recording enabled me to collect data which reflected individual and group processes in addition to the sensory and embodied experiences of individual group members.
3.9.3 Recording Observational Notes

Although video was used to capture the *Music in Mind* sessions, it was also essential to make my own observations before reviewing the footage. By actively observing within sessions I was able to understand certain group dynamics in the context of the programme. This was particularly beneficial as in some sessions there were technical difficulties with cameras, or participants moved their chairs so that they were no longer visible in the camera frame. Recording observational notes also enabled me to understand cross-circle dynamics which were not easily captured using video.

After I had left the community centre, following the end of the sessions, I would spend 20 to 30 minutes immediately after the session had ended recording my observational thoughts using a dictaphone. I transcribed these notes before reviewing the video data in order to understand which moments I had been most drawn towards, and this enabled me to examine my own subjective biases on the data as I could explore whether I was giving more time to certain group members, and whether my observations had been changed as a result of my interactions with group participants during interviews.

3.9.4 Participant Interviews

This section will provide an overview of the general characteristics of participant interviews. A more detailed account of the details surrounding each individual case will be given in the *Presentation of Case Studies* chapter (p.123).

Before the interviews, I spent time deciding which clips to show to which participants. It was not feasible to show long segments of video within these interviews as I only had limited time with each participant, and so I had to edit footage into manageable clips of five to seven minutes of footage. This meant that I was in control of what the participants did and did not see within the video-elicitation interview context. My judgements as to which videos I showed were based on a number of factors. The first factor was if the person being interviewed had made reference to a particular moment within sessions, either in the social time or during our telephone call to formalise a time to conduct the interview. This enabled an exploration of the moments that the people involved in the group deemed
as important. The second factor was my individual intrigue, which was driven by my observations in the sessions, and what I felt was important to review. This factor was very subjective and so I made sure to make notes surrounding why I had found a particular moment interesting enough to take it to participants to discussion. For example, Mary would sing the song *Oh When the Saints* during every session and I wanted to understand her motives for doing so from her perspective. This opened up an interesting dialogue between myself and Mary which is discussed at length within Case Study 5 within the Presentation of Case Studies chapter (p. 171).

During the interviews I played video clips using a laptop with a large screen in order for the video to be easily observable to participants. I made observational notes during participant interviews as they were not video recorded. These notes focussed on the non-verbal reactions of the participants with dementia in order to capture these as part of the interview as they would not be recorded otherwise. I recorded these thoughts both using pen and paper during the interview but also recorded 10 to 15 minutes of thoughts on my dictaphone immediately after the interview once I had left the homes of the participants I was interviewing. This enabled me to understand the embodied reactions of participants as well as providing the opportunity to reflect on my experiences of conducting the interview, making note of factors that enhanced or lessened the extent to which the people living with dementia were involved in the interview.

3.9.4.1 People Living with Dementia and Family Carers

Each person living with dementia and family carer took part in two interviews which were spread out across the duration of the 15-week *Music in Mind* programme. This resulted in a total of 12 interviews being conducted, which each interview lasting between 60 and 120 minutes. I conducted all interviews with people living with dementia and their family carers in their homes. I scheduled in a two hour appointment to allow time to watch a number of clips but also to provide adequate time for breaks during the interview. In most cases we sat around a dining room table with the person living with dementia in the line of sight of the laptop and their family carer sat next to them (if they were present during the interview).
During the two hour period we watched between five and eight short clips of no more than five minutes each. At first, I asked participants to pause the video when they wanted to talk about certain parts of the video, but it became clear very quickly that I had overestimated the computer-literacy of some of my group members. I had to take more control in when to start and stop the video as participants would sit and watch happily, but would not comment on the video unless it had been stopped. I consequently asked participants to start talking if there was something they wanted to comment on, and then I would stop the video so that their comments could be heard above the audio of the video on the interview recording.

Before entering the field it was anticipated that separate video-elicitation interviews would be conducted for the participants with dementia and family carers. However, when working with the couples, it appeared as though the person living with dementia was far more confident in commenting on the video during interviews if their spouse was present. The flexibility in the approach to this research meant that it was possible to accommodate for couple interviews where appropriate. The strengths of couple interviews lie in the ability to produce rich data, with the dynamic processes between the couples enabling a more complex picture of experience to be built (Bjørnholt & Farstad, 2014). Furthermore, as the couples had attended Music in Mind together, they had certain elements of shared experience which were interesting in relation to the research aim and objectives. Thus, I did not feel comfortable separating the couple when in their home environments, especially as they had shared in the Music in Mind experience jointly.

I ensured that I made it clear to the family carer that I wanted to hear from both themselves and the person living with dementia that they supported, and emphasised leaving gaps for the person living with dementia to try and verbalise their account in the first instance before providing support. This is something that I monitored carefully during interviews, ensuring that I directed questions to the person living with dementia in the interview but also allowing the family carer to contribute where they thought it was appropriate.
3.9.4.2 Project Practitioners

In total, I conducted three practitioner interviews with both Barbara and Nicola. Two interviews were conducted at The University of Manchester, and the final interview was conducted in Manchester Camerata’s meeting room. Interestingly, the project practitioners brought their research diaries to each of the interviews even though I had not specified that they needed to bring them with them. They would use their diaries to look back at what they had written about certain instances within the sessions. This meant that there was a lot of unanticipated reflective practice that happened within the practitioner interviews. For example, the practitioners reflected on how they might allow space for quieter group members to contribute without having to verbally communicate this to other group members. This is where an exploratory case study approach is useful as if I had not allowed the practitioners to engage in this reflective practice, I would not have gained detailed information about how they work within the context of *Music in Mind*. Practitioner reflection has always been a key component of *Music in Mind* (Habron, 2013a) and so to be able to pick apart this reflection within an interview setting was very interesting.

The flexibility in approach also allowed the practitioners to have a great deal of control over the interview, with them also requesting me to replay certain moments or to find specific clips within the data that they wanted to discuss. This did not happen to the same extent in the interviews with the people living with dementia/family carers, although there were some instances where family carers requested to watch a particular clip, often triggered by something they had seen in the clips that I had shared during the interview.

3.9.5 Research Diaries

Research diaries were completed by family carers and project practitioners outside of the session time. Interestingly, the family carers and project practitioners used the diaries in differing ways. Family carers used the diaries to record their feelings about certain moments within the sessions, reporting the facts and then making comments surrounding their emotional responses to these moments. In contrast, the project practitioners, used diaries in a more reflective way, making notes regarding key
moments and how to support the people living with dementia in the group to reach their full musical potential.

Only two of the four family carers filled out the diaries, and their diary entries were very short. I believe the reason for this was because of the flexibility that I allowed in recording their thoughts regarding the sessions. One family carer asked me to look over her diary entries in the first few weeks to give her reassurance that she was ‘writing the right thing’, suggesting that she felt there was a correct or incorrect way to record her thoughts within the diary. Furthermore, there is some evidence that diary methods can be viewed as an additional burden to family carers adding to an already busy schedule (Välimäki, Vehviläinen-Julkunen, & Pietilä, 2007). It may well have been that if there was more structure to the diaries, asking for reflections on given categories of experience, may have resulted in the family carers feeling more confident in reporting their experiences about the project.

The project practitioners, on the other hand, appreciated the flexibility allowed in the diaries, and used the diaries to write musical notation, draw diagrams as well as record their interpretation of individual and group musical moments. This difference may have been due to the fact that the project practitioners had engaged in diary methods as part of previous Music in Mind evaluations (New Economy, 2014) as well as their own reflective practice.

3.10 Analysis

The following section will present the overarching approach to analysis, as well as presenting the key analysis processes that were engaged with in order develop a thematic description of ‘in the moment’ experience. Table 9 provides an overview of the different data sources that were available for analysis. All names presented within the table are pseudonyms so as to protect the identities of the group members.
Table 9: Overview of research data

<table>
<thead>
<tr>
<th>Method</th>
<th>Participants</th>
<th>Data</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Video-Elicitation Interviews</strong></td>
<td>Scott, Julie</td>
<td>Interview 1 26.06.2017 [105 minutes]</td>
</tr>
<tr>
<td></td>
<td>Henry, Jenny</td>
<td>Interview 2 15.09.2017 [85 minutes]</td>
</tr>
<tr>
<td></td>
<td>Carol, Richard</td>
<td>Interview 1 31.07.2017 [60 minutes]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interview 2 02.10.2017 [65 minutes]</td>
</tr>
<tr>
<td></td>
<td>Phillip, Esther</td>
<td>Interview 1 14.09.2017 [10 minutes]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interview 2 23.10.2017 [65 minutes]</td>
</tr>
<tr>
<td>Individual interviews</td>
<td>Mary</td>
<td>Interview 1 10.08.2017 [75 minutes]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interview 2 08.09.2017 [75 minutes]</td>
</tr>
<tr>
<td>Practitioner interviews</td>
<td>Barbara</td>
<td>Interview 1 03.07.2017 [120 minutes]</td>
</tr>
<tr>
<td></td>
<td>Nicola</td>
<td>Interview 2 31.07.2017 [130 minutes]</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Interview 3 26.09.2017 [115 minutes]</td>
</tr>
<tr>
<td>Participant Diaries</td>
<td>Practitioner diaries</td>
<td>17 diary entries</td>
</tr>
<tr>
<td></td>
<td></td>
<td>10 diary entries</td>
</tr>
<tr>
<td></td>
<td>Family carer diaries</td>
<td>16 diary entries</td>
</tr>
<tr>
<td></td>
<td></td>
<td>6 diary entries</td>
</tr>
<tr>
<td>Researcher Observation</td>
<td>Myself</td>
<td>200 minutes of researcher observation audio recording</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Written observations and detailed case notes</td>
</tr>
<tr>
<td>Video Recording</td>
<td>All group members</td>
<td>42 hours of video data from three video cameras [Weeks 5-15]</td>
</tr>
<tr>
<td>Audio Recording</td>
<td>All group members</td>
<td>20 hours of audio data [Weeks 5-15]</td>
</tr>
</tbody>
</table>
There have been a number of approaches to analysis in case study research that have been suggested by the key names in the field (e.g. Stake, 2013; Yin, 2014). Although a number of authors have suggested approaches to analysis within case study research, it has been argued that the descriptions of analysis processes are often underdeveloped (Yin, 2014), with some authors suggesting that analysis is predominantly guided by the researcher’s research discipline and theoretical or epistemological positioning (Simons, 2009). However, although there are no prescriptive rules for data analysis in case study research, it has been suggested that analysis should be:

*A formal inductive process of breaking down data into segments or data sets which can then be categorised, ordered and examined for connections, patterns and propositions that seek to understand the data.* (Simons, 2009, p. 117).

I therefore considered approaches to analysis that would allow me to address the key objectives of the research, allowing for an examination of embodied and sensory practices ‘in the moment’, as well as developing an understanding of features of experience that could be translated across group members. I used combined approaches of sensory analysis (Pink, 2015) and thematic analysis (Braun & Clarke, 2006) which allowed a flexible approach to understanding both individual experience, as well as the patterns and idiosyncrasies that could be observed across the participants. These analysis processes were implemented concurrently, enabling me to observe elements of experience that were specific to each individual as well as translatable across participants.

Sensory analysis as described by Pink (2015) is an approach to the analysis of multisensory data which places emphasis on privileging sensory and embodied experiences. Pink (2015) highlights that analysis should be implicit throughout the research process, and that visual research data should be used as a means “*re-encounter[ing] the sensorial and emotional reality of research situations*” (p. 143). This approach thus enabled me to understand the experiences of people living with dementia through a sensorial and embodied lens through being able to ‘re-encounter’ the *Music in Mind* sessions through video. Another layer to the analysis was the video-elicitation interviews which allowed me to ‘re-encounter’ the *Music in Mind*
sessions with the people living with dementia themselves. This sensory analysis enabled me to develop key observations for each individual living with dementia, which I narrated through individual case studies in the Presentation of Case Studies chapter (p.123).

Although a sensory approach to analysis allowed me to develop in-depth case studies based on individual experiences, I used a more systematic approach to be able to conduct a cross-case analysis of the data, searching for patterns and idiosyncrasies that were observable across the group members (see Cross-Case Analysis, p.189). The approach that I used to build an understanding of ‘in the moment’ experience held across group members was thematic analysis (Braun & Clarke, 2006). Thematic analysis is a flexible approach to data analysis in which the researcher seeks to organise and describe data in rich detail though the categorisation of data into codes and themes (Braun & Clarke, 2006). Thematic analysis provided a platform through which I could explore what experiences were translatable across group members, in order to build a thematic description which would form the basis of a future music assessment tool.

The following section will describe how I used these two analysis techniques in order to build individual case study and cross-case analysis from the research data.

3.10.1 Developing Individual Case Studies

The first step in the analysis of each individual case study was to immerse myself in the research data. During this phase of analysis, I engaged in a number of processes in order to begin to understand the data linked to each individual living with dementia, as well as begin to examine relational, sensory and embodied elements within the data. The following section will provide an overview of the key processes through which I developed the individual case studies: video review; transcription of participant interviews; moment-by moment analysis; and thick description.

Video Review

The first review of the data was conducted in the weeks between each Music in Mind session. This initial review of the video data was primarily a means of identifying
clips to show to participants within the research interviews. However, although this was part of the data collection process, it is important to list it as a stage within the analysis as when I reviewed the footage I was making active decisions as to which data participants would see and make comment on. I also made notes about which clips might be interesting to discuss during monthly supervision meetings (see **Supervision** section, p.119, for more detail on the role of supervision within the analysis process). This meant that at this stage in the research the data collection process and analysis were intertwined.

When reviewing the video, I reflected on the embodied and sensory actions being performed by the group members living with dementia (Pink, 2015), enabling myself to be re-immersed in the data. I watched the video a number of times, and made notes regarding any segments of the data that were to be used within the video-elicitation interviews, as well as making notes regarding embodied practices and actions displayed during musicking. Pink (2015) describes the reviewing of visual data as an opportunity to re-encounter the research context, and during the process of reviewing the video I found myself reliving some of my own embodied experiences from the *Music in Mind* sessions. For example, I would laugh along with the video, understanding the ‘in jokes’ that the group had, as well as getting goose bumps during significant emotional moments of footage. Although this was an initial review data, it allowed me to begin to understand experiences that were unique to each individual, as well as experiences that carried across group members.

At this stage in the analysis process the *Music in Mind* sessions were still happening. Thus, by reviewing the video in-between the weekly sessions, I could see different embodied and sensory practices developing over time, and could test these assumptions through the video-elicitation interviews. This allowed a depth to my analysis, which first drew upon the video data as a means of understanding these practices and experiences, and also supported the participants themselves to make comments about their own experiences when reviewing the data. This enabled the embodied and sensory experiences of people living with dementia to be privileged in the data analysis, whilst seeking depth and adjustment through the participant’s interactions with the video data (Kristensen, 2018).
Transcription of Participant Interviews

Although the project had gained ethical permission to use transcription services in order to transcribe the research interviews, I felt it was important for me to transcribe the interviews myself. Although this was a time-consuming endeavour, the reasoning behind this was threefold. Firstly, transcribing the interviews personally meant that I could insert details surrounding which video clips were shown during interviews, as well as my own observational notes from the interviews. Secondly, I felt it was an important step in familiarising myself with the data, as well as a means of reflecting on my dual role as a researcher and *Music in Mind* group member (Bird, 2005; Riessman, 1993). Thirdly, I could reflect on the interview data a lot more quickly as I would be in control of when the transcripts were finalised, meaning I could review the interviews whilst still in the timeframe of the *Music in Mind* programme.

Interviews were transcribed verbatim, with key additional features, such as laughter, detailed within the transcripts. I also embedded my observational notes from the interviews, such as the reactions of the people living with dementia to the videos which were not captured in the audio recording (e.g. embodied responses to music), within the transcripts. This led to transcripts that were quite detailed, enabling a certain level of interpretation without having to refer back to the original audio recording (Braun & Clarke, 2006) and enabling the embodied practices exhibited within the interviews to be privileged through my knowledge of the interaction.

Having completed the transcription of the interviews, I began to read through the transcripts in order to develop an understanding of lenses through which the group members talked about their experiences within the sessions. I was able to use the understanding I had developed through the reading and re-reading of the participant data to re-examine the video data with new knowledge about the sensory and embodied experiences of the group members.

*Moment-by-Moment Analysis*

Having reviewed both the video and interview data a number of times, I returned to the video data in order to understand the moment-by-moment detail of each *Music in Mind* session. During this phase, I focussed on each individual living with dementia
in turn, and reviewed the video with a micro-level lens. This meant that I reviewed 30 seconds of the video at a time and made note of the occurrences within that timeframe. Figure 7 presents an excerpt from this micro-level analysis, with notes being made regarding what was happening moment-by-moment for each individual, but also considering the relational aspects of the scene. This moment-by-moment analysis allowed me to develop an understanding of the processes and interactions which led to people living with dementia to be completely immersed in the musicking activity. I then used these moment-by-moment analyses to build a ‘thick description’ (Stake, 1995) of the experiences of each group member, which I used as the basis for each case study presented in the following chapter.

Figure 7: Excerpt from moment-by-moment analysis
**Thick Description**

After having dissected moment-by-moment segments of the video data, I began to build ‘thick descriptions’ of experience for each person living with dementia. I developed these descriptions of the individual ‘in the moment’ sensory and embodied experiences of the people living with dementia who formed the case studies for this research. I produced individual documents for each person living with dementia, and then searched within these thick descriptions for key observations which represented the individual embodied and sensory experiences of each group member. I then developed these observations within a case study format, writing the background information regarding each individual’s life story and then presenting the observations under subtitles. This formed the basis of my **Presentation of Case Studies** chapter (p. 123). The process through which I reduced the data from the individual documents to the case studies presented in the following chapter was an arduous task, which required reading and re-reading the thick descriptions in order to understand the key features of experience that were evident for each person living with dementia. During this process I worked with mind maps in order to map the experiences of each person living with dementia in a visual format. This allowed me to develop more holistic observational categories of experience that could be presented within the reporting of the findings within the thesis.

### 3.10.2 Cross-Case Analysis

The following section will describe the more structured approach taken to developing a thematic description of ‘in the moment’ embodied and sensory experiences which forms the basis of the Cross-Case Analysis chapter (p.189). The following paragraphs will describe how the cross-case analysis was conducted using a thematic analysis approach. I followed Braun and Clarke’s (2006, p.87) stages of thematic analysis to build a picture of the experiences that were observable across the group members. The following section will present the stages of the thematic analysis of the data in turn, which have been defined by Braun and Clarke (2006, p.87) as:

i. Familiarising yourself with your data.
ii. Generating initial codes.

iii. Searching for themes.

iv. Reviewing themes.

v. Defining and naming themes.

vi. Producing the report.

**Familiarizing Myself with the Data**

The first stage in a thematic analysis is to familiarize yourself with the research data. This process was an iterative process with the initial stages of the development of individual case studies. I read and re-read the interview transcripts and reviewed the video data in order to re-immers myself in the data, and begin to understand the common threads of experience that were evident within the data. During this process I kept note of any common features of experience, and returned to these when developing initial codes of the data.

**Generating Initial Codes**

Having familiarised myself with the data during the familiarization stage, I began to code the data by beginning to organise the data into meaningful groups (Braun & Clarke, 2006). I began this process by importing the written data into ATLAS.ti (version 7). The decision to use Atlas.ti was influenced by the need to collate data into an easy-to-manage database, which was essential for this project considering the wide range of data sources that were collected throughout the research process (Yin, 2014). Furthermore, the use of Atlas.ti also provided a platform for categorising data for specific individuals, as well as across-cases, which was vital within the case study approach to addressing the research questions, aims and objectives.

After importing the data into Atlas.ti, I began to use the process of open coding in order to begin to categorize the data (Braun & Clarke, 2006). I coded all research data, as well as the thick descriptions that had been developed as part of the sensory analysis. The choice to use open coding was determined by the exploratory nature of the case study, allowing for the codes to be inductive rather than seeking to address any specific hypotheses. I tried to use the language of participants wherever possible when coding, meaning that the codes were semantic rather than latent (Braun &
Clarke, 2006). It was important to use the language of the participants as much as possible considering the extent to which the voices of people living with dementia have been heard in the literature to date (Dowlen et al., 2017). It was also important to use the words of the project practitioners, considering they were the ‘musical experts’ within the context of this research project. Combining the use of words from the participants with dementia along with the technical musical terminology of the project practitioners allowed for the exploration of experience and musical capabilities of the group members with dementia.

Each line of written data was coded using open line-by-line coding, with newly emerging codes being added to a spreadsheet in which I listed the code name and provided a clear operational definition. Additional codes were developed when necessary and if previously developed codes did not fit new data.

Searching for Themes

Braun and Clarke’s (2006) next stage of analysis is to develop initial themes from the coded data. This stage seeks to understand the data at a broader level, seeking to look to bring together different codes into broader overarching categories. Within case study research this stage could be equated to ‘interpretation’ of the data. Interpretation has been described as the “understanding and insight you derive from a more holistic, intuitive grasp of the data and the insights they reveal” (Simons, 2009, p. 117). I therefore used this step in order to start thinking about the relationships between codes, the relevance of certain codes to specific individuals, and the codes that applied more broadly to all group members. This allowed me to understand the concepts that could be measured across group members (i.e. cross-case analysis), but also what specific things were important for specific members of the group (i.e. individual case analysis).

Throughout this stage of the analysis I reviewed codes and re-immersed myself in the data, reading and re-reading the written data as well as reviewing the video data. Although I had labelled the initial codes using ATLAS.ti, I worked with the data manually during this phase of the analysis. Working visually allowed me to understand the relationships between codes visually, creating diagrams which allowed me to understand how different themes related to each other. I also kept
detailed notes of my decisions surrounding my reduction of the larger data set into initial themes. This enabled me to have a paper trail of my decision making processes, meaning that I could examine these decisions reflexively in order to uncover any unconscious biases that may have been influencing my interpretation of the data.

**Reviewing Themes**

The ‘reviewing themes’ stage in the analysis was focussed on refining the themes that had been developed during the previous stage of analysis (Braun & Clarke, 2006). I sought to see whether the themes that I had developed had enough data to support them as independent themes, or whether they could be collapsed into another theme. In order to achieve this I began by reading all the quotes that had been collated under each theme heading. I considered whether each of the themes created a coherent picture of experience and if a theme did not meet this requirement I reviewed the theme and considered whether it needed a new title, or to be collapsed within another theme. Once I was satisfied with the developed themes, I began to work with post-it notes in order to develop a visual representation of master themes, superordinate themes and subthemes, ensuring that themes were both distinct and worked together in the context of one another in describing the ‘in the moment’ embodied musical experiences of people living with dementia.

**Defining and Naming Themes**

The ‘defining and naming themes’ stage of the analysis allowed me to refine my themes further, and test the validity of the themes by presenting them for discussion within my supervision meetings (see *Supervision*, p.120 for more information about this process). It was during this process that I began to write concrete definitions of each theme, incorporating quotes and excerpts from the video data into a descriptive narrative in order to tell a story about what the data showed (Braun & Clarke, 2006).

**Producing the Report**

During the ‘producing the report’ stage of analysis, I began to compile the narrative with the evidence shown in the data to present a cross-case analysis of the data. This
was achieved by writing a thematic description of the ‘in the moment’ embodied musical experiences of people living with dementia, which was structured using master themes, super-ordinate themes, and subthemes in order to present the data in an organized and meaningful way to a reader. Although a descriptive account of ‘in the moment’ embodied experiences, I ensured that the writing was analytical in order to illustrate the relevance of the themes to the aims and objectives of the study.

3.10.3 Overarching Analysis Processes

Although there were a number of phases involved in the analysis process, there were a number of analytic strategies that ran through the whole analysis process. These factors were present throughout the entirety of the project, but were particularly important during the analysis process. The next section will detail the role of reflexivity, supervision, and triangulation in the analysis of research findings.

Reflexivity

Although the case study researcher has a large role in the interpretation, and description, of case study findings there is very little case study research which actively acknowledges the role of the researcher in the analysis process. For instance, Simons (2009) suggests that the researcher’s ‘self’ should be situated in every aspect of the research from the formulation of research questions, study design, analysis and writing the case study. Simons (2009) also proposes that the reflexivity of the researcher should not be limited to listing values, beliefs or life experiences within a preface to a thesis, but rather the researcher should provide examples of how these factors influenced the interpretations and conclusions that were drawn from the case study data. Braun and Clarke (2006) also advocate the active role of the researcher in the development of themes rather than themes ‘emerging from the data’. I therefore made a conscious effort to write my reflexivity into the analysis, making note of specific instances where I believed that factors relating to my core values, beliefs and life experiences had affected my interpretation of the data.
Supervision was a core part of the analysis process as it enabled me to present segments of data and my interpretations of the data to my supervision team. My PhD supervision was unusual due to the number of supervisors attached to the programme, from both academic (Professor John Keady, The University of Manchester; Dr Caroline Swarbrick, The University of Manchester; Professor Christine Milligan, Lancaster University) and industry backgrounds (Nick Ponsillo, University of Chester; and Lucy Geddes, Manchester Camerata) (See Appendix 14 for supervisor biographies).

During supervision meetings, which occurred bi-monthly within a two hour time slot, I presented a number of segments of the video data that I had chosen through the video review process. The multidisciplinary supervision sessions, led by myself, allowed me to present ideas and descriptions of the data which acted as a mechanism through which I could verify findings. Within the two hour period I would present the video data, as well as my interpretation of what was happening ‘in the moment’, focusing on embodied and sensory experiences. My supervisors would ask me questions relating to my interpretation of the data, enabling me to critically reflect on the themes developed from my own engagement with the video data. Thus, although there was no formal analysis of the data by members of the supervision team, I was able to develop and refine my thematic structure in response to discussions stimulated by the video data. These specific supervision meetings took place over the course of one year (April 2017 to April 2018) and after each supervision meeting I circulated detailed supervision notes and distributed these to the supervision team to document my own decision-making processes. This enabled a more holistic development of the thematic description of ‘in the moment’ experience presented in Chapter 5, due to the nature of the multidisciplinary discussions elicited through the presentation of video data and my own developing interpretations.

Triangulation

Within case study research it is important to examine whether it is possible to triangulate core ideas across the different methods employed within the research in
order to strengthen the validity of findings (Golafshani, 2003; Yin, 2014). The use of triangulation in qualitative research allows for the comparison of different data from multiple methods or multiple perspectives in order to validate findings (Flick, 2004). Therefore, triangulating the data was a necessary step within the data analysis process in order to test whether key themes were able to be triangulated across the multiple methods employed within this research project. I used Atlas.ti in order to map themes and codes across the data, enabling me to triangulate the findings across the multiple methods, as well as across the multiple perspectives held by the people living with dementia, family carers, project practitioners, and myself.

3.11 Presentation of Findings

The following chapter will present the findings from the research study by first presenting individual case studies of each of the six people living with dementia enrolled on the 15-week community-based Music in Mind programme. A cross-case analysis of the data will then be presented, drawing on the similarities observed across group members during the programme. The way in which I have chosen to present the data is by providing both excerpts from interviews and diaries, as well as presenting anonymised images taken from screenshots of the video data. These images have been anonymised in line with the ESRC’s National Centre for Research Methods guidance on editing visual images (Wiles et al., 2008) to maintain the anonymity of participants beyond those involved in the research project.

In editing the images, I tried a number of image manipulations in order to find the best possible way to ensure anonymity but also present the people living with dementia, and other group members, as individuals with identities. By blurring the images, or placing shapes to obscure faces, I felt as if it stripped the group members of their individuality (Wiles et al., 2012), and made it difficult to present the images as illustrations of sensory and embodied experiences, one of the primary objectives of the research study. The way in which I have manipulated the images therefore presents inverted images in black and white, which allows some facial expression to be maintained and for the individual personalities and experiences of the group members to remain at the forefront of the presentation of the research findings. To make sure that these actions met with the participants’ approval, I sent the
anonymised images back to the group members in order to gain their authorisation to use the images within my thesis as well as any subsequent publications. Although the group members had consented to the use of their images and pseudonyms at the outset of the research study, I wanted to ensure that they were satisfied with the way in which I had anonymised their images. All participants were happy for their images to be used and shared in the thesis.

3.12 Summary

This chapter presented an overview of the methodologies and methods which underpinned the research study. There were a number of practical and ethical challenges which had to be addressed during the data collection process, but the flexibility and adaptability of the research design meant that these issues could be overcome supported by my own reflexivity and my supervision meetings. The next chapter will present six individual case studies, considering key observations observed across the 15-week programme for the people living with dementia enrolled on the programme. As shared earlier, the names of the community centre in which the research was conducted and participants’ names have been changed, and visual images manipulated in order to protect their identities and to comply with all necessary ethical approval processes.
CHAPTER 4. PRESENTATION OF CASE STUDIES

4.1 Introduction

This chapter presents six case studies exploring the ‘in the moment’ embodied experiences of people living with dementia engaging with Manchester Camerata’s *Music in Mind* programme. In four of the case studies (Scott, Henry, Carol and Phillip) the spouse of the person living with dementia also took part in the research. In the remaining two case studies, only the person living with dementia took part in the research (Mary and Sam). I observed each person living with dementia within the context of the *Music in Mind* programme and visited them twice in their homes to conduct video-elicitation interviews (with the exception of Sam). Each case study features both experiences that were unique to the person living with dementia, as well as drawing upon the relational interactions that were observed within the sessions. This means that numerous group members feature in each case study, but the focus of each study remains the person living with dementia.

Although an exploration of individual experience, each case study has a similar structure in order to present the key observations from the *Music in Mind* programme; this will also facilitate cross-case analysis. I have used the same main headings within each case study and present key observations as sub-headings. Each case study opens with background information about the person living with dementia, including their relationship with the family carer who attended the *Music in Mind* sessions with them (if they were accompanied), and detail surrounding each individual’s dementia diagnosis, including the type of dementia and the process through which they received their diagnosis. For example, as many of the participants were in their early 50s when beginning to experience changes and challenges relating to memory and language, they were often misdiagnosed as having depression or anxiety rather than dementia. Following this, the key observations from the *Music in Mind* sessions, developed through a sensory analysis of the data, are presented, interspersed with data taken from participant interviews, my observational notes and excerpts from the thick description of the sessions. At the end of each case study an overview is presented to highlight the key ‘in the moment’ experiences for each individual.
4.2 Case Study 1: Scott

The first case study is that of Scott, a retired plumber and swimming teacher who attended the *Music in Mind* programme with his wife Julie. The couple had been married for over 50 years, having met as teenagers during a weekend trip to a youth hostel. Although Scott had received no formal musical training in his life, he expressed a life-long appreciation of music. Scott had been given an accordion and an electric organ by his Great Aunt, and had chosen to teach himself to play rather than receive any formal music lessons. Although Scott had not engaged with the organ or accordion in many years, Scott and Julie told me that they enjoyed listening to the radio together and singing along with familiar music when in the car. Scott expressed that he enjoyed listening to his Alfie Boe and Katherine Jenkins CDs, but was eager to tell me that he did not enjoy ‘modern’ music.

Scott was diagnosed with Alzheimer’s disease in 2010 after noticing changes in his short- and long-term memory. It took a number of years for Scott to receive his diagnosis, but Julie reported that he had deteriorated quite quickly within the two years between noticing changes in Scott’s memory and his diagnosis. Julie struggled to come to terms with Scott’s diagnosis, as along with difficulties with his short term memory he also had challenges in expressing himself verbally, showing many instances of ‘empty speech’, meaning his speech lacked meaning or context. This meant that Julie often spoke for Scott, sometimes cutting him off mid-sentence if what he was saying appeared incoherent. This meant that Scott was quite dependent on Julie, as he perhaps lacked the confidence to be able to express himself verbally.

Scott and Julie told me that they attended lunch clubs together and were regulars at their local *Singing for the Brain* group (Alzheimer's Society, 2018). They had attended a number of other social groups for people living with dementia and their carers since Scott’s diagnosis, but these had all come to an end due to a lack in funding to continue the projects. Scott and Julie attended their first Manchester Camerata project in 2014, which was a creative music and drama project, but had not taken part in a *Music in Mind* programme before.
4.2.1 Key Observations during *Music in Mind*

Scott and Julie were the only members of the group who attended all 15 sessions in the programme. They were often the first to arrive at the community centre, with there being one week where they arrived before me, meaning they were 45 minutes early. During one session I asked Julie why they arrived with so much time before the sessions started. Julie expressed that the reason that they were so early was because she wanted to beat the traffic, but the journey from their home was only a 15 minute drive, and she had allowed more than an hour to get to the venue. This perhaps suggests that the couple were eager to attend the sessions and wanted to arrive at the community centre in good time before the music-making began.

Scott and Julie sat in the same seats every week, with Julie sitting on Scott’s right-hand side (see Figure 8). I asked Scott and Julie why they had chosen those particular seats and Julie expressed that she wanted to provide consistency for Scott, sharing an anecdote about Scott getting particularly cross when someone had been sitting in ‘his seat’ at a luncheon club. This perhaps highlighted the desire Scott had to feel ownership of a space, providing him with a sense of consistency and control.

Figure 8: Scott and Julie's typical position within the musicking circle
Julie seemed to take their attendance at the project very seriously, and emphasized on a number of occasions how privileged she felt to have been asked to take part in *Music in Mind* and the research. She often asked me questions about the research, asking how I was progressing, as well as asking me to read excerpts from her research diary to make sure she was ‘writing the right thing’. She often expressed concern that she and Scott were not giving me the information that I needed, and so I needed to reiterate to Julie that the project was about learning about their experiences, with there being no incorrect responses.

### 4.2.2 Observation 1: Scott’s Comedic Presence

It was evident from early in the programme that Scott had a very good sense of humour and was especially fond of slapstick comedy. Scott’s ability to express himself verbally had somewhat diminished as a result of his dementia, and so being able to convey moments of comedy using non-verbal communication allowed Scott to connect with group members through what he showed, rather than what he said. Scott used a combination of exaggerated gesture and facial expression in order to embody his comedic self through the music. These instances of slapstick comedy increased throughout the project, with group members recognising and appreciating Scott’s comedic talents. For example, in an interview with Esther, she said the following: “he’s a nice man... he has a sense of humour, you can see that.” [Phillip and Esther Interview 07.08.2017].

Scott often incorporated the musical instruments into his visual jokes, meaning the instruments became an extension of his embodied actions. For example, on a number of occasions, Scott would use a beater in order to pretend to injure himself, or others (see Figure 9). Scott would accompany such comedic gestures with exaggerated facial expressions, such as crossing his eyes to feign injury. Scott would often seek eye contact with a particular group member before enacting his joke so as to achieve maximum comedic effect. He would sit with a mischievous grin on his face, waiting for his moment to be in the spotlight. On making another group member laugh, Scott would erupt in a loud guffaw, rocking backwards and forwards in his seat, acknowledging his recognition that the joke had landed.
Figure 9: Scott uses instruments to convey humour

Julie did not always approve of Scott’s slapstick comedy within the sessions, often asking him to stop being ‘silly’. During an interview with the project practitioners, Nicola and Barbara discussed a particular instance where it seemed as though Julie disapproved of Scott’s playful humour at times. This seemed to create a dilemma for the practitioners as they wanted to allow a space for self-expression but did not know how to cope with the fact that Julie may have disapproved of the behaviour that had happened as a result of the programme. However, as can be seen in the excerpt below, taken from the second practitioner interview, the practitioners saw Scott’s slapstick comedy as a positive behaviour that had come about due to his increased confidence, which they attributed to the freedom and flexibility of the Music in Mind programme:

*Barbara:* With Scott, do you remember two weeks ago when Julie said ‘Oh he’s started to be quite silly’, do you know about that? And there’s me thinking, oh my god, I hope we’re not encouraging that silly side...and it’s different isn’t it because Julie knows Scott as, I don’t know what his profession was, but [an] adult man being very respectable, behaving properly and he comes up with silly behaviours like making funny gestures...

*Nicola:* ...and pretending to poke her up the bum like this [repeats action].

*Barbara:* All sorts... anything he thinks of with his hands and its, and that is part of being interactive isn’t it? It’s maybe something that Julie’s not so sure about.
Nicola: She doesn’t look massively impressed when he does them... Do you think it’s alright in private but maybe in public she might not be able to handle it, that’s all?

Barbara: And this is a closed group so she’s alright with all the people who are present, yeah.

Robyn: And do you think these moments, have they been this prominent from the start [of the Music in Mind programme] or do you think it’s something you see more of over time with Scott?

Barbara: I think that’s developed, I think that wasn’t there at the beginning... but I wonder whether because we encourage any form of interaction whether that’s helped, you know, or whether that’s encouraged him to be more interactive and hold back less maybe or it’s an interesting one but I went home feeling just slightly uneasy about the whole thing.

Nicola: But it’s something we need to talk about that he didn’t, he was very quiet, he was aware of everything but he was incredibly quiet and now he’s not.

Barbara: He’s also playing louder.

Nicola: Is he?

Barbara: Definitely, I think in that session on the drum he played louder which is something I’ve been hoping that would happen with him. And we’re back to the confidence thing aren’t we? If the music therapy sessions give people more confidence, then they are more willing to open up to be more active, to play louder, to interact more, and it’s all the same.

Nicola: Yeah, so the silly is evidence of him being more relaxed in that way?

Barbara: Yes, more extroverted.

[Practitioner Interview 31.07.2017]
This extended excerpt demonstrates the ways in which Scott’s increased confidence as a result of taking part in the *Music in Mind* programme allowed him to express himself through comedic gesture and facial expression, displaying this through both verbal and non-verbal embodied practices. It also highlights the role of the practitioners in encouraging playful interaction within the sessions, and how they navigated the complexities of couple relationships in order to ensure there was still freedom and flexibility for the person living with dementia to have choice and agency within the sessions.

Interestingly, when I visited Scott and Julie in their home for the first time, Scott seemed quite distant when I first arrived to conduct the video-elicitation interview. Scott was sitting on a sofa when I entered their living space, staring out of the window, and was not seemingly aware that I had arrived. This was a different Scott to the one I had encountered within the *Music in Mind* sessions. Though quiet during sessions, Scott seemed very present from the moment he walked through the doors of the community centre (i.e. greeting everyone; making jokes; smiling and laughing) and so to see him looking disengaged from his surroundings was something that I had not yet encountered.

It took Scott a few moments to remember who I was outside of the context of the *Music in Mind* group. This recollection was triggered by Julie, who introduced me to Scott and then began to sing the Hello Song. This combination of visual and verbal cues led to Scott making the association between me and the *Music in Mind* sessions. When the association had been made, Scott became a lot more engaged and friendly. As soon as I began to share the videos to Scott and Julie, Scott’s face lit up and he laughed and joked with me about having recognised himself in the video. His re-living of the moments that he had experienced during the *Music in Mind* programme allowed Scott to reaffirm his comedic identity, making both me and Julie laugh throughout the duration of the interview. It was interesting that within the context of their own home, Scott’s ‘silliness’ did not seem to trouble Julie as much. This difference may have been due to the fact that the interview took place in Scott and Julie’s private space, and so perhaps, Julie was more comfortable with Scott expressing this part of his self-identity without an audience who could make judgement.
4.2.3 Observation 2: Musical Skill and Creativity

It was noticeable within the *Music in Mind* sessions that Scott was a gifted musician and performer. This was something that was also reiterated by practitioners within the research interviews. I think I was able to discern Scott’s musicianship due to my own musical training and musical ear, being able to determine when his rhythms were in time with the musical beat, and his understanding the role of musical phrasing in creating emotion within music. I observed that although he played quietly, there were times when his creativity shone through. For example, during one session, Scott started a musical conversation with Nicola by tapping his maraca on the back of his hand. Nicola copied this action, and then Scott lead her in an improvisation based around the body, moving the maraca up his arm, on to his shoulder and then tapping it on his cheek (See Figure 10). Nicola followed Scott’s lead in this moment, which made him more confident in his contributions. The feeling of being able to manipulate the body movements of another person may have made Scott feel a sense of connection with Nicola, knowing that she was watching his every move and responding to each of his movements in real time.

Figure 10: Scott leads Nicola in a musical improvisation using the body
I observed Scott to be particularly skilled in his rhythmic abilities, being able to hold a strong beat in line with the musical accompaniment. Scott was also able to manipulate the musical tempo by slowing down or speeding up his rhythm while keeping good eye contact with Barbara who was providing the musical accompaniment. This showed evidence of Scott’s musical skill and knowledge as being able to manipulate tempo requires very good listening skills and an awareness of what others are contributing musically. The following quotes, taken from my observational notes, highlight Scott’s rhythmic abilities and skill:

*I think Julie struggles maybe a bit more with the rhythmic element but Scott is so strong and steady with his rhythmic offerings to the group and he keeps in time very well and he’s engaged throughout the whole session in this rhythmic playing.*

[My Observational Notes 17.05.2017]

Although Scott was always seen to be actively participating, he was quite a quiet member of the group. This was something that was discussed by the project practitioners during our first and second interviews. They expressed their concerns that Scott was not given the space to be able to hear his own contribution, and considered different strategies which would enable him to be able to hear himself in the music:

*Nicola: I mean Scott doesn’t stop either does he quite often he’s…*

*Barbara: Yeah it’s not loud what he does.*

*Nicola: But he’s always noodling away so that’s quite interesting managing that.*

*Barbara: Maybe it needs really just clear visual signs? Maybe it’s, when these moments happen to direct people’s attention to it visually.*

[Practitioner Interview 03.07.2017]

*Barbara: Hmm still pretty quiet.*
Nicola: But there’s variety there and he was very aware, well we’ve said that all along he was really looking and listening wasn’t he?

Barbara: And following it.

Nicola: And your dadadadada [rhythm] he was copying that.

Barbara: I was just thinking of whether he actually hears himself, and how much more effective this would be if the group stopped playing, if we had a proper solo?

Nicola: How can we do that then? Can we make that work? Can we set it up so it’s more of a bom bom, so if we actually start, make, set the silences up.

Barbara: Well we can set it up before we hand out instruments we can say [sings] “Scott on the drum” and hand out the drum before anything else happens.

Nicola: Let’s try it shall we?

[Practitioner Interview 31.07.2017]

These excerpts demonstrate that the practitioners believed Scott had real musical skill, with him listening and nodding his head to the beat, but they wanted to provide him the opportunity to hear himself in the music. In reflecting on how to enable Scott’s contributions to hear himself in the music, the practitioners sought to use strategies which enabled Scott to have the opportunity to take musical solos. This illustrates how the video enabled the project practitioners to understand how to enable the maximum feasible musical participation by Scott, in order to allow him to sense his place within the musicking environment.

The week after the second interview (session 9) was a particularly small group, with four group members (Phillip, Esther, Henry and Jenny) sending their apologies for their absences in advance of the session. Barbara and Nicola saw this as an opportunity to enable Scott to be in the musical spotlight, offering him the opportunity to play solos on the drum and also suggesting instruments that created a louder sound (such as the cowbell). I reflected on this session with the project
practitioners during our final interview together to see whether they felt as though their strategies had enabled Scott to hear himself within the music:

Nicola: Was it after we’d had the meeting and we wanted to, we were talking about giving Scott more of a voice? And then there was that one session where we did and there weren’t many people there, was that the penultimate one? And he just came into his own and then the next session it didn’t work because there were more people and there was more going on so it didn’t seem to happen that time.

[Practitioner Interview 26.09.2017]

This quote indicates how, although the practitioners used the variety of strategies in order for Scott to be heard, it was difficult for him to remain in the musical spotlight when the whole group was present. However, even though the practitioners felt that Scott’s ability to hear himself would offer the opportunity to flourish, they still believed that his contributions enabled him to feel a sense of connection to those around him, even if he was not always heard:

Nicola: Scott, his voice isn’t what it was, he can’t express himself vocally like that but we all know that he’s speaking.

[Practitioner Interview 26.09.2017]

Overall, I was able to determine through both my own musical ear and the comments made by the project practitioners, that Scott was very skilled in his rhythmic contributions. However, it was only when he was prompted to use instruments that had a louder sound, which landed him in the musical spotlight that he really began to gain the confidence that his contributions were valid in the musicking space.

4.2.4 Observation 3: Friendship with Male Group Members

Scott seemed to have a particular affinity towards the group members who were male, in particular Sam and Phillip. Although he did not engage with those group members verbally within sessions very often, he only made reference to male group members during the video elicitation interviews:
Scott: Even when ended up here... was a lad who came up here the football.

Julie: I don’t know what you mean.

Scott: I didn’t give him any roses.

[Scott and Julie Interview 26.06.2017]

Although Scott conveys little context-specific information in this excerpt, it became clear later in the interview that Scott’s sense of connection to Sam was driven by their shared love of Manchester City Football Club. In my notes on reviewing the transcript I had written: “Is Scott referring to Sam in this moment as they have a shared interest in Manchester City?” Although this moment of conversation seemed off-topic, it was perhaps him expressing the friendship he had developed with Sam as a result of taking part in the programme. This sentiment was expanded upon later in the interview.

Scott: Yeah, yeah, yeah and we end up sometimes ‘cos we’re there in the football actually.

Julie: No, no you’re getting confused now Scott, it’s not football you know them from.

Robyn: That’s ok.

Scott: What I meant to say was...

Julie: I think he’s thinking of Sam with his umm city outfit on because Scott goes to city.

[Scott and Julie Interview 26.06.2017]

There were also instances of non-verbal communication initiated by Scott directed at the other male group members. For example, in week 12, during the singing of the group song Da Na Se, Scott reached his hand out to Phillip (See Figure 11) who had been away in respite for two weeks. This physical extension of Scott’s arm towards Phillip was mediated by Esther, who brought Phillip’s hand to meet Scott’s. The two men, both of whom had difficulties in verbal communication, connected in a way
that did not need words. Perhaps Scott’s gesture was his means of reaffirming the friendship between himself and Phillip after noticing his absence from the group.

Figure 11: Scott reaches his hand out to Phillip during Da Na Se

Music-making, therefore, enabled the opportunity for Scott to connect with the other male members of the group non-verbally. Scott would often seek eye contact with Phillip and Sam, perhaps in the attempt to engage them in musical conversations. Even though there may not have been many instances of observable reciprocal connection from Phillip or Sam, Scott seemed to feel a sense of belonging through his interactions with group members who he perhaps felt a sense of connection with.

4.2.5 Summary

Overall, *Music in Mind* enabled a platform for Scott to express himself through his embodied comedic practices, which empowered him to feel a sense of connection to other members of the group. Scott felt a particular affinity with other group members who were male, with his connection to male friends perhaps being integral to his own sense of self. Scott’s use of a variety of instruments allowed him to contribute musically, but it was only when Scott was helped into the musical spotlight by the project practitioners that he was able to be heard. These moments were when Scott really flourished, as he was met with positive feedback from the project practitioners and other group members in the way of a round of applause or positive verbal comments.
4.3 Case Study 2: Henry

The second case study is that of Henry, who attended the programme with his wife Jenny. Henry and Jenny had been married for more than 30 years and had met while Henry was working a summer job at a Manchester hospital where Jenny worked as a nurse. Henry was a graduate in English Literature and took great pleasure in reading classic literature and poetry before his diagnosis of dementia. Henry had grown up in an Irish family where music and dance were a central part of everyday life. Although music was a core part of Henry’s childhood, he received no formal musical training, with his only musical education being during school. In his adulthood, Henry developed a fondness for ‘70s rock bands and enjoyed attending an Irish club with Jenny, where they would listen to traditional Irish music. Henry had also been a member of a number of choirs over his life. Henry was a hearing aid user but this was reported, by Jenny, not to interfere with his appreciation of music within his everyday life.

Henry was diagnosed with Posterior Cortical Atrophy in 2013 after experiencing difficulties in expressing himself verbally and experiencing visual hallucinations. It took a number of years for Henry to receive his diagnosis, with a number of doctors ascribing his symptoms to depression and work-related stress. Once diagnosed, Jenny found it difficult to come to terms with Henry’s diagnosis, feeling as though the disease had ‘robbed’ Henry of his skills in poetry, cryptic crosswords and reading. Jenny chose not to attend any carer meetings that were offered by the service Henry and herself had access to, expressing that she did not want to spend any longer dwelling on her situation than she needed to.

Henry had attended previous Manchester Camerata projects but had felt that they were a little childish, and referred to the musicking activities as “banging and clanging” during our second interview. However, during the research interviews, Jenny commented that she believed Henry enjoyed the Music in Mind programme more than previous programmes because he was more ‘advanced’ in his dementia. Jenny chose not to accompany Henry to the previous Manchester Camerata projects, but had decided to attend the Music in Mind sessions with Henry.
4.3.1 Key Observations during *Music in Mind*

Henry and Jenny attended 12 of the 15 *Music in Mind* sessions. The couple were quite often the last members of the group to arrive at the community centre. There were times when Barbara and Nicola would delay the beginning of the session to allow extra time for the couple to arrive. Henry and Jenny would always sit within the same hemisphere of the circle, but where they sat was determined by which seats were available to them when they arrived (see Figure 12). Interestingly, there were always seats available to them in the general vicinity where they would typically position themselves, as if the group members knew to save seats for them on that side of the circle.

Figure 12: Henry and Jenny's typical position within the musicking circle

4.3.2 Observation 1: Improvisational Skill

Across the duration of the *Music in Mind* programme, Henry created a number of improvised melodies which drew the attention of the group members. He showed
genuine skill in being able to create melodies which were memorable, producing lines of melody and rhythm supported by the practitioners’ musical accompaniments. Henry received positive feedback from the group on his musical contributions, signalled by a round of applause and verbal comments about his performance. The following paragraphs will describe two instances which highlight Henry’s musical skill.

The first example of Henry’s musical skill was observed in week 5 of the programme. The moment of musical improvisation happened after the Hello Song had come to an end. Henry had made the decision to choose the ukulele himself, having picked up the instrument to play during the Hello Song. The following excerpt is taken from my detailed case notes from week 5 of the Music in Mind programme:

*After the round of applause at the end of the Hello song, Henry plucks an arpeggio using the open strings of the ukulele. He acknowledges the pleasantness of the sound by saying “That’s nice that”. Barbara repeats the arpeggio on the piano and says “It’s lovely”. She continues to play notes which match the notes of the open strings of the ukulele, offering up the opportunity for Henry to continue playing. Henry does not immediately pick up on this musical cue, and so Barbara asks “Are you going to strum us one?” He responds with “Might do, might not” whilst smiling and laughing. Barbara repeats his phrase saying “Might do, might not” but then Henry strums another arpeggio on the ukulele. He has a look of concentration on his face and looks down at his instrument as if completely absorbed in the sound that he has created. Barbara immediately supports his improvisation by providing a harmonic and rhythmic structure to his playing of the open strings. Nicola vocally mimics his arpeggio.*

*Henry becomes momentarily distracted by the verbal conversations happening around him, but he quickly tunes back in to Barbara’s playing after she plays an arpeggio using the notes he has at his disposal. Barbara leaves a space at the end of her arpeggio which allows Henry the opportunity to take a solo, which he does.*
Henry improvises around the open strings, using arpeggios and varying rhythms. It is not possible to see his face throughout the solo as he has sat back in his seat, meaning that the camera is no longer able to capture his entire body. Throughout his solo Henry is the centre of the group’s attention, with everyone looking in his direction and acknowledging his contribution. Jenny puts her hand over her mouth and seems to have a very emotional reaction to this moment. She watches intently as Henry is able to contribute something very aesthetically pleasing with a memorable melody line. The group give him a round of applause at the end of his solo, and Jenny appears to wipe a tear away. Henry laughs and moves forward in his chair, seemingly pleased with the contribution he has made in the musicking space.

[Excerpt from Thick Description of Week 5, 31.05.2017]

This excerpt highlights how Henry demanded the attention of the room through his improvisational skill and musical presence in this moment. Henry was clearly in the musical spotlight throughout his solo, as can be seen in Figure 13, with the other group members looking in his direction, listening intently. Henry’s performance was not limited to the playing of his instrument but incorporated gesture, facial expression and dance. Henry evidently enjoyed this moment as he laughed and smiled throughout, and seemed to appreciate the spotlight of the room being on him. In later weeks, Henry developed a fondness for the glockenspiel, choosing to play it every week from week 10 of the programme. Henry had been encouraged by the project practitioners to play the glockenspiel, driven by his liking of tuned instruments. However, in the first few weeks his offerings on the glockenspiel were random, and lacked structure. As a result of this, Barbara decided to take off some of the bars on the glockenspiel in order for it to match the harmonic structure of the musical accompaniments. From this moment on, Henry’s playing was a lot more structured and he was able to explore both melody and rhythm using an instrument that would only produce sounds that were aesthetically pleasing in the context of the musical accompaniment. This resulted in Henry engaging in sustained musical improvisation, often improvising for more than five minutes at a time.
When Henry improvised with the glockenspiel he had a look of concentration on his face as he looked at his instrument, purposefully placing his notes to create his desired melody. There was one occasion where Henry dropped the glockenspiel part way through an improvisation, meaning his concentration was momentarily broken. Once the glockenspiel had been reassembled, however, Henry returned to this moment of concentration very quickly and resumed his improvisation. It is quite possible that in this moment, Henry was able to enter a flow state (Csiksentmihalyi, 1997), forgetting the external and concentrating solely on his musical contributions ‘in the moment’.

Henry therefore showed innate improvisational skills within the context of the Music in Mind sessions and enjoyed being the focus of the group’s attention. Through the support of the project practitioners Henry was able to explore new instruments and engage in sustained musical improvisation.

4.3.3 Observation 2: Spousal Connection

There were moments across the course of the programme where Henry and Jenny connected with each other both physically and emotionally. These moments of spousal connection seemed significant for Jenny, as she had expressed to me within the context of our first interview that her experiences following Henry’s diagnosis of dementia had been particularly negative. Jenny believed that dementia had robbed
Henry of skills and talents for English literature and poetry, and worried that she could not find activities which were mentally stimulating enough for him to fulfil his academic drive and ambition. The interactions I had with Jenny outside of the *Music in Mind* sessions made me aware of the challenges that she and Henry had faced since his diagnosis. This made me really examine my conceptions of the interactions between Henry and Jenny during the sessions. Jenny would only speak of Henry’s dementia when he was out of the room, and on visiting Henry and Jenny in their home for the second time, Jenny disclosed:

*I hate all of that living well with dementia tripe I hate that. It drives me absolutely spare when I hear that ’cos I just think it’s awful. I do I hate all that.*

[Henry and Jenny Interview 02.10.2017]

Although Jenny seemed to have some antipathy towards the *Dementia Friends* initiative, she still had a lot of positive things to say about Henry’s music-making ‘in the moment’. Music seemed to connect Henry and Jenny on a level that perhaps was not experienced in their daily lives, and allowed them to be a couple, rather than being in a ‘carer’ and ‘cared-for’ relationship. Although Jenny did not disclose her own emotional reactions to such moments of connection during the research interviews, the project practitioners reflected on how such moments may have made Jenny feel:

*Nicola:* [Jenny] looked at him and she had a moment […] and it was sort of, you know when you see a flood of emotion going over somebody’s face and then she just looked down and was very thoughtful. It was very brief but I just felt there was something there that obviously really helped.

[Practitioner Interview 07.06.2017]

Jenny would always watch Henry intently, showing interest in his contributions to the group, encouraging him verbally and showing him how to use different musical instruments that he was uncertain about. This enabled Henry to have a sense of control, whilst still enabling Jenny to support him in his contributions. Jenny was very receptive to the key principles of *Music in Mind*, allowing Henry to contribute for himself rather than contributing on his behalf. Henry remained attentive and
engaged throughout the sessions, something that Jenny had told me she had become concerned about in Henry’s day-to-day life:

Jenny: ‘Cos it gets harder and harder to find something that...you know...

Henry: Yeah.

Jenny: Do you know what I mean? Now he doesn’t read or it’s harder trying to find something.

Henry: Yeah I know.

Jenny: ‘Cos I suspect you’re quite bored aren’t you, a lot of the time?

Henry: Mmm yeah it’s a shame really.

[Henry and Jenny Interview 02.10.2017]

Although Jenny’s ‘carer’ role appeared as central to her self-identity, perhaps due in part to her role as a nurse for over 30 years, there were moments within the sessions where the music allowed her and Henry to perhaps forget about the diagnosis and be a couple. There were many instances where physical touch was initiated by Jenny as a means of encouraging Henry in his playing, or showing her appreciation of his musical improvisations, such as tapping his knee after he had finished a solo activity or touching him behind his ear (see Figure 14 and Figure 15). There were also instances where Henry and Jenny were able to playfully interact through the music. These playful interactions allowed Henry and Jenny to laugh together, and share in a moment of connection which was not dependent on words.

As a result of perhaps feeling more connected to his wife, Henry would quite often express his love for Jenny within the sessions, either verbally by saying ‘I love you’ or physically, such as giving Jenny a kiss on the cheek at the end of one session. Music therefore provided a platform for Henry and Jenny to take part in an activity as a couple, forgetting factors external to the musicking space, if only briefly.
4.3.4 Observation 3: Dance

Henry was one of the most active members of the group in regards to dance and gesture. Henry was the only group member to use the centre of the musicking circle as a performance space, often getting up and dancing in the centre of the circle (see Figure 16). His enjoyment of dance was evident to other group members and the project practitioners, with Nicola often joining Henry in dancing in the middle of the circle. I was interested to learn whether Henry had always had a love of dance or
whether this was a part of his self-identity being expressed through his movements. I asked Henry during an interview if he could describe to me how it felt to dance:

Robyn: So I’ve noticed that you enjoy dancing as well to the music.

Henry: Oh I do yeah [laughs] I do yeah, I do, well in a way you know.

Jenny: You always did Henry.

Henry: I know I did.

Julie: You've always liked dancing.

Henry: I do yeah, I do my own sort of thing but yeah it's that.

Julie: Your own thing yeah, you were never afraid of for a relatively shy person, you were never afraid were you?

Henry: No, never, no no.

Jenny: So like if we went anywhere you wouldn’t think twice about getting up and dancing.

Henry: It is good yeah.

Jenny: Even if there was nobody else on the dance floor that would be.

Henry: Yeah exactly it’s like in this place I go.

[Henry and Jenny Interview 31.07.2017]

This excerpt reveals how dancing had always been a part of Henry’s sense of identity. Interestingly, the centre of the musicking circle became Henry’s ‘dance floor’ within the context of the Music in Mind sessions where he could express himself through movement and dance. Henry’s dancing was not limited to the centre of the circle as he incorporated elements of dance into his seated playing. For example, Henry would often use the maracas as part of his dancing, feeling and playing the musical beat in unison, a fully immersive multisensory experience.
Figure 16: Henry uses the centre of the musicking circle to dance
On occasion, Henry’s enthusiasm for dance would result in other members of the group joining him in dance. The images below present instances where Henry’s exaggerated movements encouraged other members of the group to engage their bodies in dance. The first image (Figure 17) is a screenshot taken from an improvisation based around salsa rhythms. Henry incorporated both of his maracas into his dance, which encouraged Jenny to do the same. They danced together for a short moment in time before laughing together. The second image (Figure 18) shows a dance between Henry and Barbara. Barbara offered up the tambourine to Henry during an improvisation game and Henry used his whole body to take an improvisational solo. Barbara began to dance with him in this moment, bending her knees and throwing her arms out to the side. Barbara incorporated more movements into the game after engaging with Henry’s full-body performance.

Figure 17: Henry and Jenny dance together using their maracas
Overall, music-making and dance were intertwined for Henry, allowing him a means of self-expression and creativity. Over the weeks, the centre of the musicking circle became used more often by other group members, perhaps following Henry’s influence within the space. In the final session, all group members were encouraged by Barbara to dance within the centre of the circle, prompted by Henry’s dancing as part of the session. Thus, Henry breathed musical life into the centre of the circle, which was predominately used as a place for the instruments to be displayed.

4.3.5 Summary

Henry was a member of the group that stood out for his confidence, his creative expression and his dancing. Although Henry found verbal communication difficult he was a central member of the group, always contributing to the best of his ability in a confident and skilled way. Henry began to flourish in the second half of the programme, having chosen tuned percussive instruments which he was able to engage in sustained musical improvisations. The focus on Henry’s music-making, rather than his dementia, allowed him and Jenny to become more connected as a couple, connecting both physically (through touch) and emotionally.
4.4 Case Study 3: Phillip

The third case study is that of Phillip, who attended *Music in Mind* with his wife Esther. The couple met when Esther visited a friend in Ghana in 2009, and the couple were married a year later. Phillip and Esther settled in the United Kingdom, with Phillip taking on the role of a security guard. In 2013, Phillip began to become confused in his daily life, and Esther suggested he see his doctor about the difficulties he had begun to face. The doctors suggested that Phillip was experiencing work-related stress and depression. It was not until Phillip got lost coming home from work, and the police had to become involved, that Phillip was diagnosed with Lewy Body Dementia. Esther told me of how Phillip found his diagnosis very distressing, often crying and seeming withdrawn.

Music had always been a big part of Phillip and Esther’s lives. Phillip, when living in Ghana, had attended a Church of England parish, where music formed a central part of each church service. Phillip was also a member of a choir linked to the church. Phillip and Esther connected over their shared love of reggae and hip hop music, often playing each other music they thought the other would like in the early stages of their relationship. Phillip and Esther had attended a project with Manchester Camerata in 2014, which explored the use of music and art with other people who had been diagnosed with young onset dementia.

4.4.1 Key Observations during *Music in Mind*

Phillip and Esther attended 11 sessions over the course of the *Music in Mind* programme, with two of the sessions being missed due to Phillip going to residential respite while Esther visited family abroad. A Manchester Camerata staff member and I attempted to arrange for Phillip to have transport from the respite home to the sessions during these weeks, but the logistics of arranging his attendance proved difficult. The group, knowing that arrangements were trying to be made, seemed saddened when they learned that Phillip was not going to be able to make the sessions while he was away in respite.

Phillip and Esther travelled to the *Music in Mind* sessions in a minibus, with Phillip arriving in a wheelchair. They often arrived moments after Scott and Julie, meaning
that they were present for the full 30 minutes of the social time. Esther would help Phillip out of his wheelchair and into a seat. Esther appeared to want Phillip to be viewed as equal within the musicking space and so positioning him in the circle on a chair seemed important to her. Phillip and Esther tended to sit in a similar location each week, in the seats in between Scott and Julie and Mary (See Figure 19). Esther told me that she had chosen these seats as it meant that Phillip could see Barbara the most clearly. This positioning also represented a claiming of space for the couple, meaning their presence was missed during weeks when they were not able to make the sessions, with these seats often being left empty.

Figure 19: Typical position of Phillip and Esther in the musicking circle

Phillip had verbal communication difficulties, often sitting in silence and not engaging with the verbal conversations going on around him, as well as having mobility issues meaning that he found walking and standing for long periods of time difficult. Consequently, Phillip’s musical contributions were often acknowledged as being more significant than other group members due to the stark contrast between his quiet, still state to a more alert, aware and active state. I was aware that I often focused my attention on Phillip within the sessions, almost waiting for those moments to come about rather than distributing my attention equally around the
group. This was something I became aware of after reviewing the video data over the first few weeks of the programme and so I made an active effort to ensure that I distributed my attention equally across the group members from that point onwards.

4.4.2 Observation 1: Musical Anticipation

Throughout the *Music in Mind* programme, Phillip showed many instances of musical anticipation. Phillip would often begin musicking within the social time of the sessions, humming and patting his legs, which was often acknowledged by Barbara, who would provide an accompaniment to his improvisations. The following excerpt from my case study notes highlights an instance where Phillip’s musical contributions in the social time were recognised by other group members:

Phillip can once again be heard humming, and Jenny says “Phillip’s started already!” to which Barbara responds “Guess who’s been doing that for the last ten minutes?” These musicking practices could show anticipation for the session or be an embodied response to being within a musicking space.

[Excerpt from Thick Description Week 6, 07.06.2017]

During one session, Phillip began musicking the moment he walked through the door of the community centre. The following excerpt, taken from my thick description of week 7, describes the improvisation that followed as a result of Phillip’s spontaneous vocal improvisations on entering the musicking space:

As soon as Phillip enters the room he begins to contribute musically. This is so immediate that I did not have a chance to set the camera up before he begins to improvise. Barbara is also out of the room during this improvisation and so Esther and Mary provide an accompaniment to Phillip’s rhythmic vocalisations. He says ‘papa’ in a repeated rhythm, and Esther and Mary begin to dance with him. Barbara enters the room and joins in with the interaction, clapping out beats in order to provide a structure to the improvisation. Barbara begins to tap a rhythm on the snare drum and Phillip continues to contribute his rhythmic phrase. He bobs in time with the accompaniment, smiling in the direction of Barbara.

[Excerpt from Thick Description 7, 14.06.2017]
Figure 20 is a screenshot of the interaction discussed in the above quote. As can be seen in the image, this interaction enabled Phillip to become the centre of Esther, Mary and Barbara’s attention, with them hanging on his every musical word. This moment was joyous for all involved, with all members of the musical interaction smiling and laughing as they improvised together. This highlights the strength of Phillip’s association between the musicking environment and the opportunity for creating music. Esther told me that the anticipation of the sessions began before Phillip entered the musicking space, with him singing and smiling as soon as she told him it was ‘time for music’. This willingness to contribute showed Phillip’s sense of agency within the musicking space, knowing that his contributions would be heard and responded to either through the practitioners’ accompaniments or positive verbal or non-verbal feedback from the other group members.

Figure 20: Phillip leads a musical improvisation

4.4.3 Observation 2: Vocal Improvisation

Phillip was the only group member who did not choose instruments for himself from the instrument table. In order to ensure his participation in the sessions, the project practitioners would offer Phillip some choices of instruments, but more often than not, Esther would choose an instrument for him. Esther often chose a tambourine that had an elastic strap, which meant that any movement Phillip made with his arm
would result in a musical contribution. However, although there were many times where Phillip was offered instruments, there were also occasions when Phillip would sit without an instrument.

At first, it appeared as if Phillip’s involvement within the sessions was passive, with it being assumed that he enjoyed listening to the music rather than contributing actively. However, on reviewing the video and audio footage from the first few weeks, it became clear to me that Phillip was improvising using his voice rather than an instrument. The reason this was not clear within the sessions was because his contributions were not very loud. On reviewing the footage, I was able to isolate Phillip’s vocals, hearing that he was contributing a low hum for the duration of most sessions. It was only when Phillip found a silence to improvise within that it became obvious to the group that he was actively contributing.

One example of this was observed within week 8 of the programme. During a moment of silence, Phillip had begun to improvise around the harmonic structure of the previous improvisation. His voice could be heard clearly and Alice (Manchester Camerata musician) repeated his musical phrases back to him, perhaps as a way of demonstrating to Phillip that his contributions were valid in the musicking space. I reflected on this moment with the project practitioners, as they had requested to review this particular moment. The excerpt below details Barbara’s interpretation of Phillip’s vocal improvisation:

*Barbara: That’s got an immediate response isn’t it? The high note on the piano makes his voice go up suddenly to the D. It just shows how tuned in he is, isn’t he? I always think that when people can’t use language to communicate then they will tune into music in such a big way because it’s something they understand and that’s a medium that is accessible. [...] What’s amazing is how he sticks with it. He just carries on singing for the best part of two minutes isn’t it? Yeah I think that tells us that it’s alright, it’s sitting alright with him, the music kind of meets him I think, and the fact that most of the group are listening to it is just wonderful and that always tells me that the connection is audible, the connection between my playing and him in this case mostly is audible to everybody and it’s musically so exciting that
they think oh, or so complete that they stop playing and they find that their attention is drawn to that.

[Practitioner Interview 14.06.2017]

This excerpt highlights the importance of this moment for Phillip. In this moment, he was able to improvise with the project practitioners in a way that he was completely in control of the musical interaction, using music as a communicative tool to allow himself to be within a musical spotlight. This sustained musical engagement allowed Phillip to become the centre of the group’s attention and he received positive verbal feedback following his improvisation. This demonstrates how it is important to consider the preferences of each individual, as had Phillip not found his voice in the silence, the group may not have realised the extent of his vocal contributions within the music.

4.4.4 Observation 3: Playing Instruments without Help

Although Phillip’s preferred instrument was his voice, there were a number of instances where he would play an instrument for himself. The majority of the time, Phillip would not be in control of his musical contributions as Esther would manipulate his hands and arms to make a sound, rather than allowing Phillip to choose for himself when he wanted to contribute musically. This may have been because she wanted to ensure Phillip was contributing music, enabling him to take part through her actions. Having observed these practices, the practitioners implemented a number of strategies to encourage Phillip to play for himself.

For example, during one improvisational exercise, Barbara moved around the perimeter of the musicking circle and encouraged each individual to tap out a solo on the tambourine she was holding. The first few times Barbara moved around the circle, Esther would take Phillip by the wrist and place his hand down on the tambourine (see Figure 21). Nicola observed this interaction, and stepped in to support Phillip’s improvisation, encouraging Esther to allow Phillip to have the opportunity to play for himself. Nicola suggested that Esther place her hand under Phillip’s wrists (see Figure 22), perhaps as a way of ensuring Esther still felt like she was supporting him but allowing him the freedom to contribute for himself. The screenshot presented in Figure 23 illustrates how Phillip was able to play the
tambourine for himself, tapping out simple rhythms but smiling and seeking eye contact with Barbara as he played.

Figure 21: Barbara encourages Phillip to play the tambourine

Figure 22: Nicola shows Esther how to support Phillip to play the instrument

Figure 23: Phillip plays the tambourine for himself without the support of Esther
This interaction demonstrated the important role of the project practitioners in enabling the person living with dementia to make active musical choices for themselves. Nicola approached the situation in a very sensitive way, enabling Esther to see the benefits of letting Phillip play for himself without her support. It may have been that Esther, in an effort to be supportive of Phillip, undertook the action of playing the tambourine on Phillip’s behalf rather than considering how she could facilitate Phillip to undertake the action for himself. The practitioners thus served a dual role in this instance, facilitating the musicking experience more generally as well as enabling Esther to learn how to support independent musical action from Phillip. During the final practitioner interview, we watched this excerpt of the video and I asked Nicola how she had felt about having to step in to enable Phillip to contribute for himself:

Robyn: I think this is one of the only instances I’ve come across where you’ve sort of stepped in and said have you tried.

Nicola: I was just, should I, I don’t know, I think maybe we knew each other well enough to do that by then, you, it’s such a thing you don’t want to step on, she gets up at four on Wednesday morning to go and work and do her cleaning job then she gets back and she gets him up and she does this and she does that. Well it’s not for me to jump in and go actually will you stop moving his arm like that […] I think we were at a point where we could do that ‘cos she could see what was happening with Henry and how that was working and so I think she was slightly receptive to it but it’s so engrained with the two of them that, that physicality […] ‘cos I think anybody else in the room would have, ‘cos I was sat for ages going like this [Nicola holds her hand out], I don’t know whether you saw I was going like this but anybody else in the room would have noticed them if it had been their partner I think but she’s just not, that’s her way of doing things I think.

[Practitioner Interview 26.09.2017]

This excerpt highlights the challenges that the practitioners faced in trying to navigate the ingrained ‘carer’ and ‘cared for’ roles that had developed between Phillip and Esther. They wanted to ensure that Phillip was free to choose when he
contributed but they also did not want to offend Esther in doing so. In this instance, the way in which Nicola approached the situation allowed for more active participation by Phillip than would have been achieved if she had not intervened. The reason that Nicola felt comfortable to intervene in this moment was because of the relationship she had built with Esther as a result of the shared musicking experience. This highlights the important role of the project practitioners within the sessions and the necessity to teach the key principles of *Music in Mind* through action rather than words.

### 4.4.5 Observation 4: Personally Significant Songs

Phillip demonstrated a number of strong reactions to personally significant songs across the duration of the *Music in Mind* programme. These songs were typically related to his religious identity, often being melodies that he had sung within church or during religious ceremonies. The two songs which really seemed to strike a chord with Phillip within the sessions were *Da Na Se* (a Ghanaian worship song) and *Abide with Me* (a Christian hymn). The following section will present an overview of the use of the song *Da Na Se* within sessions.

*Da Na Se* was introduced into the group by Esther in week 5 of the programme. In the week between weeks 4 and 5, Nicola had researched traditional Ghanaian music after having learned about Esther and Phillip’s cultural heritage. She sang them a song called *Nanuma*, which neither Esther nor Phillip appeared to recognise. Esther found this funny, and both Esther and Nicola laughed about the fact that the song was apparently Ghanaian but Esther had never heard it. This led Esther to share a Ghanaian song of her own with the group: *Da Na Se* (see Figure 24). Before teaching us the song, Esther told us that it was one of Phillip’s favourite pieces of music. Esther taught the song to the group, using a call and response method with Esther singing the melody, and the rest of the group repeating it back to her. As soon as the group had learned the song we performed it for Phillip. Phillip’s face lit up on hearing the song performed in a choral style. The words were difficult for the group to grasp, being in the *Twi* language (a Ghanaian dialect), but the strength of the simple, repeated melody resonated with Phillip, with his face beaming, sitting forward in his seat.
Da Na Se became an integral part of each *Music in Mind* session from that moment forward. Group members were able to observe the significance of the song for Phillip and Esther, and also seemed to enjoy the choral atmosphere that the song created within the musicking space. A number of the group members discussed the song within the video-elicitation interviews, as the excerpt below highlights:

**Richard:** That song, I don’t know yeah, yeah what sort of atmosphere, well it’s almost sort of hymnal, that’s what I would say [agreement from Carol] and I don’t know what it’s background is, is it a Christian song I take it?

**Robyn:** Yeah it means something like thanks be to God, it’s something very simple.

**Richard:** yeah ‘cos it is a song of praise really wasn’t it?

**Carol:** But we all liked it.

**Richard:** Yeah the tune’s lovely and it’s the sort of tune where you can make up lots of different parts to and the melody sort of carries so I think it’s lovely.

[Carol and Richard Interview 23.10.2017]

Interestingly, although the song started off as being significant for only Phillip and Esther, the rest of the group members adopted this piece of music into their own
personal repertoires. There was a sense of musical cohesiveness when group members came together to sing the song week by week. During the final week the group sang the song for 10 minutes, almost refusing to move on from the singing of the song that had now become personally significant to each member of the group. When I reviewed this particular section of the video, I got goose bumps and had my own emotional reaction to the song. This demonstrates how my own body reacted to this significant melody, which had become important to me.

The importance of this melody to Phillip and Esther also resonated within the research interviews. On arriving for the first interview, Phillip was sat in an armchair and covered in a blanket, seemingly asleep. Esther told me that Phillip had a particularly restless night the night before, and so was very tired. Esther told me that she hoped Phillip would have been awake by the time I arrived, and so I suggested we arrange the next interview for a time in the day when Phillip was typically more active. Even though Phillip was sleeping, I took the opportunity to talk to Esther about her and Phillip's experiences of the programme, using the video as a discussion point.

During this interview, Esther and I discussed Phillip’s favourite music, leading me to understand the significance of Da Na Se within Phillip’s life. Esther disclosed that the song was sung every week within Phillip’s church, with him being a member of the church choir. Although Phillip and Esther had found a church to attend within their local area, Phillip missed a lot of his friends from church who were still in Ghana. The discussion surrounding Da Na Se was prompted by watching a clip of the Music in Mind group singing the song. On packing up my laptop, Phillip began to sing Da Na Se and Esther and I joined in with his singing. Phillip made a verbal utterance that I was not able to hear but Esther repeated his phrase, telling me: “He’s saying that that day he was singing”. This demonstrated Phillip’s remembrance of the session and engagement with the video even though he appeared to have been sleeping. This once again highlights the significance of this song for Phillip, but also highlights that even though Phillip seemed disengaged during the interview he was actively listening and reflecting on his experiences despite the fact that he may not have been able to convey these experiences verbally.
4.4.6 Summary

Overall, Phillip was seen to engage with *Music in Mind* in a way that differed to the other group members. Phillip’s preferred instrument was his own voice, and he was often heard to be improvising vocally throughout the sessions. At times, because his vocal improvisations were not audible above the music being produced by the rest of the group, it appeared that Phillip was passively engaging with the programme. However, on reviewing the video and audio data it became clear that Phillip was actively engaged in every session. Nicola and Barbara worked with Esther to ensure that Phillip had musical agency, offering Phillip a sense of choice as to when he did and did not contribute to the music.

4.5 Case Study 4: Carol

Case study 4 was of Carol, a retired secondary school teacher, who attended the *Music in Mind* sessions with her husband Richard. Carol was diagnosed with young onset Alzheimer’s disease after beginning to become confused and experiencing challenges relating to her short term memory. Her diagnosis led to increased anxiety and loss of self-esteem, which meant that she relied heavily on Richard and her friends for support when outside her home. Music had always been a big part of Carol and Richard’s lives. Although neither of them had any formal musical training, they explained to me that they had been members of several choirs in Manchester over the course of their relationship. They had also been part of a ‘record collective’ that held music events where they would DJ. Richard explained that Carol was no longer as fond of a lot of music from this part of her life as with her dementia she had developed an aversion to certain loud noises. Carol and Richard had attended a number of music groups since Carol’s diagnosis. They had taken part in a Manchester Camerata music and arts programme in 2014, as well as attending their local *Singing for the Brain* and an acapella choir.

4.5.1 Key Observations during *Music in Mind*

Carol and Richard attended the *Music in Mind* programme from week 4 as they had prior commitments which meant they were unable to attend the first three weeks of the programme. Carol and Richard were quite often the last members of the group to
arrive at the community centre. This meant that they often had very little choice in where to sit, choosing the seats that were empty rather than actively choosing a chair within the musicking circle. However, although they often took the seats that were available on arrival, they were always seated in the same hemisphere of the circle (see Figure 25). There were also occasions where they did not arrive until part way through the Hello Song, and one or two occasions where they arrived after the group had welcomed each other through song. This meant that there were a number of occasions where they did not have the opportunity to take part in the social time at the beginning of the session. On weeks such as this, Richard often talked to group members in between improvisations, which could limit the flow of the music as the people living with dementia had some difficulties with expressing themselves verbally. I did not enquire as to why the couple arrived so close to the start time of the music, and so it is not possible to present information regarding this factor.

Although the couple arrived late at times, they became actively involved in the music-making as soon as they took their seats. In later weeks, Carol would quite often take an instrument from the instrument table before taking her coat off, showing her enthusiasm to begin making music.

Figure 25: Typical position of Carol and Richard within the musicking circle
4.5.2 Observation 1: Confidence

At the outset of the programme Carol was one of the least confident members of the group. On meeting Carol for the first time she appeared quite shy and tended to choose instruments that would blend into the background (such as the egg shaker or maraca). This was reflected in the fact that neither Barbara nor Nicola wrote anything about Carol in their practitioner diaries until week 8, even though Carol had attended two sessions. On week 8, Barbara wrote “Carol - musical, teaching background, shy?” [excerpt from Barbara’s diary Week 8] which was a direct contrast to what was written in later sessions, such as “Carol very talkative, active + involved before + in the session.” [excerpt from Barbara’s diary Week 11]. The following section will outline the progression of Carol’s confidence across the 15-week programme, as well as drawing on my observations of Carol’s confidence outside of the sessions within her home environment.

In her second week of attending the programme (week 5), Carol seemed hesitant to engage with instruments, waiting for other group members to make instrument choices before gaining the confidence to choose an instrument for herself. Although she appeared to lack confidence in the setting, it was clear that her body was very responsive to the music, tapping her hands on her lap and then dancing her way over to the instrument table. The first instrument that she chose was a tambourine, and she ‘tested’ the sound, bringing the tambourine to her ear and shaking it, perhaps ensuring that the sound was right for her.

Richard followed Carol’s lead in this moment and chose a tambourine for himself from the instrument table. Carol smiled as she acknowledged Richard playing the tambourine, perhaps having found a common language to communicate with through their music-making. Carol began to copy Richards’s rhythms, and they played together for the duration of a musical improvisation. Having this shared language appeared to increase Carol’s confidence, and after copying Richard’s rhythms for a few bars, she began to gain the confidence to improvise using the tambourine:

Carol is aware of when the musical phrase is ending as she plays quavers rather than crotchets leading up to the end of the musical phrase. Carol plays the tambourine on the off beats of 2 and 4. Again Carol leads up to the
end of the musical phrase by increasing the number of notes played. She starts to play more complicated rhythms but then sinks back into playing quavers. She explores the use of silences within her playing, choosing not to play constantly but to use the sounds she creates in order to bring a rhythmical structure to the piece of music.

This exploration of rhythm may suggest an increased confidence from the start to the end of the piece of music; beginning by playing simple rhythms and then building into using more complicated sounds towards the end of the improvisation. I believe that this shows an increased confidence in improvising rather than relying on call and response.

Carol is able to move towards improvisation through first feeling comfortable with the time signature, and then moving on towards creating a rhythmical structure of her own. Carol mirrors Barbara’s playing by producing a string of sounds with the tambourine. This is the first time in this piece that she shakes the tambourine constantly to make a ‘shimmering’ sound at the end of the musical phrase.

[Excerpt from Thick Description Week 4, 31.05.2017]

This excerpt highlights that Carol’s confidence to improvise was built through watching and observing other people, before feeling able to contribute herself. Her musical offerings once she had gained the confidence to contribute were very skilled, showing the use of musical phrasing and strong rhythmic capabilities. Over the duration of the following weeks, Carol received a lot of positive verbal and non-verbal feedback (e.g. applause, cheering) from the project practitioners and other group members. This may have instilled a sense of self-assurance in her own musical abilities, making her more willing to initiate musical conversations and to choose instruments which could be heard more clearly above the musical contributions of others (e.g. the cowbell and horn).

When I visited Carol and Richard at their home for the first time, I was very aware of the anxiety that Carol felt when I entered their home. Although we had talked on numerous occasions within the *Music in Mind* sessions, she seemed very quiet and revealed closed body language. During the interview, Carol moved the dictaphone
when we were arranging space on the kitchen table to place my laptop, which paused
the audio recording. I remember feeling very frustrated that the interview had not
recorded, worrying more about lost data rather than on how my presence in her
house may have made Carol feel. In the segments of the interview that were not
recorded, Richard discussed Carol’s lack of confidence and anxieties surrounding
visiting new places. Carol said that she had been persuaded to go because she had
known that there would be familiar people to her there, having taken part in a
previous Manchester Camerata project in the past together. Thus, knowing there was
a hint of something familiar was what encouraged Carol to attend the group. This
highlights how Carol’s lack of confidence and anxieties relating to leaving her home
may have resulted in her being more cautious within initial sessions, allowing her to
get to know the space, the people and the instruments before beginning to feel more
comfortable in the space.

The second interview was a total contrast to the first. Carol opened the door to me,
and hugged me on walking through the door. She was chatty and asked me about
how my PhD was progressing. Although Carol still gave very short answers in the
interview, she was very positive, and requested to be involved in any future music
programmes that Manchester Camerata was organising. She exuded confidence
throughout this interview, which was in stark contrast to the first interview. This
perhaps signified the confidence Carol gained as a result of her engagement with the
Music in Mind programme and how this confidence rippled into her everyday life.

Overall, taking part in Music in Mind allowed Carol to enhance her sense of
confidence in her musical abilities, which had ripple effects into the confidence she
felt both within the sessions and within her everyday life. Carol was a very skilled
musician and the positive feedback that she received as part of taking part in the
programme perhaps instilled a sense of achievement in Carol, which was translatable
outside of the music-making into her verbal conversation.

4.5.3 Observation 2: Musical Conversations

Carol was a very quiet member of the group, and in the first few weeks of attending
the programme did not engage in the verbal conversations as part of the social time.
Although not always confident in speaking verbally, there were a number of
instances where Carol used music as a platform to express herself without the need for words. These musical conversations, often held between Carol and the project practitioners, allowed Carol to communicate through her music-making. Group members would watch Carol intently as she took part in extended musical conversations, placing her within a musical spotlight. The musical conversations typically included a range of rhythmic improvisations, rather than being a call and response activity, where Carol would produce a variety of rhythms and wait for the response from her conversation partner before resuming her improvisations. Below is an example, taken from my case study notes, of one such musical conversation between Carol and Nicola which took place on week 6 of the programme:

Jenny returns a maraca that is not being used to the table. This leads to Nicola going to the table to change her instrument to a cowbell. This results in Carol examining the table, and she asks Richard “Can I have a go on that one?” referencing the wood block on the table. She gets up to the table and exchanges her maraca for the wood block. She returns to her chair and asks Richard to show her how to play it before she gains the confidence to play it for herself. Her sound cuts above the rest of the group’s musicking and this immediately grabs Nicola’s attention. Nicola tries to engage Carol in a musical conversation as their instruments make a similar sound and can be heard above the rest of the group. At first, Carol plays when she wants to play but then, led by Nicola, she begins to engage in a call and response style musical conversation. Both Nicola and Carol vary their rhythmic contributions in the conversation, with both contributing something original rather than simply copying the other’s rhythm.

After their initial musical conversation, Nicola and Carol begin to have a musical ‘ping pong’ match, with each player playing one note and allowing space for the other player to ‘return the serve’. Nicola’s attention is drawn to Henry who is singing the lyrics of the song, which takes her attention away from Carol. It is obvious that Carol is still trying to engage Nicola in a musical conversation as she looks in her direction when playing. Eventually, Nicola’s attention is brought back to Carol, who has been waiting patiently for the musical conversation to start again. They return to their conversation,
in call and response style, each contributing an original piece of ‘dialogue’ to the interaction.

Nicola encourages Carol to explore musical dynamics by playing her cowbell more quietly. This leads to Carol playing the woodblock more loudly as a direct musical contrast to what Nicola has played. Their exchange becomes quite playful, with them both bringing their bodies into their playing, using different facial expressions to add an element of humour into the interaction. They take turns in who is leading the interaction, enabling both parties to begin and end a particular line of conversation.

[Excerpt from Thick Description Week 6, 07.06.2017]

As this excerpt describes, Carol was able to engage in a sustained musical conversation with Nicola, and was not distracted from this moment by what was going on around her. She sat forward in her chair and maintained good eye-contact with Nicola throughout the interaction as can be seen in Figure 26 below.

Figure 26: Nicola and Carol engage in a musical conversation across the circle

During a number of the practitioner interviews, both Barbara and Nicola described instances where Carol had engaged in musical conversations. They discussed the strategies Carol used in order to engage the practitioners in creative and varied conversations, and conveyed a sense of connection with Carol due to her initiation of such conversations:
Nicola: *I think that encapsulates Carol really, she likes those conversations, she likes to have a warm but sort of funny challenging chat, musical chat doesn’t she?*

[Practitioner Interview 26.09.2017]

The practitioners also suggested that the confidence Carol had gained as a result of having musical conversations, had impacted on Carol’s abilities to communicate verbally. It is not clear whether the experiences of taking part in a musical conversation facilitated this, or whether it was the increased sense of confidence she felt as a result of taking part in such musical interactions which resulted in her engaging in more verbal conversations with the project practitioners and other group members. The following excerpt demonstrates the surprise felt by Barbara in the amount of verbal conversation Carol engaged with in the later weeks of the project:

*Barbara: The amazing thing that happened was afterwards with Carol just making conversation. I thought WHAT?*

[Practitioner Interview 14.06.2017]

*Barbara: Towards the end of the session we sang goodbye and Carol was volunteering verbal conversation, sentence after sentence, just it was staggering, just fantastic.*

[Practitioner Interview 03.07.2017]

Overall, Carol’s ability and willingness to engage in musical conversations enabled her to feel more self-assured in her own musical capabilities. Carol showed skill in being able to use a range of improvised rhythms in order to tell a story through her conversations with project practitioners, using playfulness and humour in order to create warmth and comedy in her interactions with other group members. Group members appeared absorbed by Carol’s contributions, with the focus of the room being solely on Carol in these moments of musical conversation.
4.5.4 Observation 3: Musicality and Performance

Although Carol had no formal musical training she demonstrated a good musical ear, being able to repeat back rhythms played by the project practitioners and play in time with the musical beat. The skill that Carol demonstrated quite often landed her in the musical spotlight, with other group members listening intently while she improvised. Although she was a shy character, the minute she was able to perform to the group she became a lot more extroverted, seemingly more comfortable using music and performance to express herself rather than verbally:

Barbara: What I wanted to write is how Carol comes in off-beat with long up-beats. It’s quite intricate, it’s quite varied and imaginative and it’s not copying but responding which shows a sense of independence and musicality and courage and imagination.

[Practitioner Interview 14.06.2017]

Nicola: The fact that [Carol] was completely able to... her rhythm got completely, that was obviously a good tempo, but her rhythm became faster...

Barbara: And notes got shorter...

Nicola: And in time and then she responded to you. So her ears were going in both ways and she wasn’t even looking at you and she got it. She could hear you.

Barbara: It’s so musical what she does isn’t it? And that’s how we want them, on the edge of the seat you know.

Nicola: Leaning forward...

Barbara: Leaning forward, engaged.

[Practitioner Interview 03.07.2017]

Carol tended to use her whole body in her performances and used exaggerated gesture and facial expression to convey moments of comedy or a particular emotion (see Figure 27). It was revealed within the sessions that Carol used to be a teacher
and had heavy involvement in school theatrical productions as she had a love for the performing arts and musical theatre. This part of Carol’s life story may have been able to be expressed through her music-making, creating a performance for an audience. Carol’s performances were received positively by the group, with group members giving her a round of applause or laughing at her comedic gestures. Carol’s use of performance occurred more frequently in the later weeks of the programme, perhaps meaning Carol felt more comfortable to express herself using musical performance once she was more used to the format of the sessions, and more relaxed in the company of the other group members.

Figure 27: Carol makes exaggerated gestures to accompany her performance

Carol really seemed to appreciate the opportunity to connect with other group members through music. During both interviews I conducted with Carol and Richard, she stressed the importance of friendship to her, expressing that her favourite part of Music in Mind was ‘the people’. Carol’s musical performances often acted as a catalyst for laughter and physical touch with other group members, especially between herself and Jenny, whose friendship she appeared to really value. The two friends often laughed and joked together, complemented each other on their outfit, and chose similar instruments.

Overall, Carol used embodied gesture and exaggerated facial expression in order to create musical performances. Although these instances of performance occurred later within the programme, her playfulness and humour was evident from very early in the programme. Her performances allowed her to showcase her musical and comedic
talents, which enabled her to connect with other group members, sharing in jokes and laughing together.

4.5.5 Summary

Overall, Carol transitioned from a group member who appeared shy and quiet due to her lacking in confidence, to someone who flourished through musical conversation. Over the weeks, Carol became more comfortable within the group setting and began to choose instruments that would be heard more clearly above the rest of the group. The confidence she felt as a result of expressing herself creatively extended beyond the musicking space and was seen to positively impact on her abilities to express herself verbally, as well as feeling a sense of happiness that transcended outside of the sessions into her daily life.

4.6 Case Study 5: Mary

Case study 5 was of Mary, who attended the sessions by herself without a family carer. Mary was 59 years old and had moved from Nigeria to Manchester with her husband more than a decade ago. In Nigeria, Mary first trained as a community nurse and midwife, before working for organisations such as UNICEF and the Red Cross. Her work with these humanitarian organisations led to her being invited to work in the UK, working with hard to reach groups of women who had immigrated to the UK from Africa. Alongside this work, she also worked within the National Health Service (NHS) as a nurse, but felt that her skills were not recognised and so felt underappreciated and deskillled. Working as a nurse in the NHS was her last job before being diagnosed with young onset Alzheimer’s disease.

Mary was first diagnosed with young onset Alzheimer’s disease in 2013 after her husband noticed that she was having difficulty with everyday tasks, such as cooking and writing. Mary found it hard to come to terms with her diagnosis and became depressed, withdrawing from her social circles and not leaving her home for many days at a time. She felt as if her friends had deserted her as a result of her diagnosis and did not see a future for herself:
All I could remember was just to cover my nakedness and sit there waiting for the day I will die. I will sit down, I will be thinking of which music will be best for me when I am dead and how will I arrange for my funeral.

[Mary Interview 10.08.2017]

Mary told me that she found it difficult sometimes to express her experience of living with dementia as many people did not believe that she had a diagnosis of Alzheimer’s disease as she was still very competent verbally and did not show obvious difficulty in regards to her short or long term memory. Although I had confirmed her diagnosis as a result of the consenting process for the research, she insisted on showing me her medical letters in order to ‘prove’ that she was living with dementia.

Mary had no formal musical training but predominantly engaged with music when attending church, having been a part of a number of church choirs during her lifetime. Mary made it clear to me that her favourite music was worship music and that she did not like modern music as she perceived it to be ‘sinful’.

4.6.1 Key Observations during Music in Mind

Mary would arrive at the community centre via taxi with Phillip and Esther. Mary would always offer to make other group members cups of tea, always wanting everyone to be happy and comfortable in the space. Mary would often choose to sit near to Phillip and Esther, but also had a clear friendship with Nicola, whom she would often talk to in the social time of the session. Mary’s typical position within the musicking circle is depicted in Figure 28.

Mary used the social time to talk to people about her week and would also share wisdom based on her life experiences. For example, she would often talk to me about home remedies that would help with weight loss and my tiredness. She would also use the time to evangelise to other group members, quite often asking other group members about their religious beliefs and sharing her experiences of the role of her faith in her dementia journey. Interestingly, in week 9 of the programme, Mary chose to attend the session even though she had a doctor’s appointment that overlapped with it. Mary arrived at the session half an hour early so that she could still take part
in the social time and had booked a taxi to take her to her appointment part way through the session. Mary’s taxi arrived shortly after the Hello Song had ended, but she was still able to have a cup of tea and share updates from her week as part of the social time. This demonstrates the value that Mary placed on the sessions as she chose to attend even though she knew she would have to leave early in the session time.

Figure 28: Typical position of Mary within the musicking circle

4.6.2 Observation 1: Religion, Identity and Music

Mary’s Christianity formed a central part of her self-identity. Mary and her husband were evangelical Christians who attended church regularly, as well as engaging in street evangelism. Within the context of the Music in Mind sessions it was clear that Mary associated music-making with her own religious practices. There were times in which Mary used the Music in Mind sessions as an extension of her own personal worship, leading the group in singing hymns and gospel music in the majority of sessions. The following section will explore Mary’s use of religious music within the group, drawing on observations within the sessions and my interviews with Mary and the project practitioners.
Mary had very strong beliefs regarding the role of music in helping her overcome the depression that she experienced as a result of being diagnosed with dementia. Mary often talked about the fact that she believed that music had ‘cured’ her of her dementia and that God was working through the group members in order to help her through a difficult time in her life. Mary seemed to have an overwhelmingly negative experience of diagnosis and received minimal support from healthcare professionals in adjusting to her diagnosis. She struggled with depression after her diagnosis as she described to me during both interviews I conducted with her. The following passage is a continuous excerpt taken from Mary’s second interview, which describes the challenges she faced when she was diagnosed with dementia and how she felt the Music in Mind programme had helped address the loneliness she felt:

*I appreciate the programme. How I wish it’s going for many people who are going through this [dementia] ‘cos it’s helped me as an individual. I was withdrawn to myself, I don’t talk to anybody... I don’t go out... nothing seems interesting to me […]*

*I believe many people are inside their room. Some like me then, who are ashamed to be diagnosed with Alzheimer and their dementia or how will people look at me? What will people say? ‘Cos in our own society it’s like you are mental, you are condemned, but getting to the [previous Manchester Camerata project] I saw other people so well. I said take it because something is there for you to accept and join the group and the other one is to refuse and remain in your situation. But I joined them.*

*Believing in God and believing in the people I’m working with that are looking at me, trusting that God is using them to heal me. God can come from heaven, but can pass through people to get to you and reach.*

*[Music in Mind] really helped me, so I recommend it to many other people, it’s not a waste of time. Loneliness is part of the disease ‘cos the moment they diagnose you with it you want to withdraw, and then you go into that loneliness, into yourself, which kills. Brings in many thoughts, and when you are diagnosed and you get out to meet other people you know you are not that lonely […] and you look forward to it, it help. In my situation I don’t*
know where to go ‘cos that condition was that much I don’t even know when I am hungry, if I put anything in the fryer that get burnt. And all in all I withdraw, totally withdraw, while only watching television. Television can only talk to you, you can’t talk to television.

[…]I thought my own case was worse than many people, not knowing that I was caught at the early stage so God is faithful, God is very good. All those I’m meeting is God’s plan for me, to meet them, to help me out and I will tell the story just as I tell you […] I’m not ashamed to [show] people the pictures during when I was sick. When I see the passport they used for disabled passport I looked and said ‘is that me?’ […] shook my head. So [Music in Mind] help, it helps and many people are inside their home, not knowing where to go […] so I just thank God for the music.

[Mary Interview 08.09.2017]

There were a number of instances where Mary evangelised vocally in the social times of the session. Her sense of connection to God seemed unquestionably tied to music, with her suggesting that God had provided the opportunity for her to take part in the previous Manchester Camerata project, and had worked through the project practitioners in order to ‘cure’ her of her dementia. She gave ‘sermons’ to the Music in Mind group members in order to show them how music had allowed her to be ‘cured’ and how she believed it was the strength of her faith that had allowed this to happen. Although a strong tie existed between Mary’s religious beliefs and her love of music, there were instances that I observed which showed how the intensity of her experience could sometimes alienate her from other members of the group. For example during the social time in one session, Mary was asking each group member whether they had any beliefs, which seemed to annoy Julie who stated that she had lost all faith in religion since Scott’s diagnosis of dementia. Thus, although music was beneficial for Mary in regards to her own spiritual connection to God, her mission to evangelise may have limited the connections she was able to develop with other group members. However, later in the programme, Mary’s dominance subsided as she allowed others in the group to have a musical voice, supporting them and teaching new melodies (see Observation 2, p. 176).
Mary also used religious music within the sessions as a means of evangelising to the group and introduced the melody for *Oh When the Saints* in week 5 of the programme. This was a spontaneous contribution to the group and Barbara and Nicola provided an accompaniment for Mary’s singing. This melody became a motif for Mary, with her introducing it in the majority of sessions. During the weeks when Mary was not in attendance in the session, Barbara introduced the melody enabling Mary’s presence to be in the group even though she was not physically there. The example below highlights the ways in which Mary would introduce the melody into sessions:

> Mary led everyone into “Oh When the Saints” again. I think she managed to manipulate the rhythms using the glockenspiel and then just came out with the singing. So she started singing and although it was only a few people in the group that were singing along, it was her time to shine. Really it was her moment, her song. I think “Oh When the Saints” is going to be a recurring motif for Mary. I think it’s a song that has a lot of personal significance for her and I think she just enjoys singing it and having it sung with a group.

[My Observational Notes 17.05.2017]

I was curious to know Mary’s intentions behind introducing this specific melody into the *Music in Mind* group. The following excerpt from our second interview highlights Mary’s motives for introducing the familiar melody into the group week after week:

> Robyn: So when you sing “Oh when the Saints” it’s very spontaneous, what is it that makes you want to start singing? I’m curious to know

> Mary: You want to know why I sing it? I told you this morning. My grandchildren when we are praying in the morning […] I say, give me a song and each of us will bring a song. Then the little one says [sings] “Oh when the Saints” but they sang it in their own way. It’s not the one that I sing, so I said, “What are you singing?” And they said it’s your favourite song.

> And when I’m singing it I relate it to when God says he’s coming back. He’s coming to go with the saints [sings] “Oh when the saints, go marching on,
when the saints go marching on, my Lord I pray to be in that number” so I want to go to heaven so I pray that they [the Music in Mind group] will go with me. That’s what makes me happy because I know at the end of the world we’ll all die but we’ll go to heaven […]

Me, I want to be in the number and the song is actually everybody sing [sings] “Lord I pray to be in that number” so everybody say I want to be in the number of saints that are going to march on [sings] “Oh when the saints” I forgot it [sings] “Oh when the saints, go marching on, when the saints go marching on, Lord I want to be...” you want to be in their number so you have to live a good life. You have to take everybody as yourself […] so if you want to go to heaven you have to make it alright here so that you can join the people who are going to heaven. That is the meaning and that is why I like it.

Robyn: So when you sing it with the group, is it, do you start it because you want everyone...

Mary: To go to heaven. No I don’t want anybody left out. Everybody like us, we are happy. I want us to meet there and say, oh so you made it to heaven, oh Mary you made it to heaven, Phillip you make it to heaven […] I know the saints have somewhere to go and I want the group to go there. That is why sometimes at the end; before we say [sings] “Goodbye”, I will sing that one. If we don’t meet next Wednesday, by chance, if anybody were to die, we march to heaven.

[Mary Interview 10.09.2017]

This interview excerpt quite clearly demonstrates Mary’s spiritual connection to this particular piece of music. She was strong in her conviction that singing this song with the Music in Mind group would result in her meeting with the group members in heaven. This demonstrated that she felt a great sense of attachment to the group members, as she evangelised through the music, sharing her spiritual beliefs in the hope that they would stay connected through this life and into the next. Oh When the Saints could be thought of as a typical ‘sing-along’ song in British culture and so was not necessarily attached directly with spirituality for the other group members. This highlights the potential cultural differences between Mary and the other group
members, who perhaps do not associate this piece of music with spirituality, and so did not have as much as an emotional connection to the melody.

There were times when I struggled with the extent of Mary’s religiosity. I had developed a good rapport with her across the duration of the programme, but her constant attempts to evangelise to me began to wear me down. I found myself closing up to her in an attempt to avoid the awkward encounters surrounding her attempts to convert me. I found it difficult to know what to say to her in situations where she insisted on giving me leaflets with prayers on them and appearing disappointed if I said I had not read them. I am someone who is quite firm in their beliefs about religion and spirituality and so I may have felt threatened by Mary’s strong Christian beliefs. This was difficult because it meant that I perhaps unconsciously avoided talking about Mary’s religion during the interviews as I knew that her response would include an attempt at evangelising to me. However, it is clear from the data presented above that Mary’s religion was a strong component of her self-identity and so, perhaps, I could have learned more about the intersection between music, religion and self-identity had I been able to put my own beliefs to one side to allow her to express herself freely.

4.6.3 Observation 2: From Dominant to Supportive

In the early weeks of the programme Mary took a very dominant approach to music-making. Mary would tend to choose the instruments that made the loudest sounds, often opting for the drums that were available (snare drum and ocean drum). In order to increase the sound produced by the ocean drum, Mary would hit it with a beater rather than shaking it from side to side, its traditional use. She would play her own rhythms in a different tempo to the musical accompaniments, showing her own agenda in terms of what she wanted to sing or play rather than listening to the contributions of others. The following excerpt, taken from my thick description of week 7, illustrates Mary’s dominating nature within the group, and how it impacted the musical contributions of other members of the group:

*Barbara begins playing tremolando on the piano, supporting Henry in a musical solo. Richard returns his cymbal to the table which prompts Mary to get up to the table. She chooses a beater and changes the sound of the ocean*
drum by using the beater as if the drum was a bass drum. She begins to sing “Oh when the saints” and Barbara adapts her accompaniment to hold the chords of the song in order to draw attention to Mary’s singing. This means that Henry does not have the opportunity to develop his solo. Mary manipulates the tempo at which Barbara plays, increasing the tempo so it is more lively and in line with Mary’s desired aesthetic for the piece. The attention of the room becomes focussed on Mary.

Nicola carries the melody on the horn while the other group members contribute varied rhythms to the piece. All group members take part in an instrumental chorus, without singing at first. I join in singing the lyrics with Mary and Barbara starts to repeat back the lyrics of the song, perhaps letting Mary know that her contribution is being heard.

[Excerpt from Thick Description Week 7, 14.06.2017]

This excerpt demonstrates the power that Mary had in order to be able to manipulate the sounds of the group to fit in with what she wanted to sing. However, this was to the detriment of other members of the group who had not had as much as an opportunity to shine in this session as Mary. Moments like this led to Mary being viewed as a ‘dominant’ group member by the project practitioners. As Nicola discussed during our first practitioner interview in reference to this excerpt of video: “It’s dominant […] she wants to dominate in that moment” [Practitioner Interview 03.07.2016]. Although Mary showed great musical skill in being able to manipulate the sounds of the group, she seemed initially unaware of the contributions of others, and was focussed only on what she brought to the group rather than the collective contributions of the group.

However, as the project went on, Mary began to acknowledge the contributions of other group members, allowing space for others to contribute, and offering up her musical expertise by teaching the group new musical repertoire. Perhaps because she had been given the opportunity to shine in the first few weeks of the project, she learned the value of the chance to be in the musical spotlight and so offered others the opportunity to feel the way she had felt. Mary still seemed to relish in every opportunity she was given to take a solo, but allowed others to share the spotlight...
with her. This is something that was picked up by the project practitioners who discussed this shift from being a dominant to supportive group member in two of our interviews:

**Nicola:** I’ve noticed in the past few weeks [Mary has] become less dominant […] she’s actually choosing different instruments isn’t she? She’s really listening […] You could really see it when I was having a musical conversation with her and I’ve not really experienced that […] I can’t remember what I did but in the end it said [reading from diary] “Later in the session she appeared to be taking notice of what was going on and she helped [Barbara] keep the music flowing” and she’s been like that ever since really. […] She’s really observing and she’s bounding off me. Yeah we had a musical conversation but I don’t know where her mood is, or what it’s to do with this but she’s definitely changed within the group. Her awareness of everybody else. So she was being supportive rather than dominant this week.

**Barbara:** And she felt like she had to bring this gift of lovely food to the group didn’t she? That was incredible. But her drum solo was an exciting one wasn’t it? Do you remember? That just took off and went woosh. It was really exciting that she was involved, on the edge of her seat doing all sorts, looking, and it was really fantastic.

**Nicola:** Yeah and she was looking, she wasn’t just going for it like she has previously […] She really felt much more part of the group.

[Practitioner Interview 31.07.2017]

This excerpt highlights the way in which Mary adapted her contributions in the group so as to share the musical spotlight with other group members. This is something that was never verbally expressed to Mary, but perhaps she shared empathy with the other group members and wanted them to have the same experiences that she had. As was mentioned by Barbara in this excerpt, Mary brought food at the end of the 10th session. Mary had cooked a Nigerian rice dish for the group to share in. We all sat and ate together at the end of the session, and everyone complemented Mary on her cooking. This was a very intimate moment in the group, with no-one appearing in a hurry to leave the session. In bringing food for
the group to share, Mary further highlighted her connection to the group members, wanting them to share in her culture and enjoy a meal together.

4.6.4 Observation 3: Musical Proficiency

Mary was one of the most competent musicians in the group. She played every instrument she held with confidence, showing skills in producing improvisational rhythms and melodies. Mary’s musical talents were recognised by other members of the group, and the project practitioners who commented on her abilities during research interviews:

_Julie:_ [Mary] _plays that_ [glockenspiel] _lovely doesn’t she? […] she plays that really well I think._

[Scott and Julie Interview 26.06.2017]

_“Mary- confident, soloist, singer with experience, likes ocean drum, likes repetition […]”_

[Excerpt from Barbara’s Diary, 31.05.2017]

Mary also had a talent for teaching the group new music. On a number of occasions, Mary sought to introduce her favourite hymns to the group. Mary would take on the role of a project practitioner, teaching the group how to sing the song using a ‘call and response’ method. Mary would first sing the line and then hold her hand out to the group, expecting them to repeat what she had sung (see Figure 29). This was something that was led purely by non-verbal communication, and the group followed Mary’s lead in singing a song called _I have Joy like a River_. Mary accompanied the singing of the hymn with a rhythmic beat played on the lyre.
This demonstrates how Mary was able to use her musical skills to encourage other group members to learn a new song. In order to teach the song she had to juggle a number of musical elements such as singing, playing an instrument, and leading the group in the call and response exercise. This shows an innate talent for musical multitasking. During my interview with Mary, I asked her about this moment:

Robyn: Did you enjoy being able to teach it to other people in the group?

Mary: Yes.

Robyn: You’re a very good teacher.

Mary: I was when I was, I used to be, I used to go out to teach community women. I teach them a lot, I work with them, UNICEF, British Council, mobilizing them to do something useful for themselves. So I’ve got that skill of accepting everybody and coming down to everybody’s level. Takes them short thing not long thing that they can take something from.

But this group are teachable ‘cos everybody’s looking forward to being happy at the end of the day so you have to participate to teach people, you don’t give them instruction, participate. So all of them are willing to participate so it was a good thing. They learn it quick, maybe some of them are Christian and most are not but they still join.
This excerpt highlights how Mary’s life story was projected through her music-making. The fact that her primary job role had been to teach meant that she was able to hold the attention of the room to teach group members the songs that were significant to her. As has been discussed earlier in this case study, Mary had a very strong sense of religious identity, and wanted to teach everyone about her religion through song. She therefore seemed particularly pleased that everyone chose to join in with her singing, as it perhaps extended her form of worship by being able to evangelise without the need for words.

4.6.5 Summary

Mary appeared to gain a lot from taking part in the Music in Mind sessions. She was able to connect with many elements of her self-identity through the music, showcasing her favourite hymns and gospel music, and teaching these songs through the group through her embodied practices. Mary was a very competent musician who showed great musical prowess, especially on rhythmic instruments. Although she started the programme dominating the musical space, she learned to support other members of the group in their contributions, allowing them to share the spotlight with her. Mary seemed to really appreciate the fact that she had been invited to take part in the Music in Mind programme, stating at the end of one interview:

You’ve [Music in Mind practitioners] done a very good job, you don’t know, you’ve touched people’s lives unknowingly. Imagine being a Christian or a prophet you touch people it’s what you have that you have done through your all of this work. You’ve touched, that is my own expression, and I believe it is everybody’s mind because if it’s not interesting people wouldn’t come all the way.

4.7 Case Study 6: Sam

Case study six was of Sam, who attended the group without a family carer or someone supporting him in a professional capacity. Sam attended 12 of the Music in
Mind sessions. Sam was the only member of the group who was not interviewed as part of the research and so my observations were based solely on Sam’s experiences within the Music in Mind sessions. Sam’s involvement in the research was communicated through a member of care staff who I contacted to gain personal consultee agreement from. Although this member of care staff provided agreement for Sam to take part in the research I did not receive a response from them when trying to arrange a time via their preferred means of communication (email) to meet Sam outside of the sessions to conduct the video-elicitation interview. They were responsive to my questions regarding Sam’s continued involvement in the programme, but chose not to answer my questions regarding an appropriate time to interview Sam. I therefore was unable to interview Sam as part of the research and as a consequence I had very little background information about Sam regarding his life history or how music featured within his everyday life. This means that the descriptions of this case are based solely on the interactions I had with Sam in the sessions and the observations of myself and the project practitioners.

4.7.1 Key Observations during Music in Mind

Sam was brought to the sessions by his carer who led him into the room and made sure that he was happy before leaving. Sam would take his seat within the circle, but his position in the circle changed week on week. Sam was thus the only group member to transcend the hemispheres of the circle. He would typically position himself in close proximity to the project practitioners, as he would often seek clarification on the lyrics of songs, or seek verbal or non-verbal feedback. Sam would also get up from his seat within the sessions to visit the bathroom, often returning to a different seat to where he had started. This created some challenges with the fixed-point cameras, as sometimes he moved out of the recording frame of the camera.

Sam was sometimes restless within sessions and chose to leave the room on occasion. This restlessness was particularly apparent during the Goodbye Song, when Sam would begin to ask questions about when his carer would be arriving to collect him. The project practitioners would try to keep Sam engaged in the musicking during these moments, but the Goodbye Song acted as an audible cue that
the sessions were ending which perhaps brought up concerns for Sam about when he would be meeting his carer. The practitioners would reassure Sam that his carer would arrive shortly, and encouraged him to have a cup of tea with them while he waited. Once Sam had received these reassurances he became more settled within the musicking space, laughing and joking with the project practitioners about what he had planned for the rest of the day.

Figure 30: Typical position of Sam within the musicking circle

4.7.2 Observation 1: Instrument Exploration and Musicality

Over the course of the programme, Sam was seen to actively participate in the sessions, whether through singing or playing a musical instrument. Sam appeared to need more support when singing, often looking towards Barbara for clarification of song lyrics, but had strong rhythmic abilities. Sam, more often than not, would choose a tambourine from the instrument table. He appeared to feel most comfortable with this instrument and would explore the different sounds he could make with the tambourine, varied his rhythms, and used a range of musical dynamics in his playing (loud vs. quiet). For example, during week 5 of the programme, Sam engaged in a lot of instrument exploration with a tambourine. He would use the
whole instrument in combination with his body in order to create new and interesting sounds (see Figure 31). The way in which he chose to play the tambourine was not necessarily consistent with the typical way of playing it, but this level of exploration perhaps suggested that Sam wanted to achieve a particular sound. His different playing techniques may therefore have represented his desire to meet a particular aesthetic goal. This highlights Sam’s creativity when interacting with the instruments, as he was not confined by conventional approaches to making sound but rather chose to explore the aesthetic qualities of instruments through his interactions.

Figure 31: Sam explores the different sounds of the tambourine using his body

The following excerpt, taken from the thick description of week 9, demonstrates how Sam explored the different sounds of the tambourine during one improvisation during week 9. It also demonstrates Sam’s inherent musicality in the way he was able to use musical dynamics, and musical phrasing in order to contribute musically to the musical atmosphere:

*Having chosen his instrument, Sam twirls the tambourine in his hand, rather than hitting or shaking it. This shows a level of creativity as he is not relying on conventional approaches to playing the tambourine, but rather explores the sounds of the instrument driven perhaps by the style of musical accompaniment provided by Barbara. Sam moves on from twirling the*
tambourine and begins to hit the tambourine on different parts of his body, perhaps enabling him to be able to feel the tactile sensations of the rhythmic vibrations on his body. He then moves on to playing the tambourine in the more conventional way.

He is very rhythmical and explores a variety of rhythms with the support of the musical accompaniment provided by Barbara. He returns to playing the instrument on his body, exploring the different sounds made by hitting the tambourine on his knee and his thigh. He incorporates musical phrasing into his playing, making it clear that he understands the musical structure of the piece. He explores musical dynamics within this phrasing by increasing the volume of his playing at the end of musical phrases. He appears very focussed on this playing, and does not look away from the tambourine. Even though he is not necessarily looking at Barbara or Nicola, he is repeating rhythmic patterns that Barbara has placed in the accompaniment. This shows that he is listening intently to what is being played in the supporting accompaniment, incorporating key rhythms and musical phrasing into his playing.

Sam incorporates a further method of playing the tambourine by running his hands along the metal bells. Barbara begins singing a melody to accompany the group with the lyrics “listen to the music we make”. Sam continues playing without looking up, but after the second repetition of these lyrics his gaze turns to Barbara. His playing of the tambourine becomes more exaggerated and he starts making bigger movements. His contribution on the tambourine can really be heard above the contributions of the rest of the group. Barbara begins incorporating his rhythms into her accompaniment, and Sam begins nodding his head as well as playing, bringing his whole body into his rhythmic music-making.

[Excerpt from Thick Description Week 9, 28.06.2017]

This excerpt highlights the innate musicianship held by Sam, and how the principles of choice and co-created music within the context of Music in Mind allowed Sam to express himself creatively through his interactions with the tambourine and other instruments. Although there were many moments of restlessness from Sam during
each *Music in Mind* sessions, he appeared most engaged when engaging in these moments of strong rhythmic improvisation.

The practitioners also commented on Sam’s creativity, discussing it within research interviews and their diary entries:

*Nicola: Sam’s so creative when he’s, with his instrument playing.*

[Practitioner Interview 03.07.2017]

*There were great moments of rhythmic presence from Sam.*

[Excerpt from Barbara’s Diary 09.08.2017]

*Sam – more relaxed this week. [...] very creative with tambourine.*

[Excerpt from Nicola’s Diary 31.05.2017]

### 4.7.3 Observation 2: Theatricality and Performance

Sam was a member of the group who created performances within the musical space, adding exaggerated gesture and facial expressions into his improvisations in order to convey a story. During one *Music in Mind* session, Sam initiated a musical conversation with me using a tambourine. Sam would shake his tambourine in my direction, seeking eye contact with me. I shook my tambourine in his direction as a direct response to his musical initiation. Sam began to vocalise alongside his tambourine playing, gasping and wailing, as if we were using the tambourines to fight one another. I joined in with this vocalisation, and our joint performance made the other group members laugh and smile. Barbara improvised an accompaniment alongside our musical ‘fight’ which was in the minor key, using a number of tremolando (a wavering musical tone) to build the tension and drama to our performance. In this moment, the focus of the whole room was on Sam and I, with everyone laughing along with us in this moment of musical comedy. Interestingly, I was so swept up in this moment that I did not change the view of the camera I was operating to be able to film Sam’s performance in this moment. Capturing the reactions became secondary to our shared experience ‘in the moment’. Sam gained a lot of confidence from this performance and subsequently initiated another musical
conversation with Nicola. Sam’s ability to add ‘drama’ to his improvisation allowed him to be in the musical spotlight, and express himself non-verbally through the music.

Another instance of Sam initiating a musical performance was observed when Sam engaged Alice (Manchester Camerata musician) in a ‘sword’ fight during an improvisation using the snare drum. The following passage, taken from my detailed case notes, describes the performance that was played out between Sam and Alice:

Alice places a beat on the drum and Sam clicks his drum stick on top of hers. This is another example of Sam exploring the different sounds that can be made by instruments. Alice plays the drum again and Sam exclaims “How dare you!” and then engages Alice in a mock sword fight using the drum sticks.

Barbara adopts a minor tone to accompany the sword fight. The attention of the room is on this interaction between Sam, Alice and Barbara. Sam then jokes saying “I don’t know who you are” to which Alice responds “I know who you are” which leads Sam to say “At least you do!”. This is perhaps some insight into his dementia, knowing that he has the condition and acknowledging that there is a possibility that he might ‘forget’ who he is. The trio laugh at this as it is very light hearted.

Barbara starts singing “Sam’s on the drum” and Sam begins to sing along with the melody, something he had not done before the interaction with Alice. Alice continues to play a variety of rhythms on the drum, and Sam copies these exactly, showing a good musical ear. The ‘sword fight’ resumes, with Barbara again adopting a minor tone to suit the acting out of a sword fight.

Sam says “I’m special” whilst looking towards Barbara, and Alice responds with ‘you are’. Although the comment made by Sam is a little tongue in cheek it might be him seeking reassurance that his contributions during the solo were valid.

[Excerpt from Thick Description Week 7, 14.06.2017]
This excerpt highlights how being in the musical spotlight allowed Sam the opportunity to communicate through musical performances, creating comedy through his playful interactions with instruments and other group members. It was rare during the programme for two practitioners to be focussed on one individual at the same time, and so this moment gave Sam a real opportunity to explore the drum musically and to perform to an ‘audience’.

4.7.4 Summary

Overall, although Sam was able to contribute a range of musical improvisations within the sessions due to his innate musicality and the support of the project practitioners. Sam became more relaxed within the sessions, and laughed and joked with the other group members. Although he would still ask where his carer was, Sam became absorbed within the music-making, especially during moments of joint performance with other group members (including myself). Sam had a preference for improvising using the tambourine and was seen to be less confident when contributing using other instruments. Although Sam joined in with the singing of familiar songs, he appeared to seek reassurance from the project practitioners perhaps because he lacked confidence in recalling the words to the melodies. Sam was able to incorporate theatricalities into his musical contributions, using exaggerated facial expressions and embodied comedic gesture in order to add life to his performances.

4.8 Summary of Case Studies

This chapter has presented six case studies, detailing the ‘in the moment’ embodied experiences of people living with dementia who took part in Manchester Camerata’s *Music in Mind* programme. Each case study highlighted key observations for each person living with dementia which were developed through a sensory analysis of the research data. These observations clearly illustrate each individual’s musical story within the context of *Music in Mind*, creating a musical narrative which privileges the voice of each person living with dementia. The case studies also highlight the relational and dynamic practices evident within musicking, recognising the shared notion of musical experience within a group setting. The next chapter draws together findings from a cross-case analysis of the data, highlighting elements of measurable experience which were translatable across group members.
CHAPTER 5. CROSS-CASE ANALYSIS

5.1 Introduction

This chapter presents the findings from the cross-case analysis of the data which was achieved using a thematic analysis approach. The aim of conducting a cross-case analysis was to enable the development of a thematic description of ‘in the moment’ embodied experiences, which would be translatable across people living with dementia, as well as to define elements of experience which would be measurable in the development of a future music assessment tool. The chapter presents three master themes: Sharing a Life Story through Music; Being ‘In the Moment’ with Music; and Musical Ripples into Everyday Life. Underlying each of these master themes are superordinate themes which capture holistic elements of experience, with the subthemes presenting ‘measurable qualities’ of such experiences. These ‘measurable qualities’ define elements of ‘in the moment’ experience which could be tangibly measured within a future music assessment tool, using an interactive and sensory lens. These measurable qualities were derived from codes underlying each subtheme which were triangulated across the video data, participant interviews and participant diaries. The chapter concludes with a table that summarises the cross-case analysis.

5.2 Overview of Case Studies

The following section will provide a brief overview of each case study as a means of contextualising the cross-case analysis.

Case Study 1: Scott

Scott was the only person living with dementia to attend all 15 sessions of the Music in Mind programme. He attended the programme with his wife Julie, who took their attendance in the programme very seriously. Scott used humour and physical comedy in order to make other members of the group laugh, often portraying his comedy through the music. Scott was also observed to be able to hold a strong, rhythmic beat but often could not hear himself in the music because he chose instruments which were not very loud. After encouragement from the project practitioners he began to
play louder instruments, and therefore received positive oral feedback that his contributions were valid in the musicking space. Scott formed a sense of connection with the other male members of the group, feeling a sense of affinity with Sam because of their shared love of Manchester City Football Club, and reaching out to Phillip during personally significant songs.

*Case Study 2: Henry*

Henry had a love of dance and Irish music, and was said to be the “life and soul of the party”. Henry and Jenny attended the *Music in Mind* sessions together, even though Jenny had chosen not to accompany Henry to other Manchester Camerata programmes. They shared moments of spousal connection throughout the programme, perhaps being able to forget the stresses of the external world, if only for a moment. Henry showed great skill in playing the glockenspiel. He would spend long periods of time improvising around the musical accompaniments of the project practitioners, showing extended periods of intense concentration and creativity.

*Case Study 3: Carol*

Music had always been a big part of Carol and Richard’s lives, having been members of several choirs and being part of a ‘record collective’ in the 1980’s. Carol had developed a number of anxieties since her diagnosis of dementia, and it took a lot of persuasion from Richard before she agreed to take part in the *Music in Mind* programme. Carol, though quiet at first, showed skills in rhythmic improvisation and began to gain the confidence to initiate musical conversations with the project practitioners. This confidence led to her incorporating performance into her improvisations, using exaggerated gesture and facial expressions to convey comedy. She felt a sense of connection to the other group members, stating that her favourite thing about *Music in Mind* was ‘the people’. Carol became more talkative in the later stages of the programme, with the project practitioners believing that this was due the transfer of confidence from being able to have sustained musical conversations.
Case Study 4: Phillip

Phillip was the group member who had challenges in expressing himself verbally. Phillip would not often play instruments spontaneously, and it would take a lot of support from project practitioners in order for him to play instruments by himself. Although Phillip did not actively engage with instruments on very many occasions, he did vocally improvise throughout the majority of sessions. This was only observable on the video and when Phillip found silences to improvise within. During these moments, Phillip became the centre of the group’s attention, positioning himself within a musical spotlight through his skilled vocal improvisation. Phillip also had strong emotional reactions to personally significant songs, which were introduced to the group by Esther, showcasing the strong link between his self-identity and music.

Case Study 5: Mary

Mary held strong Christian beliefs and believed that God had worked through the Manchester Camerata to allow her the opportunity to take part in the Music in Mind programme. Mary enjoyed introducing hymns and gospel music to the group, enabling her platform to extend her own worship and evangelise to the group. Mary particularly enjoyed singing Oh When the Saints and would manipulate the accompaniment being provided by Barbara in order to lead the group in song. In the first few weeks of the programme Mary was quite dominant in her playing, often choosing the loudest instruments. However, she began to see her role as more supportive in the later weeks of the programme, helping others to contribute actively within the music-making through allowing them to share the musical spotlight with her.

Case Study 6: Sam

Sam was the only member of the group who was not interviewed. However, it was possible to begin to understand Sam’s experiences through observations during the sessions and through interviews with project practitioners. Sam was very skilled in rhythmic improvisation, and would produce sustained improvisations on the tambourine (his favourite instrument). Sam would explore the different sounds that could be produced by the instruments, exploring the whole instrument rather than
relying on traditional methods of playing. This showed Sam’s creativity in searching for aesthetically pleasing sounds. Sam was not always confident in the lyrics to the songs that were being sung, but would look towards Barbara or Nicola for reassurance, seeking eye contact and mimicking the practitioners’ facial expression.

5.3 Thematic Description of ‘In the Moment’ Experience

The following section will present a thematic description of ‘in the moment’ experience derived from a cross-case analysis of the research data. As has been discussed in the Methods of Study chapter (p.108), this was achieved by considering elements of experience which were translatable across group members using a thematic analysis approach (Braun & Clarke, 2006). This approach to analysis was complemented by an in-depth understanding of each individual case through a lens of sensory and embodied experiences (Kontos, 2004, 2005; Pink, 2015). Each master theme will be presented in turn, with the underlying superordinate themes and subthemes presented alongside. This thematic description of ‘in the moment’ experience seeks to address objective (ii), as presented in the study aims and objectives (p.72)

Within each subtheme, I outline elements of musical experience which I believe would be measurable within the context of a future music assessment tool (research objective iii, p.72). I have used the term ‘measurable qualities’ as a way to define this concept. For each subtheme, there is a table including elements of ‘measurable qualities’ which provide an operational term for each quality as well as providing a definition. By providing elements of experience which are ‘measurable’, it provides a platform to bridge the gap between pure-quantitative and pure-qualitative research within this area, enabling an understanding based on embodied and sensory experiences while still satisfying the need to produce outcomes which can be compared across people living with dementia.

5.4 Master Theme 1: Sharing a Life Story through Music

This master theme encapsulates what the person living with dementia brought to the Music in Mind sessions from their previous life experiences. Although the aim of the research was to understand the ‘in the moment’ experiences of people living with
dementia when they engaged with music, it was difficult to disentangle such experiences from each individual’s life story. Each person’s life story had an influence on how they responded to the music and the way in which they interacted with the instruments. Although some elements of each individual’s life story became apparent within the context of *Music in Mind*, such as a preference for a particular musical style or a strong embodied or emotional reaction to a particular song, there were elements of experience that I only gained privileged access into through the research interviews.

Although the focus of the interviews was on the video of the *Music in Mind* sessions, I learned a lot about each couple, or individual, simply by entering their homes. For example, I learned of Scott’s love of wooden cuckoo clocks, and was told the story of how he came to acquire a particularly intricate clock which was hung in the dining room where the interview took place. I was shown photographs by Mary, who wanted to share images of her life in Nigeria before moving to the UK. I was shown Henry’s memory book that he had put together as part of a dementia support group, which Jenny was quick to point out was littered with errors. I did not actively seek out information about the group members’ life stories, but they were revealed to me in the contexts of their homes. Sam was the exception to this, as I was unable to interview him within the context of his home.

This theme highlights the importance of understanding the life stories of people living with dementia in order to contextualise their embodied and sensory responses to music. This is particularly important if the person living with dementia is unable to verbalise their life story for themselves, if their capacity to communicate through words has diminished as a result of their dementia.

This master theme has two superordinate themes: *Life History* and *Musical History*.

### 5.4.1 Superordinate Theme 1: Life History

Each individual’s life history contributed to their experiences within the *Music in Mind* sessions. Although I learned some aspects of each individual’s life history within the context of the *Music in Mind* sessions, there were many aspects of their personal biography that I was not aware of before asking questions within the
research interviews. For example, in order to gain contextual information to present alongside each case study, I asked questions surrounding when the couples had met, how long they had been married, and what their professions were. Even these very basic questions opened up a wealth of information about the individual’s life history, providing me with contextual information which may have influenced the individual living with dementia’s experience ‘in the moment’. These elements of each individual’s life story helped me to understand some of the embodied practices that were displayed during the sessions. Each individual’s body played a central role in expressing their own personal biographies through their bodily movements and their interactions with instruments. There were two very pertinent examples of embodied narratives observed through the ways in which Henry and Scott interacted with different instruments.

During one session Henry chose an ocean drum to play. On picking up the ocean drum, Henry tilted it on its side and began to play with his thumb and little finger. This was not the typical way in which the ocean drum should be played, with it usually making sound by the player rotating the drum so that the metal beads inside make a sound similar to the water rolling across the shore. Henry’s adoption of the position displayed in Figure 32, however, was more representative of the way in which a Bodhrán (an Irish frame drum) would be played, with the drum played on the knee and beater poised between the thumb and middle finger.

Figure 32: Henry plays the ocean drum in the style of a Bodhrán
It was not until interviewing Henry and Jenny that I learned of Henry’s Irish heritage, as indicated in the following quote:

*Henry: I’ve got a lot of Irish.*

*Jenny: Well all your family, you’re Irish bred weren’t you? English born but Irish bred.*

*Henry: Yeah. [Laughs]*

*Robyn: I think you said in one of the sessions about going to the clubs and the Irish music.*

*Henry: Oh yeah that’s right.*

*Jenny: The Clarence in Rusholme.*

*Henry: That’s what we would do, the Clarence yeah.*

*Jenny: On a Saturday or Sunday all the music, oh it was great, great, really great, yeah the old lady playing the Bodhrán, do you remember?*

*Henry: That’s right yeah.*

*Jenny: She was fabulous, a little old lady with a bun.*

*Henry: Yeah [laughing].*

*Jenny: Oh it was fabulous there then.*

[Henry and Jenny Interview 31.07.2017]

This could suggest that Henry’s adoption of this playing position may have been a bodily representation of his own life story, which may have been looked over had I not learned more about his previous life experiences outside the context of the *Music in Mind* sessions.

The second example was the way in which Scott chose to play the snare drum during a number of sessions. Scott, having seemingly no formal musical training in his life, adopted a ‘traditional grip’ of the drum sticks in order to play a solo during a game called *Who’s on the Drum?* which gave group members the opportunity to take a
drum solo, supported by a musical accompaniment. The confidence in which Scott picked up the drum sticks and adopted the playing position in Figure 33, suggested to me that Scott may have previous experience either observing others playing the drum or having some experience himself. During the first interview I conducted with Scott and Julie it was revealed that Scott had been a scout leader. It could well have been that Scott’s experiences with scouting could have influenced the ways in which he interacted with the snare drum.

These two examples demonstrate the intersection between a person’s life story, musical history and their ‘in the moment’ experience. Without my knowledge about the individuals’ life stories, moments like this would have gone unacknowledged. This further highlights the necessity to understand the biographical context that each individual brings to the musicking space, as their experiences ‘in the moment’ cannot be disentangled from the backdrop of their individual life story.

Figure 33: Scott adapts a ‘traditional grip’ hold of the drum sticks

Error! Not a valid bookmark self-reference. outlines measurable qualities of life histories derived from the research data.
Embedded within each individual’s life story was their own individualized and shared musical history. The term musical history encapsulates the experiences with music each person living with dementia had across their life time, whether it be experience of playing an instrument, or of biographically and/or culturally significant songs. For example, the song *Abide with Me* was a favourite song of Phillip’s because he chose the song for his confirmation at his church when he was younger. This element of his musical history was revealed during one *Music in Mind* session when Phillip became particularly teary over the singing of this melody. However, some group members did not recognise the significance of this song to Phillip, instead associating the song with rugby matches rather than it being a melody of religious importance. This demonstrates how each individual came to the group with their own musical experiences and preferences, which influenced the way they interacted with certain melodies or musical elements within the *Music in Mind* sessions.

As well as having an individual musical history, group members also demonstrated elements of a shared musical history with other group members, and this was determined by key demographic factors, such as age, gender and cultural background. For example, Barbara introduced the Hebrew song *Kol Ha’Olam Kulo* during one session, and Jenny commented on how it sounded very similar to *Chim Chimney* from the film *Mary Poppins*, which was a more relevant cultural reference to the majority of the group. However, this musical reference was not so clear to the group members.

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Profession</strong></td>
<td>The profession held by the person living with dementia.</td>
</tr>
<tr>
<td><strong>Significant Relationships</strong></td>
<td>Relationships that have been significant in the person living with dementia’s life (e.g. spouse, parents, children, friends etc.)</td>
</tr>
<tr>
<td><strong>Cultural Identity</strong></td>
<td>Information regarding group membership relating to nationality, ethnicity, social class etc.</td>
</tr>
<tr>
<td><strong>Hobbies and Interests</strong></td>
<td>Activities engaged with for leisure purposes (e.g. sport, art, literature etc.)</td>
</tr>
</tbody>
</table>

**5.4.2 Superordinate Theme 2: Musical History**

Table 10: Measurable qualities of life history
who had spent the majority of their lives living outside of the United Kingdom (Phillip, Esther and Mary). Thus, although the song was cemented within the musical histories of most group members, it was not within Phillip, Esther or Mary’s personal repertoire.

This perhaps provides additional validation of the *Music in Mind* improvisatory approach as it highlights how existing songs can alienate certain members of the group. Whilst individuals are not discouraged from bringing songs into the musicking space, the project practitioners are careful not to introduce new songs unless they have a relevance to the whole group. In this context, Barbara may have introduced the song as a ‘new’ musical reference for the group, having witnessed the value of the song *Da Na Se* within the sessions, and may not have realised the connections the melodic line of the piece may have evoked in the group members.

Table 11 presents measurable qualities of musical history which were derived from the research data.

Table 11: Measurable qualities of musical history

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Music of Cultural Significance</td>
<td>Music that has a shared component with other people who have had shared experiences due to demographic factors such as age, gender, culture etc.</td>
</tr>
<tr>
<td>Favourite Music</td>
<td>The particular songs or musical styles that resonate most with the individual.</td>
</tr>
<tr>
<td>Musical Experience</td>
<td>The interactions the person has had with musical instruments or choirs. Whether the person has had any formal musical training.</td>
</tr>
<tr>
<td>Music of Biographical Significance</td>
<td>Music that has played a role in significant life events such as birthdays, religious holidays, religious ceremonies etc.</td>
</tr>
</tbody>
</table>

5.5 Master Theme 2: Being ‘In the Moment’ with Music

This theme highlights the embodied and sensory experiences held by people living with dementia within the context of the *Music in Mind* sessions. These experiences were observable within the *Music in Mind* context, but at times transcended the boundaries of the musicking space into the everyday lives of people living with
dementia (See Master Theme 3: Musical Ripples into Everyday Life, p. 224). However, each superordinate theme had measurable qualities that were observable within the *Music in Mind* sessions.

This master theme is underpinned by four superordinate themes: *Musical Preferences, Musicianship, The Musical Body, and Connecting through Music.*

### 5.5.1 Superordinate Theme 1: Musical Preferences

This theme highlights the musical preferences of people living with dementia which were demonstrated through embodied and sensory practices. Though elements of musical preference were specific to the sessions themselves, there was also an interaction between a person’s present musical preferences and past musical history. For example, there were instances of people living with dementia offering up their ‘favourite songs’ within the context of the sessions, illustrating a verbal preference for particular songs or melodies which had been significant in their lives. Musical preferences were demonstrated through a change in seated posture, making movements or dancing to the musical beat, or cheering, whistling or laughing. People living with dementia were also shown to have preferences for certain musical instruments, returning to the same instruments week after week. Although some musical preferences were determined by previous musical histories, people living with dementia were also shown to develop new musical preferences throughout the duration of the *Music in Mind* programme.

This theme is comprised of two subthemes: *Instrument Preference* and *Preferred Music.*

#### 5.5.1.1 Subtheme 1: Instrument Preference

One of the key principles of *Music in Mind* is musical choice, and this was reflected through the ways in which group members interacted with the musical instruments across the duration of the programme. In the earlier weeks, while group members were learning the principles of *Music in Mind*, practitioners would ask group members to choose their instruments, often signalling towards the instrument table as a means of inviting people to choose for themselves. Participants would wait for a
member of the group to go to the table and choose, before gaining the confidence to choose an instrument for themselves. However, in the later weeks of the programme, the group members had learned of their musical agency and that they were not confined by any musical boundaries. This, combined with the failure-free musicking space, allowed participants to be more confident in their instrument selections. They no longer waited for the instruction to select an instrument, but acted with greater spontaneity. One example of this was when Carol and Richard joined the session part way through the Hello Song. Before even sitting down or taking off her coat, Carol walked with assertion to the instrument table upon entering the musicking space, selecting a maraca and moving rhythmically towards her seat in the circle. This musical agency was something that was supported by the practitioners who would bring a selection of instruments to those who could not leave their seats due to physical disability (e.g. Phillip and Scott). By bringing a selection of instruments it still afforded musical agency, allowing people living with dementia to feel a sense of choice even if they were unable to travel towards the instrument table unassisted.

From very early on in the programme it was evident that there were particular instruments that each group member was drawn to. Group members tended to return to the same instruments time and time again, unless encouraged to try something different by the project practitioners. This perhaps showed that each individual had a fondness for particular musical timbres (e.g. tonal qualities which differentiate the sounds of a tambourine and a woodblock). Group members were also aware of the instrument preferences of others, without these preferences having to be vocalised by the person living with dementia, with many group members mentioning the preferences of others within research interviews as the excerpt below highlights:

_Richard: And people certainly had their favourites in terms of instruments_  
[agreement from Carol] _Henry with the glockenspiel [Carol laughs] and Mary liked the pluck guitar thing [lyre]._

[Carol and Richard Interview 23.10.2017]

The image in Figure 34 depicts my interpretation of the instrument preferences of each individual living with dementia based on my reviewing of the video data and through conversations as part of research interviews. This is not to say that group
members did not develop new instrument preferences over the course of the programme. Henry, for example, started off the programme with a preference for maracas and bells but in the last five weeks of the programme was encouraged to play the glockenspiel and then this became his preferred instrument. He really thrived with this instrument once it was adapted by the project practitioners to only include notes which fitted within the musical keys being used as supporting accompaniment. This meant that no matter what notes Henry contributed it sounded aesthetically pleasing in the context of the musical accompaniment. This positive aural feedback led to sustained musical involvement from Henry, as every contribution he made was aesthetically pleasing.

Figure 34: The instrument preferences of group members

Interestingly, the group members also picked up on my own instrument preferences. I tended to choose a castanet in most sessions as it was a rhythmic instrument but was not a loud sound. It was also simple to play the instrument with one hand, which was essential as I was operating the video camera with the other hand. This meant that my playing was more in the background rather than being an instrument that would land me in the musical spotlight. This demonstrated by ability to reflect on my own instrument preferences, which highlighted to me that I had made active decisions surrounding the instruments I chose, and perhaps this strengthens the idea that
instrument choices by people living with dementia were active rather than passive driven by their own sensory preferences and embodied life stories.

Overall, this subtheme highlights that each person living with dementia resonated with a particular instrument, or group of instruments, within the *Music in Mind* sessions. These choices may have been a result of their previous interactions with such instruments, or due to the different sensory experiences that each instrument afforded.

Table 12 presents the measurable qualities of instrument preferences derived from the research data.

Table 12: Measurable qualities of instrument preferences

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instrument Choice</td>
<td>The person living with dementia chooses an instrument for themselves.</td>
</tr>
<tr>
<td>Favoured Instrument</td>
<td>The person living with dementia engages with the same instrument(s) over an extended period of time, whether this is during one session, or over a number of sessions.</td>
</tr>
<tr>
<td>New Instrument Preferences</td>
<td>The person living with dementia develops new instrument preferences through engaging with novel instruments.</td>
</tr>
</tbody>
</table>

5.5.1.2 Subtheme 2: Preferred Music

This theme highlights that there were different types of musical accompaniment, or melodies, which resonated with different individuals in the group. Such preferences were outwardly displayed both verbally and non-verbally (e.g. cheering, sitting forward in their seat, dancing). Individuals showed both a preference for certain musical styles (often familiar songs) but also different musical elements (harmony, rhythm and melody). There were a range of different musical styles that group members resonated with. For example, Mary enjoyed melodies which were in a major key with simple chord progressions, perhaps reflective of many of the gospel songs that were an integral part of her life, whereas Henry really appreciated rhythms and melodies from Cuban music, as well as Rock ‘n’ Roll. These preferred musical styles
seemed to therefore have a connection to the individuals’ musical history and life story, with each member of the group resonating with different musical styles.

The quotes below are taken from participant interviews demonstrate the different music preferences of the group members both in terms of the music they liked within the session, and their preferences outside of the session:

*Mary:* We pray before they [grandchildren] go to school and they bring up [sings] “Oh when the saints go marching on” which is my favourite.

[Mary Interview 08.09.2017]

*Jenny:* you’ve always loved different music. You like your heavy rock didn’t you?

*Henry:* Yeah it was a bit.

*Jenny:* That bloody Kerrang stuff that was never, but yeah, we’ve always liked music haven’t we?

[Henry and Jenny Interview 02.10.2017]

*Barbara:* They say that we’re all rhythmic, I mean, that’s we’ve got predominantly one or the other, rhythmic beings, harmonic beings, I mean each of these musical parameters define any individual I think.

[Practitioner Interview 31.07.2017]

Table 13 highlights the measurable qualities of the preferred music derived from the research data.
Musicianship is an overarching term which encompasses musical skill and performative abilities which enabled an individual to both contribute musically and bring their performance to life. In a biomedical or care discourse, it may be easy to forget that people living with dementia have creative abilities and talents. The word ‘talent’ is often reserved for those who are highly proficient in musical skill, having nurtured their skill over many years. However, there were innate talents (such as rhythmic abilities, musical phrasing and the use of embodied gesture to convey a story through the music) that the group members displayed during their creative music-making.

Such talents were often acknowledged through the group by means of a round of applause and/or cheering. This positive feedback may have instilled a sense of belief in the person living with dementia, reinforcing their sense of contributing as equals within the musicking space. This creative equality was illustrated in a number of quotes from the research interviews:

*Julie: I think [music] just puts everybody on a level. You don’t realise some of them are disabled, you know, because they don’t need to they just do it. I mean*
some of them need a bit of help to get going but once they get going I think that it masks, not masks the disability, but the disability isn’t important. We’re all equal and it equalises them all I think.

[Scott and Julie Interview 26.06.2017]

Nicola: And you just hear people’s voices when their voices, like Scott, his voice isn’t what it was, he can’t express himself vocally like that but we all know that he’s speaking [agreement from Barbara] ... It’s just so equal isn’t it? That’s what’s so nice about it [agreement from Barbara].

[Practitioner Interview 26.09.2017]

Nicola: I think it’s also with knowledge, everyone in the group knows that Phillip knows [Da Na Se] and loves it as well. So that’s when we’re talking about all being equal that’s the point in the session, when you know that there’s something that every single person will connect with.

[Practitioner Interview 26.09.2017]

The following section will outline the three subthemes underlying the Musicianship theme: Musical Skill, Musical Performance, and The Flow of the Moment.

5.5.2.1 Subtheme 1: Musical Skill

The Musical Skill theme highlights the technical abilities held by the people living with dementia in contributing music during the sessions. These skills were recognised by other group members both in the sessions (signified by the giving of a round of applause) or discussed within interview settings. Below are a number of quotes taken from participants that illustrate the musical skill of the people living with dementia enrolled in the Music in Mind programme:

Julie: [Mary] plays that [glockenspiel] lovely doesn’t she? Yes, she plays it really well I think... You look very professional there Scott [referring to his ukulele playing].

[Scott makes a saluting action and we laugh together]
Julie: Gosh, he’s playing really well isn’t he! […] I hadn’t realised you’d played that much. You obviously enjoyed playing that Scott. That was amazing. With him sitting next to me I didn’t realise he’d played it quite so well…

[Scott and Julie Interview 26.06.2017]

Barbara: Carol comes in off-beat with long up beats. It’s quite intricate, it’s quite varied and imaginative and it’s not copying but responding, which shows a sense of independence and musicality and courage and imagination.

[Practitioner Interview 14.06.2017]

These quotes demonstrate how the musical skills of the people living with dementia were acknowledged by other group members, with there often being a level of surprise at how well the person was able to contribute musically. These skills were also seen to develop over time, with some of the group members living with dementia showing improvements in their musical skill over the duration of the Music in Mind programme. For example, the two excerpts below demonstrate the difference in the conversation surrounding Henry’s rhythmic abilities between the first few weeks of the programme, and those further down the line:

Barbara: It’s a puzzle because I wrote up last session and I thought when he played the drum it was very active and very vigorous and very energetic but it was musically incoherent.

[Practitioner Interview 07.06.2017]

Barbara: […] within the last 30 seconds or so he’s [Henry], decided to get involved isn’t he, he’s decided to play longer phrases.

Nicola: And exploring more of the instrument, he was only exploring the top end at first.

Barbara: That’s it he’s gone to the bottom end and [sings] and a mixture of semi-quavers and quavers.
Nicola: *In a way that fits more with the pulse, whereas it was more random before.*

[Practitioner Interview 31.07.2017]

These quotes from the practitioner interviews demonstrate how Henry’s musical skill improved over time, moving from playing randomly to then being able to play with the musical beat. This shows an improvement in technical musical ability over time, yet previously developed music assessment tools might not take into consideration the importance of learned skills.

Table 14, highlights the measurable qualities of musical skill which were derived from the research data.

Table 14: Measurable qualities of musical skill

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Rhythmic Abilities</strong></td>
<td>The person living with dementia is able to keep in time with the musical beat.</td>
</tr>
<tr>
<td><strong>Tempo Manipulation</strong></td>
<td>The person living with dementia is able to change the tempo by speeding it up, or slowing it down.</td>
</tr>
<tr>
<td><strong>Improvisational skill</strong></td>
<td>The person living with dementia is able to create new music (improvise) around an accompaniment, showing evidence of a novel musical contribution.</td>
</tr>
<tr>
<td><strong>Instrument Exploration</strong></td>
<td>The person living with dementia explores the different sounds that can be produced by an instrument. This exploration may contain unconventional means of playing the instrument (e.g. using the rim of a drum to produce a different sound to the skin of a drum).</td>
</tr>
<tr>
<td><strong>Musical Leadership</strong></td>
<td>The person living with dementia is able to lead the group in musicking, whether this is through conducting, or gesturing to encourage the involvement of others.</td>
</tr>
<tr>
<td><strong>Musical Dynamics</strong></td>
<td>The person living with dementia uses musical dynamics (loud vs. soft) in order to convey emotion through their playing.</td>
</tr>
</tbody>
</table>

### 5.5.2.2 Subtheme 2: Musical Performance

This theme highlights the performative abilities of people living with dementia during the *Music in Mind* programme. People living with dementia were able to not only...
contribute skilled music, but also bring their performances to life. This often resulted in the people living with dementia being in a ‘musical spotlight’ with all group members focussing their attention on the performance that was taking place. The performative elements of an individual’s musical contribution were often driven by embodied musical gesture, with group members incorporating their bodies into their performances, producing exaggerated and often comedic gestures. The images on Figure 35 present two examples of how gesture was incorporated into musical performance, with both Scott (left) and Carol (right) making exaggerated gestures and facial expressions in order to add a performative element to their musical contribution. Both of these movements warranted laughter from other group members, who recognised the humour in their performances.

Figure 35: Exaggerated gestures and facial expression in musical performance

There were also examples of joint performance between a person living with dementia and other group members, often the project practitioners. In the image below (see Figure 36), Anne (left) and Sam (centre) engaged in a mock sword fight during a moment of musical improvisation. The focus of the room was directed towards this interaction as it unfolded, and the group laughed at the comedic moments created by the musical performance. Such musical performances therefore enabled the person living with dementia to use embodied gesture to be able to tell stories through their music making, assuming different character roles and portraying comedic moments through their creative interactions with instruments and other group members.
Figure 36: Sam and Anne engage in a play fight

Table 15 outlines the measurable qualities of musical performance which were derived from the research data.

Table 15: Measurable qualities of musical performance

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Playfulness</strong></td>
<td>The person living with dementia engages with their instrument or another group member in a way that is light-hearted and fun.</td>
</tr>
<tr>
<td><strong>Comedic Gesture</strong></td>
<td>The person living with dementia uses gesture to express a comedic idea, such as wiping their forehead to express ‘fatigue’ after a particularly long improvisation.</td>
</tr>
<tr>
<td><strong>Joint Performance</strong></td>
<td>The person living with dementia tells a story through their performance with another person. Each person in the performance takes on the role of a character which is expressed through altering facial expression and gait.</td>
</tr>
<tr>
<td><strong>Exaggerated Facial Expression</strong></td>
<td>The person living with dementia adopts exaggerated facial expression, often to convey comedy, such as looking aghast or curious.</td>
</tr>
</tbody>
</table>
5.5.2.3 Subtheme 3: The Flow of the Moment

This theme represents the sustained musical contributions of people living with dementia. People living with dementia were able to engage in continuous improvisation over many minutes, appearing completely immersed in the music-making experience. During these moments, the people living with dementia were shown to take little notice of what was going on around them, getting swept up in their creation of melodies and rhythms. These instances were perhaps signifying that the people living with dementia were entering a flow state, which is a creative state of complete concentration and full involvement (Csikszentmihalyi, 1997, 2014). During these moments of flow, people living with dementia showed sustained and creative musical improvisation, and returned quickly to their flow state even if they were distracted by something external to their musicking experience. The quote below illustrates how Henry returned quickly to his flow state, even when his instrument momentarily failed him:

Nicola: What was interesting was when he turned [the glockenspiel] upside down he was still in the zone then [agreement from Barbara] cos he immediately...

Barbara: ...came back to it.

Nicola: Immediately came back to it. He’s still there, he’s still focussed, he’s thinking about it you know, yeah.

[Practitioner Interview 31.07.2017]

Mary was the only person living with dementia in the group who was able to articulate her flow state. The following quote from Mary highlights the feelings of intense concentration she experienced while improvising:

Mary: I was able to play all things, makes meaning to me, I don’t know whether it’s making any meaning to anybody else but it’s giving me concentration. You know I found it difficult to concentrate, first I wanted I would stop it, I’d start another thing, I’d stop it but when I’m playing one thing I tend to get the concentration. I want to hear what I’m playing whether
it’s making any good sound that makes meaning or I’m just making a noise but I can see it bringing down my concentration and I would like to focus on it for the period I’m holding that particular one, I want to make good use of it. Then that is the spirit of the music bringing down, but after I drop it there I can start doing anything that doesn’t coordinate before that period I want the best, I think I’m putting my best, it’s like putting your best, play what you can play that is why you see me, I play many many things but I think it makes sense to me ’cos I can hear the sound and I’m enjoying it. It might not be pleasant to another person ’cos I’m not listening to that one, I’m listening to what I am but when we do like this you know that somebody’s listening to you that.

[Mary Interview 08.09.2017]

This excerpt illustrates that music enabled Mary to experience a state of intense concentration in which she was fully immersed. She highlights that the music she made in these moments was for her own goals alone, as she was not worrying about how others would perceive the music she is making. It is evident that these moments were significant and meaningful for Mary, and allowed her to produce music that was aesthetically pleasing to her.

Flow states are not easy to measure through observation alone as they are purely subjective experiences. However, it was possible to gauge moments of flow through the reactions of other group members. Those in a flow state often entered a ‘musical spotlight’ in which the person living with dementia would become the focus of the group’s attention. This was indicated through group members orienting their bodies towards the person in the musical spotlight, watching the musical performance unfold (see Figure 37). This was an interesting phenomenon to observe, as often the person living with dementia would be unaware of being in a ‘musical spotlight’ due to their intense involvement in their own musicking practices.
Table 16: Measurable qualities of the flow of the moment

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sustained Concentration</strong></td>
<td>The person living with dementia has a sustained moment of concentration. They are completely focused on the instrument they are playing and not on external factors to this experience.</td>
</tr>
<tr>
<td><strong>Returning to Flow</strong></td>
<td>The person living with dementia returns to a flow state after the flow of the moment has broken. They return to playing their instrument with complete concentration.</td>
</tr>
<tr>
<td><strong>Being in the Musical Spotlight</strong></td>
<td>The focus of the room is on the person living with dementia. Group members orient their bodies towards the person living with dementia, listening to and watching their musical contributions intently.</td>
</tr>
</tbody>
</table>
5.5.3 Superordinate Theme 3: The Musical Body

This theme illustrates the role of the body in producing music, as well as examining the role of dance as a bodily response during musicking. This theme places the body as central to musical experiences, meaning the interaction between music, the body, and sensory experience is emphasized. People living with dementia were observed to engage their whole bodies in the musicking process, often using instruments as an extension of their bodies. All group members used their bodies as a means of connecting with the music, with each member of the group contributing their own musical improvisations rather than passively listening to contributions made by others. This gave the people living with dementia a sense of agency which was acted through their musical bodies.

The two subthemes underlying this theme are: Active Musicking and Dance.

5.5.3.1 Subtheme 1: Active Musicking

This theme highlights the active musical contributions of people living with dementia. People living with dementia showed active musicking through the use of instruments and their own vocalisations. The musicking was defined as active because the person living with dementia was making music, rather than listening only. The bodies of people living with dementia held a central role within active musicking, whether it is through using the body as an instrument in its own right (e.g. clapping, tapping, singing), or through the interactions between body and instrument (e.g. tapping the instrument on different parts of the body as a means of exploring sound). There were many examples of active musicking within the context of Music in Mind, which reflects the key principles of the programme such as improvisation and choice.

Music in Mind participants were seen to be very creative in the ways in which they explored sound using their bodies. For example, Sam and Scott would explore the different sounds of the instruments by tapping them on different parts of their bodies, perhaps seeking a particular aesthetic quality to the sound. Furthermore, group members such as Mary would seek novel ways of playing instruments, by adapting instruments to achieve a desired sound (e.g. playing the ocean drum in the style of a bass drum). The availability and choice surrounding the instruments allowed for this
creative exploration of sound by the group members, meaning they made active choices within a musical environment which encouraged instrument exploration and improvisation.

It was not always easy to discern when a person living with dementia was making an active musical contribution. Phillip, for example, chose to contribute through his own voice rather than engaging with any of the instruments that were available to him. It was only through Phillip finding silences within the sessions that his voice was able to be heard, and group members began to acknowledge his active contributions within the musicking space. Phillip’s contributions that were not in the silences were more difficult to hear within the sessions and it was not until reviewing the video and audio data that it became apparent quite how frequent his musical vocalisations were. Thus, active musicking was not dependent on the playing of musical instruments.

Table 17 presents the measurable qualities of active musicking, derived from the research data.

Table 17: Measurable qualities of active musicking

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clapping</td>
<td>The person living with dementia rhythmically taps their hands creating audible sound.</td>
</tr>
<tr>
<td>Tapping Feet</td>
<td>The person living with dementia rhythmically taps their feet creating audible sound.</td>
</tr>
<tr>
<td>Thigh Tapping</td>
<td>The person living with dementia rhythmically taps their thighs creating audible sound.</td>
</tr>
<tr>
<td>Vocalization</td>
<td>The person living with dementia uses their voice to make audible sounds (other than singing), such as humming, clicking and whistling.</td>
</tr>
<tr>
<td>Singing</td>
<td>The person living with dementia sings along with a melody or improvises a melody line with lyrics.</td>
</tr>
<tr>
<td>Body Tapping</td>
<td>The person living with dementia taps their instrument on different parts of their body to produce rhythm.</td>
</tr>
</tbody>
</table>

5.5.3.2 Subtheme 2: Dance

There was an abundance of dance and movement within the *Music in Mind* sessions. There were certain group members who showed instances of spontaneous dance, such as Henry and Mary, and others who were encouraged to dance by their spouse, or the
project practitioners. Dance was present as a volunteered contribution within every session. For the most part, the dancing was observed whilst participants were seated (see Figure 38), but there were a number of occasions where participants got up out of their seats in order to dance in the middle of the circle (see Figure 39). The middle of the circle was reserved predominantly as a place for the instrument table, but as the weeks went on it became a performance space where people living with dementia could be the focus of the group’s attention whilst dancing or enacting a story through musicking.

Figure 38: Henry and Jenny dance while seated

![Figure 38: Henry and Jenny dance while seated](image)

Figure 39: Phillip, Esther and Barbara dance together in the centre of the circle

![Figure 39: Phillip, Esther and Barbara dance together in the centre of the circle](image)

The notion of dance was discussed in a number of interviews across the *Music in Mind* programme. Dance seemed impulsive rather than pre-planned, allowing the
group members to express themselves freely through bodily expression as and when they pleased. The following quotes highlight the incidence of dance within the *Music in Mind* sessions:

*Esther: Phillip started with the beat and then I join in and then it started, we started dancing, it is just wonderful what happened there*

[Phillip and Esther Interview 07.08.2017]

*Mary: If there is music they remember in their youth you know the music I had when I was young is not the one you had when you were young, that you like to dance give opportunity to people to dance the music of their own age. Music to remember, music to remember and the way they dance.*

[Mary Interview 08.09.2017]

Table 18 presents the measurable qualities which underlie the dance subtheme, derived from the research data.

Table 18: Measurable qualities of dance

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Seated Dance</strong></td>
<td>The person living with dementia dances in their seat, moving their body in time to the musical beat.</td>
</tr>
<tr>
<td><strong>Standing Dance</strong></td>
<td>The person living with dementia dances out of their seat, with or without the support of another person.</td>
</tr>
<tr>
<td><strong>Dancing Together</strong></td>
<td>The person living with dementia dances with another person, whether this is seated or standing.</td>
</tr>
</tbody>
</table>

5.5.4 **Superordinate Theme 4: Connecting through Music**

This theme highlights the way in which music-making enabled the person living with dementia to feel connected to other members of the group. This theme is based around the relational aspects of ‘in the moment’ experience. Sharing in a unifying experience enabled the person living with dementia to make meaningful connections with other group members, whether it was their spouse, other group members or the project practitioners. This sense of connection allowed the person living with dementia to feel more confident in their musical contributions, feeling more relaxed in the company of
the other group members as the sessions went on. There were instances of enhanced physical contact and eye contact within the sessions. The feeling of being connected through music enabled group members to connect physically through touch (see Figures 40 and 41) and enhanced the eye contact between group members (see Figure 42).

This theme is underpinned by three subthemes: *Body Synchrony*, *Musical Communication*, and *Emotional Experience*.

Figure 40: Physical connection between myself and Scott

![Image of people sitting close together, possibly indicating physical connection.](image1)

Figure 41: Jenny and Mary embrace one another

![Image of two people embracing, indicating physical and emotional connection.](image2)
5.5.4.1 Subtheme 1: Body Synchrony

In the *Music in Mind* group, people’s bodies were seen to synchronise both with the musical beat and the bodies of others. This was most obviously observed when individuals swayed from side to side with the music, their bodies almost taking on the role of a metronome. Synchronisation was not only experienced by single group members, but rather the experience extended to other group members, meaning that there were instances where three or four group members would be moving their bodies in synchrony with each other. This subconscious bodily entrainment could have enabled the people living with dementia in the group to feel more connected to other group members because their experiences were in synchrony. The image below (Figure 43) presents the ways in which group member’s bodies moved in synchrony with the musical beat. Although these are static images it is still possible to see the ways in which group member’s bodies synchronised when musicking.

The notion of synchronisation was also picked up upon during research interviews with participants commenting on the swaying in the video, or swaying themselves when watching back the motions on screen:

*Julie: Look we’re all swaying… Even you!* [Robyn]

[Scott and Julie Interview 26.06.2017]
The other means through which the bodies of the people living with dementia synchronised with the bodies of others was through mimicry. People living with dementia were skilled imitators of gesture, facial expression and musical phrases. For example, during one warm up activity, group member’s mimicked Mary’s gestures after her requests to sing a song which incorporated movements. She made this suggestion after hearing that I had registered for a 10 kilometre run, and expressed that she wanted to help me train for it. Figure 44, below, depicts the group mimicking the gestures offered up by Mary, perhaps enabling the group to feel a sense of cohesion, moving as a collective body.
People living with dementia were also able to mimic musical phrases, repeating back melodies or rhythms offered up by the project practitioners or other group members. Although there were no members of the group who had received formal music training, the people living with dementia were able to listen to the musical phrases that were offered by other group members, and repeat them back. This created a sense of musical cohesion, signalling that the person living with dementia was actively listening to the contributions of others, and responding through mimicry.

Table 19 outlines the measurable qualities of the body synchrony which were derived from the research data.

Table 19: Measurable qualities of body synchrony

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Swaying</strong></td>
<td>The person living with dementia sways in time to the musical beat.</td>
</tr>
<tr>
<td><strong>Synchronised Swaying</strong></td>
<td>The person living with dementia sways in time with one or more people.</td>
</tr>
<tr>
<td><strong>Body Mimicry</strong></td>
<td>The person living with dementia mimics the body movements of another person, such as gesture and facial expression.</td>
</tr>
<tr>
<td><strong>Musical Mimicry</strong></td>
<td>The person living with dementia mimics musical phrases offered up by others, such as melodic or rhythmic musical phrases.</td>
</tr>
</tbody>
</table>
5.5.4.2 Subtheme 2: Musical Communication

People living with dementia were able to use music as a communicative device within the *Music in Mind* sessions. Within the social time, people living with dementia tended not to join in with the conversations that were going on around them unless they were asked questions. This perhaps showed that they were less confident in communicating verbally. This was also seen within the music-making part of the sessions when members of the group erupted into verbal conversation which was more difficult for the person living with dementia to contribute to. However, when working with the tools of music, the people living with dementia could engage in meaningful communication without the need for words. This enabled the people living with dementia to have a sense of agency within the sessions, connecting them to other people in the group through the common language that was music.

Some members of the group were able to sustain a musical conversation for far longer than a verbal conversation. For example, Henry often lost his trail of thought when trying to express himself verbally but when he was able to express himself musically he was able to use his instrument as his voice, playing loudly and confidently, seemingly unafraid of forgetting his words. Furthermore, Henry used his instrument to convey melodies from songs that he knew but could not remember the title of as this excerpt reveals:

*Nicola: I knew straight away what he was thinking* [in reference to melody Henry has played on the glockenspiel] *and I held off saying but I knew exactly what it was ‘cos he’d just done* [sings Heidi Hi melody] *Heidi Hi, I just knew, I just knew what it was ‘cos it did the same to me ‘cos that’s what I thought the moment he did it.*

[Practitioner Interview 31.07.2017]

These moments of musical connection between the person living with dementia and other group members allowed them to develop new relationships or enhance the relationships they already had, such as the relationship between them and their spouse. The quote below highlights Mary’s view that musical communication made for a unifying experience:
Mary: Yeah you feel, you feel you are coordinating it’s a communication, you can see all of us when somebody plays this one, plays another one, that is communication accepting the music that we are one because we want to make something good out of what we are doing.

[Mary Interview 08.09.2017]

Table 20 outlines the measurable qualities within the musical communication theme, which were derived from the research data.

Table 20: Measurable qualities of musical communication

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Initiating Musical Conversation</td>
<td>The person living with dementia starts a musical conversation with another person.</td>
</tr>
<tr>
<td>Sustained Musical Conversation</td>
<td>The musical conversation between a person living with dementia and another individual lasts over an extended period of time, usually longer than four bars of musical accompaniment.</td>
</tr>
<tr>
<td>Responding to Musical Contributions of Others</td>
<td>The person living with dementia notices a musical idea provided by another person and responds with their own musical idea, which begins a musical conversation.</td>
</tr>
<tr>
<td>Sound Matching</td>
<td>The person living with dementia produces a sound that matches the contributions of another group member, which begins a musical conversation.</td>
</tr>
</tbody>
</table>

5.5.4.3 Subtheme 3: Emotional Experience

This subtheme highlights the incidence of expressed emotions with the Music in Mind sessions. Engaging in creative-music-making resulted in a number of emotions being expressed by people living with dementia and other group members. The emotions that were expressed by individuals seemed to transfer to other group members, which created an overwhelmingly positive and supportive environment in which to create new music, with group members smiling, laughing and expressing pride during the sessions. Laughter was the most common outwards expression of emotion within the sessions, with this laughter extending outside the sessions within research interviews. Group members would laugh when reflecting on their experiences within the group, perhaps reliving the emotions whilst watching the video. Laughter was mentioned on
numerous occasions within interviews with the people living with dementia and their family members, such as with the following quote:

\[\text{Julie: It just shows how much how relaxed they are and how much they're enjoying it and gelling together, you know. Nobody's laughing at anybody they're all laughing together. [...] until you see it back you don't realise to what extent it is. I mean I've learnt a lot from just watching these and I think you know I hadn't realised how much we laughed and how much we... I mean I knew we laughed in these and it's enjoyable but it's just how much and I think it's part of the enjoyment of the of the session I think, the laughter, 'cos it, well it would be awful if we didn't laugh and we just sat there and just played wouldn't it really.}\]

[Scott and Julie interview 26.06.2017]

When negative emotions were expressed they tended to be reflective, such as crying as a result of hearing a personally significant song being played in the group, for example:

\[\text{Esther: Phillip...ahh can you see that, he's emotion, he's emotion. That's the day that he cried. It's the song, yeah.}\]

[Phillip and Esther interview 07.08.2017]

Although Philip experienced a perceived ‘negative’ emotion, he was able to show his connection to the song through his embodied response to hearing it. Group members became very supportive in this moment, allowing Phillip to process this emotion in the context of the musicking. The strength of receiving this piece of music within the supportive context of the \textit{Music in Mind} session may have allowed Phillip the space and time to process his emotion, and respond to this significant piece of music without fear of judgement. Although the expression of sadness may be seen in other contexts in a person with dementia’s everyday life as a sign of distress, discomfort or pain, for example, the musical context in which these emotions were experienced allowed space for emotional catharsis in a supported environment. The presence of the music therapist, and the dynamic that had been built across the group over the programme, allowed each individual to have a safe space in which to experience and
reflect upon the different emotions that were evoked. The skill of the trained music therapist within these emotionally inducing musical moments was to allow space for the person to process their emotions, and support them through using music as a platform through which to share their musical story, emotions and life story.

Table 21 presents the measurable qualities of emotional experience, as derived from the research data.

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laughter</td>
<td>The person living with dementia is seen to be laughing.</td>
</tr>
<tr>
<td>Smiling</td>
<td>The person living with dementia is seen to be smiling.</td>
</tr>
<tr>
<td>Reflective Emotion</td>
<td>The person living with dementia cries, or expresses sadness as a result of hearing a personally significant song or piece of music.</td>
</tr>
</tbody>
</table>

### 5.6 Master Theme 3: Musical Ripples in Everyday Life

Although the primary aim of this research project was to understand the ‘in the moment’ experiences of people living with dementia when engaging in creative music-making, it became evident that there were ripple effects of sustained benefit outside of the Music in Mind sessions. In the wider literature, the focus is often on whether a person living with dementia can remember the music session or has observable benefits in terms of the reduction of ‘behavioural and psychological symptoms of dementia’. However, the findings from the data collected in this study gave a more intricate sense of the benefits that lasted outside of the session, which included benefits at home, as well as in the wider community.

The Musical Ripples in Everyday Life theme consists of two superordinate themes: Home and Community

#### 5.6.1 Superordinate Theme 1: Home

This theme represents the ripple effects that were observed within the home environments of the people living with dementia and family carers. These observations were recorded as a result of me visiting the homes of the people living with dementia in order to conduct the research interviews. A number of group
members had made changes to their home environments in order to allow for the presence of music in their day-to-day lives outside of the musicking space. For example, on visiting Mary for the second interview, which took place after the *Music in Mind* programme had ended, she showed me that she had purchased a digital radio. She told me that she found that she was able to listen to her favourite gospel songs because there was a radio station dedicated to worship songs that she tuned into every day. During the *Music in Mind* sessions Mary connected spiritually with God through her music-making, and so actively sought to find a means of maintaining that religious connection outside of the sessions within her home environment.

Jenny also sought strategies in order to bring music in to her and Henry’s home. Jenny purchased a glockenspiel perhaps as a result of acknowledging Henry’s talent for playing the instrument. Jenny expressed concern in our second interview that Henry got bored very easily at home and acknowledged that making music was something that kept him engaged far longer than any other activity she had thought of before. Jenny may have seen the musical potential that Henry had through attending the sessions together, and then made changes to their home environment in order to keep Henry stimulated and engaged whilst at home.

Another example of how music transcended into the home environments of people living with dementia was the requests by family carers to be given DVD or audio of the *Music in Mind* programme, perhaps as a means of ‘re-living the moment’. It was evident during the video-elicitation interviews that the people living with dementia involved in the programme recognised themselves and the core songs that were learnt during the sessions. I believe that requesting copies of the video was a means of potentially ‘reliving the moment’, where the person living with dementia and their family member could return to the music together outside of the session time. However, as ethical approval was not sought for such a possibility, I was not able to give participants the video footage to be able to use within their own homes.

Table 22 presents the measurable qualities of ripple effects into the home environments of people living with dementia.
Table 22: Measurable qualities of ripple effects into the home

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alterations to Home Environment</td>
<td>The person living with dementia, or their family carer, brings music into the home such as through the purchase of musical equipment.</td>
</tr>
<tr>
<td>Re-Living the Moment</td>
<td>The person living with dementia sings songs, makes vocalisations or embodied movements related to the music programme or reminisces about their time in the programme.</td>
</tr>
</tbody>
</table>

5.6.2 Superordinate Theme 2: Community

This theme highlights the ripple effects of experience taken with the person living with dementia into their wider communities. There was evidence of people living with dementia, and their family carers, becoming more involved in their wider communities as a result of taking part in the *Music in Mind* programme. For example, during one session, Carol and Richard brought leaflets with them advertising an exhibition at the Whitworth Art Gallery (part of The University of Manchester) called *Beyond Dementia*. As a result of this invitation, Jenny, Henry, Julie and Scott attended the exhibition and thus engaged with the wider arts community in Manchester. Jenny described to me how Henry had become so entranced by the music exhibit as part of the exhibition that he became tangled in the headphones because he wanted to dance, forgetting that he had been wearing them:

*Jenny:* ‘Cos we went to that thing at the Whitworth, that dementia thing and he had it on then and it was somebody’s playlist and he was listening to it and of course he gets up dancing in the Whitworth, forgot he was attached you know with [headphones].

*Henry:* Yeah! [laughs]

[Henry and Jenny Interview 02.10.2017]

This demonstrates how people living with dementia were able to engage with cultural institutions that they had not engaged with before, perhaps seeking experiences similar to that held within the context of the *Music in Mind* programme.
As well as engaging with arts institutions within the local community, the people living with dementia and their family members taking part in the study were also invited to talk at workshops and conferences in order to directly share their experiences of being involved in the *Music in Mind* programme. In order to protect the identities of those involved in the project I will not disclose the events that the group members spoke at. Furthermore, the group members were invited to consult on the development of a children’s show which had ‘dementia’ as a core theme, in order to share their views on the content of the show, as well as contribute artistically to the development of dance movements which were used in the show.

Table 23 defines measurable qualities of ripple effects into the communities the people living with dementia lived in.

Table 23: Measurable qualities of ripple effects into the community

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Engaging with Cultural Institutions</td>
<td>The person living with dementia engages with other arts institutions within their community, such as art galleries and music venues.</td>
</tr>
<tr>
<td>Sharing Musical Stories</td>
<td>The person living with dementia shares their experience of taking part in the music programme whether this is in more formal settings, or sharing with family and friends.</td>
</tr>
</tbody>
</table>

5.7 Cross-Case Analysis Overview

The cross-case analysis of the research data revealed a number of ‘in the moment’ embodied and sensory experiences held by people living with dementia engaging in *Music in Mind*. Table 10 presents an overview of the master themes, superordinate themes and subthemes that were developed as part of the thematic description of such ‘in the moment’ embodied and sensory experiences. Underpinning these themes were measurable qualities of experience which presented elements of embodied and sensory practices that were observable within the video data, and could be used as units of measurement within a future music assessment tool. These measurable qualities have been combined within Appendix 15 as a means of illustrating the potential domains of measurement within such a tool.
Table 24: Presentation of cross-case analysis themes

<table>
<thead>
<tr>
<th>Master Themes</th>
<th>Superordinate Themes</th>
<th>Subthemes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing a Life Story through Music</td>
<td>Life History</td>
<td>Musical History</td>
</tr>
<tr>
<td>Being ‘In the Moment’ with Music</td>
<td>Musical Preferences</td>
<td>Instrument Preference</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Preferred Music</td>
</tr>
<tr>
<td></td>
<td>Musicianship</td>
<td>Musical Skill</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Musical Performance</td>
</tr>
<tr>
<td></td>
<td>The Musical Body</td>
<td>The Flow of the Moment</td>
</tr>
<tr>
<td></td>
<td>Connecting through</td>
<td>Active Musicking</td>
</tr>
<tr>
<td></td>
<td>Music</td>
<td>Dance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Musical Communication</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Body Synchrony</td>
</tr>
<tr>
<td>Musical Ripples into Everyday Life</td>
<td>Home</td>
<td>Emotional Experience</td>
</tr>
<tr>
<td></td>
<td>Community</td>
<td></td>
</tr>
</tbody>
</table>

The themes themselves present a new way of understanding the benefits of music for people living with dementia by bringing together each person’s life story, ‘in the moment’ experiences, and musical ripples into everyday life. This approach differs to ‘before and after’ methods of measuring the benefits of music for a person living with dementia and allows the voice of the person living with dementia to be central within such assessment. This approach to measuring ‘in the moment’ experience, combined with an individual case study approach allowed for a more holistic account of experience than current approaches to measuring the impacts of music allow for. This method therefore advocates longitudinal case study approaches to understanding the benefits of music, following the person living with dementia throughout a musicking programme and observing the benefits within their everyday lives. By shifting the discourse from the measurement of ‘behavioural and psychological symptoms of dementia’ on to the musical contributions and creativity of people living with dementia, it is possible that the music and dementia literature can move beyond a discourse that values music as a method for ‘symptom’ reduction alone.

5.8 Summary

This chapter has presented a cross-case analysis and thematic description of the ‘in the moment’ embodied and sensory musical experiences of people living with dementia engaging with Manchester Camerata’s Music in Mind programme. Although
the focus of the research was to determine the ‘in the moment’ experiences of people living with dementia, it was difficult to disentangle such experiences from the individual’s life stories and the ripple effects into their everyday lives. Thus, this dynamic interaction over time begins to build a picture of the benefits of music across the duration of a music programme, which is information that would have been overlooked had standardised outcome measures been used in the context of this research. The next chapter will seek to contextualise these findings in the broader literature, and consider the methodological and theoretical implications of the research.
CHAPTER 6. DISCUSSION AND CONCLUSIONS

6.1 Introduction

This chapter will begin by presenting an overview of the key findings of the study, emphasising a new way of understanding the ‘in the moment’ embodied musical experiences of people living with dementia. The findings of this research will be linked to the wider music and dementia literature, and a new framework for measuring ‘in the moment’ musical experience will be presented. Following this, there will be a reflection on the theoretical implications of this research study, considering broadening the scope of positive psychology to include notions of embodiment and citizenship. Next, I will critically appraise the research methods for this study, returning to the objectives of the research outlined in the Methods of Study chapter. This section will include a critical reflection on the strengths and limitations of the research, as well as a reflection on my role as a participant-observer. The chapter will end with an overview of the implications this research has for practice, policy, research and education.

6.2 Summary of Findings

This study sought to understand the ‘in the moment’ embodied and sensory experiences of people living with dementia when engaging with a creative music-making programme. The research utilised a multiple-case study design, drawing on multiple methods (video-observation, video elicitation interviews, participant diaries and researcher reflexivity) and multiple perspectives (the person living with dementia, family carers, project practitioners and my own perspective as participant-observer) in order to gain an in-depth, exploratory account of ‘in the moment’ experience. As far as I am aware, this is the first study to explore the ‘in the moment’ musical experiences of people living with dementia where the focus has been placed on understanding embodied and sensory experiences.

The findings of this research were narrated through individual case studies of people living with dementia, combined with a cross-case analysis of the data. Each case study introduced key observations, developed through a sensory analysis of the data,
which highlighted how people living with dementia connected or re-connected to their self-identity through embodied and sensory practices, and to other group members through their creative music-making. The music that was created within the *Music in Mind* sessions had centrality within the case studies, allowing for a demonstration of the skills and creativity of people living with dementia rather than focussing upon how music alleviated ‘behavioural and psychological symptoms of dementia’. This approach thus privileges the voices of people living with dementia, allowing a narrative to be developed which highlights each person’s life story and creative contributions within the musicking space.

The cross-case analysis presented in Chapter 5 illustrated three master themes (*Living a Life Story through Music*, *Being ‘In the Moment’ with Music*, and *Musical Ripples into Everyday Life*), which were underpinned by superordinate and subthemes, as summarised in Table 24 (see p.228). The cross-case analysis also presented measurable qualities of experience, which provide a new means of measuring the impacts of music for a person living with dementia, as summarised in Appendix 15. The themes presented as part of the cross-case analysis will form the basis of a new music assessment framework called *In the Moment Profiles*, which will be developed as part of on-going research (see p.246). By following this approach, this study has presented an original and theoretical contribution to the literature.

Drawing on the longitudinal nature of this research engagement, Figure 45 is a further attempt to place the three master themes’ headings in a heuristic which frames the importance of time. I will now discuss each of the master themes in turn, linking them to the wider dementia studies literature.

**Figure 45: Conceptual model of 'in the moment' musical experience**
6.2.1 Living a Life Story through Music

The first master theme presented as part of the cross-case analysis of the data was *Living a Life Story through Music*. Although the aim of this study was to develop an understanding of ‘in the moment’ experience, the role of each individual’s life story and musical history was shown through their embodied practices within ‘the moment’. I was able to gain privileged access to group members’ life stories by being able to conduct the video-elicitation interviews within participants’ homes. This information allowed me to contextualise some of the embodied reactions to music within the sessions (e.g. Phillip’s reaction to the singing of *Abide with Me*; Henry’s Bodhrán playing etc.) and understand expressions of embodied selfhood through gesture and performance (Kontos, 2004, 2005). The importance of understanding each individual’s life story was highlighted particularly within Sam’s case study as there was an absence of interview data. This meant that my understandings of his experiences were based solely on what was observed within the sessions. My interpretations of Sam’s experiences within the sessions were therefore less holistic accounts of experience than I was able to produce for the other group members. Life story thus seemed an important factor in creating a backdrop to each individual’s ‘in the moment’ musical experience. The following section will explore current understandings of life story work with people living with dementia, and examine the applicability of life story work within the context of music programmes for people living with dementia.

Life story work has become increasingly common in recent years, particularly within dementia care settings (i.e. care homes). Life Story has been defined by McAdams (2001) as “*psychosocial constructions, co-authored by the person himself or herself and the cultural context within which that person’s life is embedded*” (p.101). This definition first highlights the telling of life story from the person themselves, as well as embedding life story within the context of the person’s life. When living with dementia, a person may not be able to retell their own story verbally, but with support from those who have played a central role in that individual’s life it is possible to construct the life story of an individual from multiple perspectives (Gaughan et al., 2016). Thus, understanding ‘in the moment’ musical experiences through the lens of each individual’s life story, and drawing on the multiple perspectives of those who
have played central roles within such life stories, we may begin to be able to further understand the expression of embodied selfhood (Kontos, 2005) within the context of creative music-making.

On examining the music and dementia literature, there appears to only be one example of an intervention that combined life story approaches with music. Kindell et al. (2018) designed an individually tailored life story intervention based around music for a person living with semantic dementia. The aim of the intervention was to facilitate enhanced interactions between the person living with dementia and their family members through the use of a co-produced life story music DVD. This approach differs to reminiscence-based musicking programmes, as the core aim was to improve communication rather than to evoke memories through music. The DVD enabled the person living with dementia to connect to family members through song, and enhanced participation in everyday interactions. This research demonstrates the applicability of combined music and life story approaches which aim to enhance interactions between people living with dementia and family members. This approach is equally as valuable within creative music-making programmes such as *Music in Mind*, as gaining an understanding of the life stories of those living with dementia both through what is revealed during musicking, as well as what is learned as contextual information outside of the musicking setting, provides a more holistic account of experience then current methods of evaluation would allow for.

An element of life story that was particularly relevant in the *Music in Mind* sessions was individual cultural heritage. There were many different cultural heritages represented within the group, including three group members who had spent the majority of their adult lives living outside of the UK. Although everyone in the group was viewed as equal within the musicking space, there were musical references that were not as obvious for those who had not lived in the UK their entire lives. For example, songs emerged within sessions which resonated strongly with certain group members (e.g. *Singing in the Rain*; *The YMCA*; *In the Summertime*), but were unfamiliar to other group members (e.g. Mary, Phillip and Esther). This demonstrates that although there was a shared musical history between those from a specific cultural background, these parts of the *Music in Mind* session may not have been as inclusive to those from different cultural backgrounds. However, the focus of *Music
in Mind is not on the singing of familiar repertoire, with the key principles of the programme being based around improvisation and choice. This focus on improvisation and creating new music presents a more accessible musicking programme for people living with dementia from different cultural backgrounds. The immersive and creative experience allows for a group culture to be developed in which there is a shared musical history which is unique to each Music in Mind programme.

It has been proposed that the majority of those taking part in music programmes, and the arts more generally, for people living with dementia are White women (Bellass et al., 2018) and so it is important that when developing existing programmes, or creating new programmes of activity, that they are inclusive as possible for those from Black and Minority Ethnic (BME) groups, who are underrepresented in research (Cooper, Tandy, Balamurali, & Livingston, 2010) and receive more challenges relating to their access to support and services following a dementia diagnosis (Moriarty, Sharif, & Robinson, 2011). There are currently very few examples of musicking programmes which are specifically developed for BME populations (see for example: Together in Song Gospel Choir, Together Dementia Support, 2018) and there is a lack of reporting regarding the ethnicities and cultural backgrounds of music group research participants within the music and dementia literature. Within the context of this research, this issue was evident when collating information regarding the studies that were included within the literature review presented in Chapter 2. Although I attempted to obtain information regarding the ethnicities of those involved within research it was not widely reported and so it was not possible to present this information within the review. This illustrates the need for more transparency in the reporting of the ethnicities and cultural backgrounds of those taking part in music activities, but also a push towards ensuring access to both music programmes and research studies for BME groups.

Overall, understanding the life stories and musical histories of people living with dementia appears to be a fundamental component of contextualising ‘in the moment’ musical experiences. By obtaining information relating to each individual’s life story, it may be possible to begin to understand expressions of embodied selfhood which transpire through the medium of music. Music appears to be a tool through which the
musical identities and preferences of people living with dementia can begin to emerge, and so it is important to consider life story when interpreting outwards expressions of identity through the bodies of people living with dementia.

6.2.2 Being ‘In the Moment’ with Music

The second master theme developed through the cross-case analysis of the data was being in the moment with music. This theme encapsulated the embodied and sensory experiences held by people living with dementia whilst they were engaging with music. Creative practices and musical processes were incorporated within this theme, placing emphasis on the retained skills of people living with dementia which were showcased through improvised music-making. The embodied and sensory experiences were defined as measurable qualities, and were observable within the video data. This theme was underpinned by four superordinate themes: Musical Preferences, Musicianship, The Musical Body, and Musical Communication. The following section will outline the superordinate themes in turn and discuss their applicability to the wider music and dementia literature.

Musical Preferences

The first superordinate theme was Musical Preferences. This theme brought to light individual preferences towards particular instruments, musical styles, melodies and rhythms. Such preferences were consciously acknowledged by people living with dementia on a number of occasions (through phrases such as ‘that’s nice’ or ‘I like that’) but in many instances people demonstrated embodied preferences which did not need to be articulated to be understood. For example, salsa rhythms and musical accompaniments representative of Cuban musical styles would always resonate strongly with Henry, and he would often get up and dance within the centre of the musicking circle. Henry, thus, did not need to articulate his preference for such genres of music, but rather showed the group his preferences through his embodied actions. This resulted in such musical styles becoming more frequently used within sessions, as an acknowledgement to Henry’s musical preferences and identity. Such embodied responses to music, may be representative of an embodied musical self (Kontos et al., 2014), where people living with dementia are able to communicate their musical preferences through embodied action, as well as verbally.
People living with dementia were also shown to develop new musical preferences across the duration of the *Music in Mind* programme. For example, in the earlier weeks of the programme, Carol chose instruments that produced sounds which merged with the musical contributions of others (maracas, egg shakers), but was drawn to louder instruments later in the project (such as the cowbell and horn). This change in musical preference was perhaps as a result of the confidence she had developed as part of the programme, but may also have been facilitated through the key principles of choice and creativity which were central within the *Music in Mind* programme. This clearly demonstrates the changes in musical preferences across the duration of the programme, and highlights the necessity to provide opportunities for people living with dementia to engage with a range of musical repertoire and styles (Dowlen et al., 2017; Unadkat et al., 2017).

_Musicianship_

The second superordinate theme was *Musicianship*. This theme highlighted the musical skills of the person living with dementia, their use of performance within music and the experience of flow within the context of the *Music in Mind* sessions. Within the wider dementia studies literature there is a tendency for a focus to be placed on what is ‘lost’ as a result of a diagnosis of dementia rather than the capabilities a person retains throughout their dementia journey (Reed et al., 2017). However, in the music and dementia literature the acknowledgement of the musical skills of people living with dementia seems almost exclusively reserved for those who have been professional musicians or had formal musical training (see for example: Arts 4 Dementia, 2015; Cowles et al., 2003). The current literature therefore overlooks the innate musical skills held by people living with dementia who have not had formal musical training.

The findings of this study make it clear that the acknowledgement of musical skill should not only be reserved for those who have formal musical training, but should be recognised in those who engage with music more informally. This acknowledgement would enable people living with dementia to be seen as people with agency, rather than there being a focus on what the person has ‘lost’ as a result of their dementia (Boyle, 2014). Furthermore, it highlights the necessity for stimulating and exciting
musical interactions, where skill is recognised beyond the remit of remembering song lyrics and positions people living with dementia as active musical contributors.

As part of their musicianship, people living with dementia were observed to bring their musical improvisations to life, creating stories and conveying emotions through their embodied musical performances. People living with dementia used a range of facial expressions and exaggerated gesture in order to convey comedy and emotion through their musical performances, often using instruments as an extension of these embodied practices. Many of the musical performances created by people living with dementia had the goal of comedy or humour. For example, Scott would often use slapstick comedy and Carol would use exaggerated facial expression and gestures within her musical performances. Within positive psychology frameworks, humour and playfulness have been presented as positive character traits (Peterson & Park, 2004), which enable a person to develop meaningful connections to other people. There are a number of different types of humour that have been defined, but the one most associated with the displays of humour observed during musical performances is Affiliative humour, which is humour used to amuse others and strengthen social relationships (Martin et al., 2003). There is very little focus placed on humour within the dementia studies literature, even though many people living with dementia report the importance of playfulness and humour in their lived experience of dementia (Grierson, 2008). Music, in the context of this research, provided an opportunity to create playful exchanges and seek moments of comedy which enabled the people living with dementia to express themselves through the telling of musical stories. Such embodied performances may have been enabled through the Music in Mind programme as it is viewed as a ‘failure free’ environment where every contribution is recognised and valued.

Finally, the musicianship displayed by people living with dementia enabled them to enter a flow state during musicking. Flow has been defined as “the holistic sensation present when we act with total involvement” (Csikszentmihalyi, 2014b, p.136) and is a central component of the ‘Engagement’ domain of Seligman’s (2011) PERMA model of positive functioning and flourishing. Flow states have been reported to have strong links to self-reported wellbeing and life satisfaction (Seligman, 2011) and are said to be achieved when the activity being engaged with is challenging and meets the
skills of the person engaging with the activity (Csikszentmihalyi, 2014b). If an activity is too challenging the person may feel a sense of anxiety or worry, but if it is too easy the person may experience boredom (Csikszentmihalyi, 2014b). It could be argued that Music in Mind provided an opportunity for people living with dementia to have flow experiences through the combination of challenging and stimulating improvisatory music-making matched with the inherent musical skills of people living with dementia.

Flow is a subjective experience and thus is notoriously difficult to quantify (Nakamura & Csikszentmihalyi, 2014). There have been a number of scales which have been developed in order to measure flow experiences through self-report questionnaires (see for example: The Dispositional Flow Scale – 2, Jackson & Eklund, 2002) but it has been proposed that such scales reduce the experience of flow to a number, losing the richness of the subjective experience (Sinnamon, Moran & O’Connell, 2012). Within this research there was only one group member (Mary) who was able to verbally articulate the feeling of being in a flow state, asserting that she felt moments of intense concentration where she forgot factors external to the musicking space. However, although the other group members with dementia were not able to articulate such experiences verbally, their embodied practices within the context of Music in Mind strongly suggested an experience of flow. For example, people living with dementia were observed to engage in sustained improvisation over extended periods of time, wholly focussed on their instrument. Furthermore, people living with dementia were shown to return to flow states quickly, even in the face of distraction from external factors (e.g. other group members having verbal conversations). This research therefore demonstrates that although people living with dementia may not be able to articulate flow states verbally, there is a possibility to examine flow experiences through the embodied practices of people living with dementia during musicking.

The Musical Body

The third superordinate theme was The Musical Body. This theme highlighted the ways in which the person living with dementia actively contributed within the musicking space, using their bodies as a means of producing sounds or interacting
with the instruments. It also revealed the centrality of dance and movement within embodied musical experiences.

The first subtheme, *Active Musicking*, recognised the agency of the person living with dementia in producing music through their bodies. Although there were musical instruments available to group members, the people living with dementia were the instruments, using their bodies to produce sound either through singing, vocalisations, or the playing of instruments. People living with dementia were very creative in the ways in which they interacted with the instruments, such as tapping the instruments on different parts of their bodies to find the musical aesthetic they were seeking. The acknowledgement of active musicking by people living with dementia presents them as having agency through their embodied musicking practices (Kontos et al., 2014). Such active musicking was enabled through the *Music in Mind* programme, with there being many instruments available to people living with dementia, as well as opportunities for vocal improvisation. Group members appeared to be most comfortable improvising using the instruments, but one group member (Phillip) showed active musicking through his vocalizations throughout the programme. Active music therapy techniques stress the importance of providing a wide range of sound possibilities, which enable the person living with dementia to contribute based on their own preferences (Guetin et al., 2012). Having access to such a wide array of instruments, combined with the expertise of the *Music in Mind* practitioners may have enabled a greater degree of active musicking than may have been observed in programmes which do not offer such a wide range of sound possibilities.

This theme also highlighted the musical agency and creative choices which were shown by people living with dementia. The *Music in Mind* programme allowed a platform for the feeling of agency and choice, with one of the key principles of *Music in Mind* being ‘choice’. This means group members are encouraged to explore the instrument table themselves and to have freedom to play instruments, or vocalise, in any way they choose: knowing they are heard by others in the group through practitioner-supported musical development. As has been discussed within the cross-case analysis chapter, the array of instruments on offer, as well as the encouragement offered by project practitioners, allowed people living with dementia to recognise their own agency within the context of sessions, knowing that they did not have to
wait to be told to choose an instrument. This process was non-verbal, with practitioners first facilitating understanding of the central role of the instrument table, but then allowing space for group members to develop their own sense of agency through their choice in instrument, and creative choices in how they choose to use those instruments. Recognising the agency of people with dementia through embodied action is something that has received very little attention within the literature (Kontos, 2004), yet this research has shown the capacity for musical agency and creative choice by people living with dementia in the context of a music programme.

The key elements of *Music in Mind* which allow for the embodied expression of agency by a person living with dementia are brought about by translatable principles of enthusiasm by practitioners, playfulness, and failure-free environments. Such elements are directly translatable to other arts-based programmes, such as dance and visual arts, and place the person living with dementia as a creative equal. The role of the arts in providing opportunity for expressions of embodied agency is a new, and vital, realm of research which needs further exploration. This research has clearly demonstrated the potential of improvisation-based music programmes in enabling a person living with dementia to develop their own sense of agency, and for others to witness these intact abilities for choice and control.

The second subtheme, *Dance*, recognised the abundance of dance and seated movement across the duration of the *Music in Mind* programme. People living with dementia would dance in their seats, moving their bodies in time with the musical beat, or would use the centre of the circle as a performance space. Although dance and movement were observed to be central within the *Music in Mind* sessions, the role of dance is very rarely recognised within the music and dementia literature even though there are many overlaps between the two art forms. For example, when the focus of investigation is examining movement and music, emphasis is often placed on how music enables increased movement to meet physical outcomes. However, it is clear that music and dance are intertwined, with dance being an embodied response to musicking. In some cultures there is no distinction between the words for music and dance, with a single word being used interchangeably to convey the meaning of both, thus suggesting there is not one without the other. For example, there are several African languages which use the same words to refer to both music and dance,
suggesting a clear link between music and embodied action (Besson & Schön, 2001). It is therefore clear that the role of dance and movement within musicking practices is lacking within the music and dementia literature, further highlighting the disembodiment narrative which is common in studies to date. This research, however, has placed the body as central within musicking experiences and has highlighted the strong connection between music and embodied practices.

Connecting through Music

The final superordinate theme was: Connecting through Music. This theme highlighted the relational nature of musicking, and how music acted as a tool for making, or enhancing the connections felt between the person living with dementia and other group members. Group members related to each other through embodied practices, enabling connections to be developed through non-verbal practices. This highlighted the creative equality within the musicking space, where each person’s contributions were recognised and valued both verbally (through applause and cheering) and non-verbally (through physical touch, eye contact and sustained musical conversations).

The first subtheme underlying this superordinate theme was Body Synchronisation. This theme outlined the ways in which the person living with dementia’s body synchronised with others’ bodies through musical entrainment. Group members were often seen to be swaying in synchrony, their bodies entrained to the musical beat being provided through the musical accompaniment. Entrainment has been described as the process by which the human body synchronises with a musical beat (Clayton, 2012) and is typically measured through the measurement of physiological factors such as heart rate or skin conductance (see for example: Khalfa et al., 2008; Trost, Labbé & Grandjean, 2017). However, the synchronisation of the group members’ bodies to the musical beat was an observable phenomenon which did not require the measurement of physiological responses. This may have enhanced the sense of connection felt between the person living with dementia and other group members because it enabled them to embody the actions of others, building a sense of oneness with the other members of the group (Hefferon, 2015).
People with dementia were also seen to mimic the gestures, facial expressions and musical contributions of others, or be mimicked themselves. These mimicking actions were often non-conscious, with the person living with dementia spontaneously mimicking the actions others. There has been a wide body of work which has sought to understand the role of mimicry within interpersonal relationships (see for example: Chartrand & Dalton, 2009), with some proposing that mimicry enables enhanced social connectedness and empathy between individuals (see for example: Stel & Vonk, 2010). The process of musicking may have enhanced the possibility for conscious mimicry within the Music in Mind sessions due to the emphasis placed on play and improvisation, but also the occurrence of non-conscious mimicry driven by the social bonds developed through making music together. Thus, the sense of musical equality created through the Music in Mind sessions enabled a sense of connectedness to be built between the person living with dementia, their family carers, and the rest of the musicking group.

The second subtheme was Musical Communication. People living with dementia were able to use music as a communicative tool in order to connect with other group members. For example, there were instances of group members engaging in musical conversations with another musical partner, exchanging musical phrases as if in a musical ‘ping-pong’ match. People living with dementia would, on occasion, initiate these conversations themselves, seeking eye contact with their intended musical partner before initiating their opening musical phrase. This enabled people living with dementia to connect on a level that did not require words, with music becoming a universal language across group members.

There are a number of theoretical links between language and music which have been presented within evolutionary psychology literature (see for example: Mithen et al., 2006; Molino, 2000), with it being proposed that music and language may have co-evolved within human culture (Mithen, 2009). This highlights the idea there is something innately human about using music as a form of non-verbal communication. Although a number of studies have discussed the role of musical communication as non-verbal language (Campbell et al., 2017; Habron, 2013b; Vink et al., 2011), there has yet to be a detailed exploration surrounding the dynamic interactions and processes that underlie this process. Further research needs to be conducted which
focuses on the use of music as a communicative tool for people living with dementia, in order to disentangle the complexities of this non-verbal language. These questions were beyond the scope of the research presented in this thesis, but reveal interesting opportunities for future research.

The final subtheme was Emotional Experience. People living with dementia were shown to display a number of emotions across the duration of the Music in Mind programme. Laughter and smiling were prevalent features within each of the sessions, and such emotional experience transferred into the video-elicitation interviews. The displaying and experience of emotions was observed to be a social action, enabling the person living with dementia to display their enjoyment of musicking through facial expression and outwards emotional expression. These expressions of emotion were typically categorised as ‘positive emotions’, such as laughter and smiling, but on occasion people living with dementia were seen to appear saddened by particular pieces of music that were brought into the sessions. This was often because the piece of music was related to their personal biography, with Phillip, for example, becoming emotional after hearing his favourite song Abide with Me. I interpreted Phillip’s emotion in this moment as reflective, as he did not appear distressed by the experience. Esther also showed no concerns during this moment, placing her hand on Phillip’s knee while he cried, perhaps as a means of showing her support of him in this moment. Such ‘reflective emotions’ are very rarely acknowledged within the music and dementia literature, with a focus being placed on the experience of ‘positive emotions’. However, it is important to acknowledge that music does not always induce such positive emotions, and can be used as a means of processing challenging emotions (see for example: Ahmadi, 2013; Lenette, Weston, Wise, Sunderland, & Bristed, 2016).

There have been a number of studies which have sought to understand the emotional value of music for people living with dementia (see for example: Götell et al., 2009). However, the majority of these studies examine the potential of music to improve mood, rather than considering the ways in which emotions evoked during musicking can enhance a sense of connection between a person living with dementia and other people. Within the context of this research, music provided a platform for the experiencing of shared emotions, with laughter being a core component of each Music
in Mind session. Such emotional transference may have enabled the people living with dementia to feel a sense of emotional connection with the other group members, with many different emotions being evoked through musical improvisation, performance and storytelling.

Overall, the Being in the Moment master theme emphasised the role embodied and sensory experiences had within the context of Music in Mind. Embodied practices were central within the sessions and enabled people living with dementia to have active agency through their bodily interactions within the musicking space. Music therefore acted as a vehicle for embodied selfhood, interconnectedness with other group members and the showcasing of musical skills. The following section will present the elements of experience which transcended the boundaries of the musicking space into the everyday lives of the people living with dementia.

### 6.2.3 Musical Ripples into Everyday Life

The final master theme that emerged as part of the thematic description of ‘in the moment’ experience was Musical Ripples into Everyday Life. This master theme highlighted the effects of music that were observed outside of the Music in Mind sessions within the homes and wider communities of people living with dementia enrolled in the programme. For example, some group members made alterations within their homes through the purchasing of musical equipment, such as a digital radio and a glockenspiel; while others connected with cultural institutions within their communities, such as attending the Beyond Dementia exhibition at the Whitworth Art Gallery. This meant that the experiences held by the people living with dementia transcended the boundaries of the musicking space, enabling them to engage with music in their everyday lives.

Within the research literature, there has been very little examination of the benefits of music beyond the remit of the musicking spaces. The current approaches to measuring impact, as discussed in Chapter 1, often include measuring ‘behavioural and psychological symptoms of dementia’ at a follow-up point a number of weeks after a programme has come to a close, but does not consider how musicking might influence the daily lives of people living with dementia. This was especially important in the context of this research as the group members were all living within the community.
rather than within a care setting. Music provision within care homes is often part of scheduled activity, but there is far less known about how people living outside of care settings engage with music in their day-to-day lives (Elliott & Gardner, 2018). The development of this theme demonstrates the utility of case study research in gaining a holistic account of a given context, as I had not entered the field expecting to gather any data relating to the musicking practices that were adopted within the everyday lives of people living with dementia but they were revealed to me as a result of visiting the group members within the contexts of their homes.

This theme also highlights the possibility of leaving a musical legacy in the lives of people living with dementia beyond the remit of a structured music programme. There is a possibility that there are a number of ethical issues related to the withdrawal of such meaningful activity, with music programmes often coming to an abrupt end due to the nature of funding or because of the length of a trial within research. Although this research has demonstrated that there are benefits for the person living with dementia outside the Music in Mind sessions, it was evident from the group members that they would miss partaking in the musicking activities as well as being able to meet with the other group members. For example, although living in close proximity to one another, Mary discussed how difficult it would be for her to meet with Phillip and Esther due to her inability to drive and lack of confidence in using public transport.

Manchester Camerata as an organisation is aware of the potential ethical issues attached to a short project length and so has begun to trial approaches to enable the continued engagement with improvisatory music-making after the programme comes to an end. Music in Mind brings together a musician and music therapist across 15-weeks, but the costs associated with this co-facilitated approach equate to more than a music listening only approach. Thus, with elevated costs, it is difficult to run Music in Mind programmes for longer than 15-weeks at a time. Although the health economic benefits of Music in Mind were not explored within the scope and remit of this study, and have not been formally evaluated for any other Music in Mind programme, this is something that could be of high importance within future planning in regards to research and evaluation.
Although there has yet to be a formal evaluation of the health economic benefits of *Music in Mind*, Manchester Camerata is seeking to develop new means of ensuring the legacy of the programme lasts beyond the 15-week timeframe. In a new co-delivery approach, Manchester Camerata have trained activities co-ordinators in improvisational techniques in order to be able to extend the legacy left by the *Music in Mind* programme. The evaluation of this pilot co-delivery approach to *Music in Mind* (HKD Research, 2018) resulted in the development of a *Music in Mind* CD which included musical accompaniments in different styles which could be used as a backdrop for the music therapeutic techniques that the activities coordinators had been trained in. One activity coordinator highlighted the difference in the CD compared to other music tools they had engaged with in the past, highlighting that the key principles of *Music in Mind* were still central to the music activities once the project practitioners had concluded the programme. Although this approach has been trialled within a care home setting, there is potential for this approach to be used for those engaging with community-based *Music in Mind* programmes. There appears to be scope to deliver a similar style of training for family carers, enabling them to engage with the *Music in Mind* principles within the contexts of their own homes.

Overall, there are many impacts of musicking beyond the musicking space which go beyond the measurement of ‘behavioural and psychological symptoms of dementia’. Though the primary aim of this research was to explore ‘in the moment’ experience, it is clear that it is necessary to measure musical engagement outside the context of the musicking space in order to build a more holistic account of the benefits of music for the person living with dementia.

**6.2.4 Future Directions: In the Moment Profiles**

This research has developed a thematic description of the ‘in the moment’ musical experiences of people living with dementia as experienced during the *Music in Mind* programme. The themes and measurable qualities of experience presented in Chapter 5 will form the basis for the development of a new music assessment framework named *In the Moment Profiles* (see Figure 46). The aim of this framework will be to provide a means of measuring ‘in the moment’ musical experience where the person living with dementia is placed centrally, enabling the telling of individual musical stories, as well as the measurement of tangible outcomes across the duration of a
music programme. The themes developed as part of the thematic description of experience will be used as domain headings in order to capture the different elements of experience within the framework protocol. In order to provide contextual detail to the interpretation of ‘in the moment’ musical experiences, the framework recommends the use of an interview prior to the outset of a music programme, in order to understand the individual’s life story and musical history.

The use of video and audio data collection will form a core basis of the tool, as a means of recording the multisensory experiences of people living with dementia during musicking. This means that the tool will not be a ‘pen and paper’ measure, as many standardised outcomes are, but will rather capture multisensory data as a means of building a holistic account of experience for each person living with dementia. Thus, the *In the Moment Profile* framework will be developed to be a computer tablet-based application which can capture the multisensory elements of experience through the built in camera and microphone of the computer tablet. The findings presented in this study establish the foundations for this framework and future research will seek to develop and pilot the application to test its applicability and feasibility within the context of music programmes for people living with dementia. Specifically, it is important to consider the development of the *In the Moment Profiles* framework within a myriad of contexts, especially examining the translatability of findings to care home settings, BME populations and a wider range of dementia diagnoses than those represented within this research.

The key emphasis within the tool combines music and embodied experience. There are currently no standardised outcome measures used within the music and dementia literature which place music centrally within understanding. The only tools which currently examine the musical skills of people living with dementia are those from a music therapy discipline (Cripps et al., 2016), which are used in the context of music therapy assessment rather than within research. The exclusion of musical concepts in current outcome measures overlooks the creativity of the person living with dementia, placing them as a passive recipient of an ‘intervention’ rather than an active musical contributor. This shift in focus towards ‘in the moment’ musical experience will allow the emphasis to be placed on musical processes rather than clinical outcomes alone.
Another key component of the tool will be the emphasis which is placed on the person living with dementia recording their own experiences, in the first instance, with capacity built into the application for the person to be supported in recording their experiences. This is an essential component of development, as both quantitative and qualitative research to date neglects the voices of people living with dementia (Dowlen et al., 2017; McDermott et al., 2013). Thus, by providing a platform where the person living with dementia can record their own experiences, through what is shown rather than what is said, it may be possible to gain more insight into subjective musical experiences, such as the experience of flow. This approach to measurement differs to previous attempts to measure the impacts of music as it will enable the person living with dementia to be visible within measurement, with their experiences being told through their embodied and sensory experiences, rather than reduced to a single number which can be compared over two points in time.

6.3 Theoretical Reflection

This study was underpinned by a positive psychological approach, but also recognised the importance of embodiment (Kontos, 2004, 2005), citizenship (Bartlett & O'Connor, 2010) and relational citizenship (Kontos et al., 2017) approaches to
dementia. All three of these approaches have something to offer in understanding the ‘in the moment’ musical experiences of people living with dementia. However, not one of these models is specific to musicking, and so further theoretical formulation is needed in order to encapsulate why music is so powerful for people living with dementia. In the arts and health field, more generally, it has been acknowledged that there is very little theoretical development (Stickley et al., 2017), and more needs to be done in order to develop theory which can influence and strengthen practice and research. The following section will discuss the notions of citizenship, embodiment and positive psychology, and highlight areas for theoretical development that could be examined in order to gain more holistic accounts of musical, and broader arts, experiences.

### 6.3.1 Broadening Dementia Discourses Surrounding Music

In the Introduction chapter to this thesis, it was highlighted that although alternative lenses to biomedical approaches that have been proposed, the music and dementia literature still remains largely positioned within the biomedical model of dementia. This resistance to a change within this field has led to the continued use of standardised outcome measures, even in the face of review papers which suggest more appropriate outcome measures need to be developed (McDermott et al., 2013; van der Steen et al., 2017). What is clear from the findings of this research study is that the impact of music goes far beyond reducing the ‘behavioural and psychological symptoms of dementia’ and there is potential in the use of music for enabling people living with dementia to connect through their bodies to other people and to their wider communities. The following paragraphs will discuss the relationship of this work to citizenship and embodiment discourses, and how these approaches can be applied to ensure that music goes beyond the remit of ‘therapy’ alone.

Kontos, Miller, and Kontos (2017) recently proposed applying the notion of relational citizenship approach to the notion of musicality, which they define as musical participation and engagement. They propose that musicality is an embodied action which allows a person living with dementia to feel a sense of connectedness due to the interaction with others’ musical bodies. This is something that was observed within the data from this research study. The musical contributions of people living
with dementia enabled them to feel a sense of connection through improvised music-making, musical conversations, and synchronising with the bodies of others. Though there were some group members whose capacity to use verbal language was a challenge, they were still able to feel a sense of connection through their musical contributions, which could be argued to be an expression of their embodied selfhood (Kontos, 2005). Thus, creative music-making enabled the people living with dementia to express themselves through an embodied musicality, and in turn connect with the musical bodies of others who were present in the musicking space.

Kontos, Miller, and Kontos’ (2017) notion of relational citizenship extends the potential role of a citizenship approach by including the ways in which people living with dementia are able to connect with the world through their bodies. Music, and the arts more generally, appear to provide a platform for citizenship (Dupuis et al., 2016), enabling people living with dementia to feel more connected to themselves, to other people, and the sensory world around them. This notion of connectivity was highlighted by Basting (2006, p.16), when describing the value of the arts for people living with dementia:

People with dementia who have edited themselves into silence for fear of saying the wrong thing, or shut themselves down to avoid contact they cannot understand, can use the arts to reconnect with themselves and the people who care for them. And perhaps most important, the arts offer a chance for people with dementia to connect with the people who have forgotten them – their communities at large.

This quote highlights the important role of the arts in enabling the inclusion of people living with dementia within their communities and within society more generally. Much of the research that has been conducted in the area of music and dementia focusses on music as a care initiative, rather than framing musicking as a means through which people living with dementia might facilitate active citizenship. Music appears to become ‘therapy’ as soon as a person is diagnosed with dementia, even if the person has engaged with music throughout their lives (de Medeiros & Basting, 2014). There is therefore little research regarding how music, and other arts programmes, can facilitate a connection between the person living with dementia and the communities in which they live. This research, however, has begun to paint a
picture of how music can enable people living with dementia to experience relational citizenship through their musicking practices. This work therefore stresses the importance of citizenship approaches within the context of music and arts programmes for people living with dementia. The arts have strong potential to empower people living with dementia to be active citizens, enabling them to shape their own lives and experiences (Dupuis et al., 2016), promoting them to the status of an “equal citizen, with the same entitlements as everyone else” (Bartlett & O’Connor, 2007, p.108).

Although a relatively new discourse, the notion of relational citizenship (Kontos, Miller, & Kontos, 2017) has real potential within this area, as it allows for the consideration of the ways in which people living with dementia connect to the world through their embodied actions. This study provides some evidence relating to the notions of relational citizenship. For example, the research presented in this thesis has demonstrated how music enables a common language through which to communicate; how embodied musical practices represent elements of individual life story; and how music enabled people living with dementia to become more engaged in the communities in which they lived. Such relational citizenship was possible through creative music-making in which people living with dementia were viewed as people with agency. Thus, a combined approach which seeks to contextualise embodied expression against the backdrops of the individual life stories of people living with dementia may begin to strengthen understanding surrounding the role of musical bodies in the context of creative musicking activities.

6.3.2 Positive Psychology: Broadening the Scope of Positive Functioning

As has been discussed in Chapter 3, a positive psychology theoretical framework has underpinned this research study. Positive psychology was applied due to its emphasis on creativity, meaning and experience, as well as flourishing (Seligman, 2011), which was in contrast to the majority of published studies which followed a more biomedical discourse (de Medeiros & Basting, 2014). Many of the superordinate themes that were developed as part of this research study were consistent with a positive psychological approach to understanding the role of music for people living with dementia, such as the observed experiences of flow, positive emotions and developing meaningful
connections (Seligman, 2011). Using a positive psychological lens within the research study allowed for the consideration of the individual personal strengths of people living with dementia, with a particular focus on creative musicking ‘in the moment’.

Although a positive psychological framework allowed for the examination of creativity as part of ‘in the moment’ musical experience, there is a tendency for positive psychology scholars to reserve the term ‘creativity’ for so-called ‘maestros’ and ‘geniuses’. For example, Csikszentmihalyi (1996), in his book *Creativity: The Psychology of Discovery and Invention*, dedicates the focus of the creativity narrative to that of ‘Big-C’ creativity, which neglects notions of everyday, or ‘Small-c’ creativity (Bellass et al., 2018). This means that the current focus of positive psychological frameworks on ‘Big-C’ creativity completely excludes the notion that everyday creative activity can contribute to wellbeing and provide opportunities for flourishing. Approaching creativity from a ‘Small-c’ perspective, may allow for the elevation of the creative process over clinical outcomes (de Medeiros & Basting, 2014). By focusing on ‘in the moment’ creativity, with a focus on ‘in the moment’ experience, which acknowledges the musical skills and musicianship of people living with dementia, it may be possible to learn more about the role of ‘Small-c’ creativity in the everyday lives of people living with dementia.

This research has also highlighted that positive psychology approaches neglect the role of the body in its theoretical frameworks of positive human functioning and wellbeing (Hefferon, 2013). This research has demonstrated that the body was a key component of musical experience, and should be considered as a possible extension of current positive psychological models (e.g. PERMA, Seligman, 2011) in order to understand the lived experiences of people living with dementia. There is currently very little research examining the body and embodiment within the positive psychological literature and so this research contributes evidence to the necessity of understanding the body within positive psychological frameworks of human wellbeing and flourishing. There is a growing movement of positive psychology scholars who are beginning to examine the role of the body in positive functioning. For example, Hefferon (2013) dedicated an entire book to the understanding of the body within positive psychology approaches. However, this book focussed predominantly on physiological bodily responses, rather than considering the role of
embodied practices within positive functioning and wellbeing. Thus, although there has been an increased interest in the role the body can play within positive functioning and flourishing, there is still a dearth of evidence which explores how bodily experiences can enable a person to function positively and flourish within their everyday lives.

Furthermore, this research has highlighted the importance of the role of musical agency and creative choice in instilling a sense of confidence for people living with dementia, as well as allowing them to become an equal within the musicking space. The exploration of embodied agency is something that is still in its infancy, but Kontos, Miller and Kontos’ (2017) work on relational citizenship may be a further platform for the exploration of enhancing the means of agency for people living with dementia. This, combined with the principles of wellbeing that are so closely associated with the positive psychological movement, may provide a theoretical platform which could underpin understanding of ‘in the moment’ embodied and sensory experiences of people living with dementia when they engage with music.

It is evident that citizenship, embodiment, and positive psychological lenses have something to offer in understanding the benefits of music, and perhaps the wider arts, for people living with dementia. However, further theoretical development is necessary in order to develop new frameworks which are specific to the musical experiences of dementia. The development of theory has the potential to influence policy and practice regarding the use of music with people living with dementia, and thus is a necessary step forward in order to challenge the biomedical discourse that continues to feature heavily within this research area. Figure 47, presents a possible extension to the PERMA (Seligman, 2011) model of positive functioning and flourishing, which encapsulates notions of active citizenship and embodied experience.
6.4 Methodological Reflection

The following section will reflect on the methods used to collect the research data, in line with the second objective of the research which was to:

*Use a range of creative social research methods within a multiple-case study design, including visual research methods, as part of a flexible approach to research that ensures the maximum feasible participation of people living with dementia, their family members and project practitioners.*

The study implemented a range of creative methods as a means of enabling this flexible approach to research, namely video-observation, video-elicitation interviews and participant diaries. As has been discussed in the Methods of Study chapter, creative methods can be defined as “the physical making of something, leading to communication, expression or revelation” (Gauntlett, 2007, p.25). In the context of this research study, the video data acted as the ‘physical something’ which was reflected upon by the people living with dementia, their family carers, the project
practitioners, and myself in order to develop an understanding of ‘in the moment’ embodied and sensory experiences during musicking. The following paragraphs will evaluate the use of such methods within the context of this research, and reflect on whether these methods allowed for flexibility in approach which privileged the voices of people living with dementia. This section will also consider the limitations of the study.

6.4.1 Multiple-Case Study Approach and Visual Methods

This study used a multiple-case study approach (Stake, 1995, 2013) in order to gain an in-depth understanding of the ‘in the moment’ embodied and sensory experiences of people living with dementia when they engaged with music. Although case study is not a new research method, the application of this method to studying such embodied and sensory experiences within the context of a music programme is novel. The multiple-case study design allowed me to situate myself within the Music in Mind sessions and use multiple methods as a means of gathering multisensory data which could be reflected on from multiple perspectives. This allowed for flexibility in the research design, with the video data allowing for an exploration of experience through both what was said, and through what was shown (Kontos, 2004, 2005; Pink, 2015). Thus, even those living with dementia that had challenges relating to expressing themselves using verbal language, could contribute actively within the research process.

Within the multiple-case study design, two visual research methods were used as a means of disentangling the experiences of people living with dementia during Music in Mind. The use of video within the context of Music in Mind facilitated the capture of complex experience and the video-elicitation interviews allowed for an exploration of such experiences through the lens of the person living with dementia themselves, as well as family carers and project practitioners. This meant that the use of video was used as an exploratory tool for examining embodied and sensory experiences. This approach differs to the way in which video has been used in the context of music programmes for people living with dementia in the past, where video has been as a means of understanding pre-determined outcomes rather than being a means of providing a multisensory account of experience (Cook, 2002). Video is a particularly
valuable tool in understanding the lived experiences of people living with dementia, and this research has demonstrated the power of video in disentangling the embodied and sensory experiences of people living with dementia, allowing their voices to be privileged within the research findings.

Although video was essential in gaining an in-depth understanding of ‘in the moment’ experience, the method came with a number of challenges which needed to be navigated within the field. Firstly, a number of technical challenges were encountered throughout the research. The decision to use two stationery cameras, and one camera operated by hand, meant that some aspects of the scene were not able to be captured in the recording frame of the cameras. For example, on occasion, participants would change seats, or move the position of their chairs, which resulted in them coming out of the recording frame. Because I was actively taking part in the sessions I could not see such instances until reviewing the footage, meaning that it was not possible to know whether the person who had moved out of the recording frame.

Secondly, the use of video-elicitation interviews was a method that was unusual for participants, and so it took them a while to engage with the method. Many of the participants would choose to watch the video, but would not stop the video themselves as per the instructions I had given at the outset of the interview. This was particularly evident in my first interview with Mary, where she watched the video and would make comments such as: “Yeah that was nice too. Mmm. Good” [Mary Interview 10.08.2017]. However, when I asked her some prompting questions about the video she was much more vocal, describing her experiences with enthusiasm and vigour. This highlights that the participants may not have been comfortable engaging with the laptop computer or technology within the context of a research interview. The use of video-elicitation interviews, however, provided flexibility in its format, allowing for participants to reflect on the video clips they were shown without having to stop the video themselves. The method was chosen as a means of affording people living with dementia the opportunity to share their lived experience through non-verbal communication, as previous research had shown the possibility for eliciting
such responses using video-elicitation techniques (Morris et al., 2015). People living with dementia were shown to engage with the video through embodied gesture and through the re-living of musical moments within the context of their own homes. Thus, on reflection, the flexibility in the methods that were adopted for this research enabled me to adapt my approaches within the research interviews, enabling the group members to contribute using their preferred methods of communication.

Finally, I encountered challenges when finding appropriate ways in which to present the visual data within my thesis and in wider dissemination. As has been discussed in the **Methods of Study** chapter, I chose to alter screenshots from the video in a way that both ensured the anonymity of participants without depersonalising their experiences (Wiles et al., 2008, 2012). I chose to use artistic filters rather than blur the faces of the group members, as it allowed for the images to display faces and embodied gesture while still maintaining the anonymity of group members. I sought confirmation from the group members in using these images, ensuring they were comfortable with the ways in which I had presented them within the altered images. These altered images combined with the thick description developed within the analysis stages of the research, enabled me to present a picture of experience in which the voices of people living with dementia were privileged, presenting images of enjoyment, fun and creativity.

Although there were many challenges associated with the use of video methods within the context of this research, the use of video was able to help meet the key aim of the research by providing a platform through which to understand the embodied and sensory experiences of people living with dementia during the musicking process. However, the use of video in the context of understanding the embodied and sensory experiences of people living with dementia is relatively novel within the field. The use of video therefore has a number of perceived disbenefits. For example, there are some who suggest that the level of control held by the researcher in when to turn the camera on and off means that data collection is partial and not representative of events as a whole (Jewitt, 2012). Furthermore, the use of video within this research was time intensive due to the use of multiple cameras across the 15-week programme. The level of depth that I was able to obtain throughout the analysis process may not be possible within larger scale studies. Thus, there still remains much which can be
learned from the undertaking of research underpinned by visual methods. However, there is still more exploration that needs to be undertaken: not only of the phenomenon under study, but also an understanding of the method itself and the roles that both researcher and participant plays within the research process (Keady, Hydén, Johnson, & Swarbrick, 2017).

Overall, although the use of video methods presented a number of ethical and practical challenges, the use of such methods allowed for an in-depth exploration of the ‘in the moment’ embodied and sensory experiences of people living with dementia when they engaged with music. This approach thus enabled the voices of people living with dementia to be privileged within this research, expanding the current knowledge base which relies heavily on understanding the musical experiences of people living with dementia through proxy accounts (Dowlen et al., 2017).

6.4.2 Diary Method

The study also used solicited diaries to complement the video methods and elicit further reflection on the multisensory and embodied experiences of people living with dementia in the group. Although the primary focus of this research was on the ‘in the moment’ experiences of people living with dementia, the use of participant diaries allowed for an opportunity for the family carers and project practitioners to record their own personal reflections, which were not guided by predetermined categories. However, although all four family carers were given diaries, only two completed diary entries, and only one reflected on each of the Music in Mind sessions. The project practitioners, on the other hand, used the diaries for extensive reflection outside of the Music in Mind session. The project practitioners also brought their diaries with them to research interviews, using them as a means reflecting on the sessions as an additional layer to understanding the video that was presented to them in video-elicitation interviews.

I interpreted these differences in approach to have been underpinned by a number of factors. Firstly, the project practitioners had engaged with diary methods in previous Manchester Camerata evaluations, meaning that they had experience in using research diaries to reflect on outcomes determined by the evaluators. This previous experience with a diary method may have enabled the project practitioners to have more
confidence in using an unstructured approach to writing diary entries. Family carers, on the other hand, may have felt the diaries were an additional burden on their already busy schedules (Välimäki et al., 2007), and a more structured diary may have been more appropriate as a means of reflection. Although I did not collect any data which evaluated the methods used within this study, it is clear that the diary method was not engaged with as fully by family carers as it was with the project practitioners. Thus, although the diaries were helpful in the triangulation of research findings, there was very little revealed within the diaries which was not discussed within the video-elicitation interviews, or observed within the Music in Mind sessions.

### 6.4.3 My Role as Participant-Observer

One of the objectives of the research was to explore my role as a participant-observer. I made the decision to be both a participant in the Music in Mind programme, as well as being a researcher in this context. This meant that I actively took part in the musicking while making observations within the programme setting. This approach had a number of strengths and challenges, which will now be reflected upon.

The strengths of being a participant-observer lay in the rapport that I was able to develop with the group members. I was able to develop deep connections with the group members, which I believe was facilitated through our shared musicking. I was also able to have my own ‘in the moment’ embodied and sensory experiences within the context of the sessions, which allowed me to develop my analysis of the data, through an understanding of my own reactions within the sessions (Pink, 2015). I believe this allowed me to become fully immersed within the data collection, with the video data allowing me the privilege of re-living these moments outside of the context of the sessions.

One challenge relating to my role as participant-observer was defining my role within the context of the programme. I had to ensure that participants were aware of my role as a researcher, while actively taking part in the music group as an ‘equal’ participant. Although I made my dual role clear to the group when discussing the research study before the commencement of the Music in Mind programme, group members still showed some confusion surrounding my role in the group. Participants would become more formal in their tone when I talked to them about the research, which was a direct
contrast to the fun, informal interactions we had in the context of the *Music in Mind* sessions. For example, when I went to visit Mary in her home to conduct the first research interview she was very formal in her tone, speaking directly into the dictaphone as if being recorded for a radio interview. At one point she scolded her grandchildren for making too much noise during her ‘important interview’. It was unusual for me to see Mary being so formal in the interview setting, as only moments before I began the interview we were having an informal exchange over a cup of tea. Thus, although my participant-observer role allowed me to develop a greater rapport with group members in the context of the *Music in Mind* sessions, there were still apparent reservations from the group members when talking to me as a ‘researcher’.

I presented this occurrence within one of my supervision meetings and it was decided that it might be helpful for me to wear a visual symbol which would act as a cue to my role as a researcher. Although I had been wearing a lanyard which presented my University of Manchester identity card, the lanyard strap was a plain black colour. I therefore purchased a University of Manchester lanyard which was a bright purple colour, with ‘The University of Manchester’ written on it in white. This lanyard acted as a visual cue within the research context and within participants’ homes, providing a constant reminder of my role as both *Music in Mind* participant and observer.

Researcher reflexivity was a key component in disentangling and understanding my role as a participant-observer. Ongoing reflexivity throughout the research, analysis and write-up enabled me to examine how my own life experiences and biases may have impacted on the data collection, analysis and write-up of the research (Berger, 2015; Braun & Clarke, 2006; Pillow, 2003). This process was essential within the study as it enabled me to consider my central role in the interpretation of the embodied and sensory experiences of people living with dementia through multiple methods and multiple perspectives (Pink, 2015). Furthermore, reflexive practice is something which is underreported within the music and dementia literature as a whole, as was indicated in my appraisal of qualitative studies within the literature review presented in Chapter 2 (see p.41). Reflexivity was such an integral part of this case study research, and yet, there is relatively little that has been written about reflexive practice and case study research (Simons, 2009). It seems imperative that a reflexive stance is engaged with throughout the duration of a case study research
project, in order to examine the influence of a researcher on data collection, analysis and dissemination. The following paragraphs will outline a reflection on the reflexivity that I engaged with over the duration of the programme.

As I have presented in the Methods of Study chapter, there were a number of personal beliefs and life experiences that I perceived would influence both data collection and analysis. I re-engaged with the features examined as part of the reflexive exercise I undertook before entering the field throughout the data collection, analysis, and report writing phases of the research. An updated table of this reflexive exercise is presented in Appendix 16, which outlines how I thought my beliefs would influence data collection and what their influence was in reality. This self-reflection exercise (Simons, 2009) was particularly important to return to in the analysis phase of the research, allowing me to explore my own influence on the data analysis process. I have also added unanticipated influences, which were brought to the surface as a result of being in the field. I believe this reflexive practice exercise really helped to ground me within the data collection and analysis processes, helping me to disentangle my own experiences from the experiences of the group, where necessary.

One particular factor that I reflected on extensively was how my own musical training and experience influenced the data collection and analysis processes. Although I had anticipated that my own musical ear would influence my interpretation of the data, it was clear that I was only able to pick up on specific musical skills held by people living with dementia because I had experience of these factors myself. For example, I was able to hear and understand the role of musical phrasing in conveying emotion and meaning through music because I had awareness of how I had used musical phrasing in my own past musical performances. However, my own musical background and training enabled me to gain deeper insight into the musical processes that occurred within the sessions, which subsequently meant such practices were central within the development of the In the Moment Profiles framework. Therefore, my own musical ear had a significant influence on the ways in which I engaged within the Music in Mind sessions and subsequent data analysis.

Overall, my role as participant-observer allowed me to situate myself within the Music in Mind sessions as a group member rather than an ‘outsider’. Although this came with a number of challenges, I believe this gave me access to privileged
information as I could gain greater understanding of the dynamic nature of musical experience, as well as developing a greater rapport with the group members than sitting outside the musicking circle would have afforded. My own reflexivity was a key process in understanding my role as a participant-observer, and how my own life experiences may have influenced my interpretation of the data.

### 6.4.4 Study Limitations

Although a multiple-case study design allowed for an in-depth exploration of ‘in the moment’ embodied experiences of people living with dementia, there were a number of limitations associated with this approach. Firstly, there are questions surrounding the generalisability of the findings from this research. Although the purpose of case study is to provide an in-depth exploration of specific cases, the purpose is not to produce findings which are necessarily generalizable outside of the contexts in which the case was situated (Stake, 1995, 2013). This research was based in a community setting and examined experience in the context of an innovative music programme for people living with dementia. This means that the findings of this research may not be easily generalisable to the other contexts in which people living with dementia may reside. It is clear that further research needs to be conducted in order to test the applicability of the research findings beyond the realm of community-based musicking.

Although the findings from the study may not be able to be generalised beyond the remit of the population that was studied, the use of a multiple-case study approach allowed for an understanding of the complexities of experiences held by the people living with dementia enrolled in the *Music in Mind* group, and was more representative of ‘real world’ situations. There have been a number of studies in the music and dementia literature that actively exclude people living with dementia who have factors in their personal biography, such as previous musical experience and hearing impairments, which are seen as confounding factors in larger scale studies (see for example: Raglio et al., 2015). A case study approach in this context, with broad inclusion criteria, allowed for a more diverse range of diagnoses, biographical histories and cultures, ensuring an exploration of experience in which the person was placed centrally rather than the intervention or the diagnosis they had received. Such
‘bottom-up’ approaches have the possibility to be as inclusive as possible, in order to understand the complexities of embodied and sensory experiences.

Secondly, the multiple-case study approach to the research resulted in a large amount of visual and written data being produced. Although the large amount of video data and multiple interviews with each group member allowed for an in-depth exploration of ‘in the moment’ experiences it was a large data set for a solo researcher within the strict time constraints of a PhD research programme. Whilst I was able to focus on the experiences of the people living with dementia in the group, there were new research questions that arose as part of the research project which were not able to be explored within the timeframe of the research. However, there is scope to engage with a secondary analysis of the research data. For example, there was a great deal of practitioner reflexivity that happened during the video-elicitation interviews, and an exploration of how the reflection influenced the ways in which the practitioners adapted their approaches based on their reflections would have been an interesting avenue to explore as part of future research. However, for the purposes of this research study, the emphasis was placed on understanding the experiences of the people living with dementia in the group and future analysis could look to disentangle the experiences of other group members further.

A third limitation of the study was the way in which group members were recruited into the study. All group members had all taken part in previous Manchester Camerata projects, and the majority of the group had known each other from these previous projects (with the exception of Scott and Julie). Thus, it may have been the case that the group warmed up to each other faster compared to Music in Mind groups where the participants did not know each other. However, Scott and Julie, the only members of the group who had not taken part in a Manchester Camerata project with other members of the group before, seemed to meet key milestones at similar parts of the project to the other group members. Furthermore, I believe that the recruitment strategy that was adopted allowed for the inclusion of those from more ethnically and culturally diverse backgrounds. The fact that Phillip, Esther and Mary had built trust with Manchester Camerata through their engagement with previous research programmes, may have made them more trusting of the research attached to the Music in Mind programme (Yancey, Ortega, & Kumanyika, 2006). Thus, it may not have
been possible to have such a diverse group of people taking part in the research had group members been recruited through advertisement in the community alone.

6.5 Implications and Directions for Future Research

The findings of this research have a number of implications for practice, policy, research and education. The following section will outline the implications for each of these agendas in turn. Appendix 17 presents a summary of dissemination activities across the duration of the PhD programme, highlighting publications and conference presentations.

6.5.1 Recommendations for Practice

- This study demonstrated the complexities of ‘in the moment’ musical experiences which are currently overlooked because of the dominance of standardised outcome measures in the music and dementia literature. It seems necessary, based on the findings of this research, that musical experience should be measured longitudinally rather than using before/after approaches, and individuals’ life stories should be taken into consideration when interpreting ‘in the moment’ musical experiences.

- This study also highlighted the importance of understanding embodied and sensory responses to music, presenting people living with dementia as active contributors within the musicking space. The musical creativity and skills of the person living with dementia should be acknowledged centrally, demonstrating how people living with dementia can flourish through music rather than music being used as a tool for meeting care needs.

- Examining video and audio from the Music in Mind sessions allowed for detailed knowledge of such embodied and sensory experiences, with the video-elicitation providing the opportunity for people living with dementia to provide their own interpretations of the data rather than analysis being purely driven by me as a researcher. Video and audio should be incorporated into future music assessment tools as a means of privileging embodied and sensory experiences, as well as providing a platform for showcasing the musical skills and creativity of people living with dementia.
• There is scope for the *Music in Mind* programme to be manualised in order for the programme to be implemented on a larger scale. Manualisation, whereby the key principles of *Music in Mind* are outlined alongside practical examples of how to implement these principles in practice, would allow for the cementing of the key defining features of the programme, enabling it to be applied in numerous settings.

• There needs to be a stronger link between research and practice, as the project practitioners provided expertise in the research context, allowing for the development of an ‘in the moment’ framework which places music and creativity centrally. The expertise of musicians in particular seems to be neglected within the field to date, with there being no apparent resources available to musicians for reflective practice and supervision. This seems an important area for future research, in order to enable the voices of musicians and music therapists to also be heard within this research area.

• There is a necessity to explore the role of culture and ethnicity within the music and dementia literature. There needs to be a greater emphasis placed on promoting diversity within music programmes, ensuring that music is an activity accessible to all, rather than those from a particular culture or social class.

6.5.2 **Recommendations for Policy**

• There is a need to broaden the policy debate to include sensory and embodied experience as a means of understanding the lived experience of dementia. In understanding the benefits of music within the lived experience of dementia it is necessary to consider individual life stories, ‘in the moment’ sensory and embodied experiences, as well as seeking to understand the ripple effects of music into the everyday lives of people living with dementia.

• ‘Bottom-up’ approaches to understanding music programmes for people living with dementia are necessary within the broader policy agenda. Music interventions should be driven by the individual needs of the person living with dementia rather than offering blanket approaches to music, which do not place the person living with dementia centrally.
• Engagement with the arts should be built into health and social care agendas for people living with dementia. One such example of this can be found in the Greater Manchester Population Health Plan (Greater Manchester Health and Social Care Partnership, 2017), which highlights the importance of the arts in fostering social connections, enabling self-expression, and create the means for social-action. Furthermore, a dedicated Manchester Institute for Arts Health and Social Change has recently been established this year, with the key aims of improving public health and addressing inequalities through the arts.

• There is a need to address the ethical policy surrounding the use of creative research methods with people living with dementia, whether they have capacity to consent or not. Although this study gained ethical approval for the use of video on the context of Music in Mind within a community setting, the process for enabling research using such methods within care home setting might have come up against significant challenges from ethics boards. It is essential that the ethics process empowers people living with dementia by enabling processes which privilege their voices rather than acting as gatekeeper to participation.

• There is little focus on the everyday lives of people living with dementia within the music and dementia literature. Many programmes are designed as interventions which run for a set number of weeks, rather than considering how we can ensure active engagement with music, and the arts more generally, in the everyday lives of people living with dementia.

6.5.3 Recommendations for Research

• There is strong potential for the use of video in exploring the ‘in the moment’ sensory and embodied experiences of people living with dementia when they engage with music. Future research should consider the role of video as an exploratory tool rather than focussing purely on using video to assess predetermined factors.

• There is a necessity to take a longitudinal approach to understanding musical experience, rather than measuring ‘behavioural and psychological symptoms of dementia’ before and after a music intervention. Longitudinal approaches
allow for the development of more holistic accounts of experience which privilege the voices of people living with dementia.

- There should be multi-disciplinary conversations in order to develop new research questions and develop innovative and creative approaches to understanding the role of music, and other arts-based programmes, for people living with dementia. In this research, the combination of supervisors from academic and industry backgrounds allowed for a more holistic perspective in developing the research, data collection, analysis and the dissemination of findings. Such approaches may go some way to bridging the gap between artist experiences and the need for scientific rigor in evaluating the impacts of music programmes for people living with dementia.

- The reflexive practices of researchers engaging in case study research should be made more explicit in order to understand the influences of the researcher on the data, especially if the researcher is immersed in a musicking activity in a participant-observer role.

- The inclusion of a more diverse population group within research is an important next step. It is particularly important to target harder to reach populations, such as those from BME populations who are living with dementia. Further reporting regarding the demographics of people living with dementia who are taking part in music-based research is an important step in enhancing the transparency of research in this area.

6.5.4 Recommendations for Education

- This study has demonstrated that it is possible to understand the role of music through a positive psychological lens, including embodied and sensorial experience. This is a contrast to the dominant biomedical discourses within the music and dementia literature. The framing of musical experience through a positive psychological lens could allow for more holistic approaches to evaluation within this area.

- Creative research methods, including video-based methods, were essential in disentangling the ‘in the moment’ embodied and sensory musical experience so people living with dementia. It is therefore necessary that a range of creative and visual research methods are explored within research training.
programmes in dementia studies. This will enable the consideration of such research methods within dissertation and doctoral work.

- This study highlighted the role of multidisciplinary supervision in developing holistic research programmes for disentangling complex phenomena. The role of supervision should be explored in relation to the conducting of PhD research. Highlighting the processes and dynamic factors within the process of multidisciplinary supervision will illuminate processes which often go unacknowledged within the research literature. By understanding the role of supervision teams in comparison to the traditional supervisor-student relationship, there is potential to explore the strengths of such approaches as well as to understand where there is potential for challenges. For example, the skills of the doctoral student in managing a larger supervision team and the willingness of the CASE partner to be involved within PhD supervision may have an impact on the development of research questions, data collection and analysis, as well as the presentation of research findings.

### 6.6 Summary and Conclusions

The primary aim of this research was to develop an in-depth understanding of the ‘in the moment’ musical experiences of people living with dementia engaging with *Music in Mind* as a creative music-making programme. This was achieved through implementing a multiple-case study approach, drawing on the multiple perspectives of people living with dementia, their family carers, project practitioners, and my own interpretations of the data. Six case studies were presented which highlighted the uniqueness of each person living with dementia’s experience within the musicking space. The cross-case analysis of the data revealed ‘measurable qualities’ of experience which were common across the group members living with dementia. These findings will be used to form the basis of a new music assessment framework which enables the musical stories of people living with dementia to be told, while providing a platform to measure common experience across musicking participants. This framework is underpinned by notions of positive psychology, citizenship and sensory embodiment, which view music as a creative venture that can both fulfil the individual needs through meaningful and stimulating activity, as well as allowing a platform through which people living with dementia can remain active citizens.
throughout the progression of their condition. Using such an approach to understanding the musical experiences of people living with dementia will enable creativity and agency to shine through in a research area currently dominated by biomedical approaches to understanding.
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APPENDICES

Appendix 1: Published literature review

The personal benefits of musicking for people living with dementia: a thematic synthesis of the qualitative literature

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ABSTRACT
This review aimed to explore the psychological, social and emotional benefits of music activities for people living with dementia through a systematic review of qualitative literature. Eighteen studies were identified that covered a wide range of music programmes for people with dementia, with the majority of programmes focusing on active musical participation. A thematic synthesis revealed four key benefits of music engagement for people with dementia, namely: Taking Part, Being Connected, Affirming, Identity and Immersion “in the moment”. Overall, engaging with music was seen to have a number of psychological, social and emotional benefits for people with dementia. However, only seven studies actively included people with dementia in the research process. Going forward, it would appear essential that people with dementia are encouraged to take a more active role in research exploring musical experiences and that a heightened emphasis is placed upon participatory approaches to knowledge generation.

Background
There is a growing recognition that the arts can foster improved health and well-being in the general population (Cayton, 2007; Stickley et al., 2017), as well as for those living with dementia (Beard, 2012; de Medeiros & Basting, 2014). The arts and health movement promotes a “wellness agenda” focusing on psychological well-being rather than on mental illness or distress (Clift, 2012). In recent years, a growing number of arts-based activities have been developed for people with dementia in order to create meaningful and personally significant experiences, including creating visual art (Camic, Tischler, & Pearman, 2014), theatrical productions (Basting, Towey, & Rose, 2016) and improvised music making (Campbell, Ponsillo, Budd, & Keady, 2017).

Music is the most commonly reported and accessed arts-based activity for people with dementia (Beard, 2012). Music is viewed not only as a relatively cost-effective and safe means...
of reducing “behaviours that challenge”, such as agitation and behavioural disturbances (McDermott, Crellin, Ridder, & Orrell, 2013), but also as a powerful means of enhancing a person with dementia’s sense of well-being and agency (Sixsmith & Gibson, 2007). Music programmes have been implemented across all time-points in the trajectory of dementia, from its early onset where retained capacity is a key feature (e.g. Särkämö et al., 2014) to its more advanced stages when communication through the spoken word may be at its most challenging (e.g. Sakamoto, Ando, & Tsutou, 2013). Indeed, the latter focus constitutes the primary area of research to date where the person with dementia’s experience has a tendency to be reported through proxy accounts provided by family and/or staff carers (McDermott et al., 2013).

To date, the focus of systematic literature reviews in this area has been on the correlated effects of music on “behaviours that challenge” and cognitive performance (e.g. Raglio et al., 2015). However, in recent years, there has been an emerging interest in understanding how taking part in music-based activities can strengthen familial and care relationships (McDermott, Orrell, & Ridder, 2014), and increase quality of life and well-being (Särkämö et al., 2014; Sixsmith & Gibson, 2007). Yet, even with this shift away from using music to ameliorate “behaviours that challenge”, published reviews have so far failed to identify the personal benefits of engaging with music for people with dementia. The exploration of such factors may lead to a greater understanding of why music has positive effects on the quality of life and well-being of people with dementia. Exploring this phenomenon through a systematic process forms the primary focus of this review.

**Methods**

**Definitions**

The term *musicking* modifies the meaning of the word “music” from that of a noun to a verb, meaning “to engage with music” (Small, 1998). Accordingly, musicking can be used as an umbrella term for any musical activity from listening to music on one’s own through to performing opera on stage. Levels of engagement can differ between musicking activities, with the use of instruments and the human voice being viewed as “active participation”, and listening to music deemed as “passive participation”. It is also possible to combine active and passive approaches within a single musicking activity (Guetin et al., 2013). By adopting the term musicking as a key operational definition for this review, the authors view musicking as a creative activity rather than solely aligning music to therapy. This subtle shift of emphasis allows all levels of engagement with music to be reported in the review.

**Aims**

The overarching aim of this review is to explore the personal benefits of musicking for people with dementia by systematically reviewing the qualitative literature in order to understand its emotional, psychological and social impacts.

The secondary aim is to report upon the involvement of people with dementia within the research studies as, to date, much of the literature in this area has relied on proxy accounts to understand and represent lived experience.
**Search terms**

The search terms were pre-planned and combined terms from MeSH headings with terms observed frequently in the literature (see Table 1). Key terms relating to the topic area were combined with key terms associated with qualitative methods to increase the likelihood of identifying qualitative research studies.

**Inclusion/exclusion criteria**

Studies were eligible for inclusion if they were written in English, used a qualitative or mixed-methods design, included individuals with a diagnosis of a dementia, and focussed on outcomes relating to the impact of music on people with dementia.

Studies were excluded if the focus was solely on caregiver experiences, if music was combined with another activity (e.g. music and exercise programmes) or where it was not possible to disentangle the results of the participants with dementia from other participants (e.g. in mixed populations of participants with dementia and older people without a diagnosis of dementia). Non-primary research articles were also excluded.

**Search strategy**

Searches were originally conducted in February 2016 and updated in January 2017 using PsycINFO (via Ovid search platform), Cumulative Index to Nursing & Allied Health Literature (via Ebsco) and Web of Science (Arts and Humanities Citation Index and Social Sciences Citation Index). No date restrictions were placed on the database searches.

Hand-searches of relevant journals and reference lists were conducted to ensure all relevant qualitative research had been identified. Unpublished theses were identified using Open Grey and Proquest Theses and Dissertations: American and International databases.

**Analysis**

Analysis was conducted in three phases, in accordance with Thomas and Harden’s (2008) guidance on Thematic Synthesis. Firstly, each line of text was examined in its entirety. Following this, each line of data was coded by hand using free line-by-line coding. Newly emerging codes were added to a coding bank which was used iteratively when analysing successive literature.

Secondly, descriptive themes were formulated and refined through several meetings of the whole research team.

Finally, analytical themes were developed in order to “go beyond” what was said in the primary research, which was achieved through understanding the themes in the context of the research questions posed for the review. The research team met regularly to authenticate the inclusivity and representativeness of the final set of generated themes.

**Table 1. Search terms.**

<table>
<thead>
<tr>
<th>Population</th>
<th>Intervention</th>
<th>Methodology/Methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>dementia OR Alzheimer’s</td>
<td>music OR musicking OR music therapy OR singing OR preferred listening</td>
<td>qualitative OR mixed methods OR interview OR focus group OR observation</td>
</tr>
</tbody>
</table>
Results

Search results

A total of 195 articles and 6 theses were identified through database and hand searches (see Figure 1). Duplicate articles were removed, and the remaining 144 texts were subject to title and abstract review. After title and abstract review, 21 articles were fully screened having met the inclusion criteria for the review. Following full text screening, three studies were removed as on closer inspection they did not meet the inclusion criteria for the review. This resulted in a total of 18 studies being included within the thematic synthesis.

Characteristics of included studies

The characteristics of included studies are presented in Table 2. The majority of studies were from a music therapy discipline, with other studies being from nursing or social science disciplines. Musicking activities varied substantially, but the majority required active participation through singing or playing instruments.

The majority of studies chose to explore the impacts of musicking through proxy accounts provided by caregivers; with only seven studies collecting first-hand accounts from people with dementia (Camie, Williams, & Meeten, 2013; Hara, 2013; McCabe, Greasley-Adams, &

Figure 1. Flow diagram of database and grey literature searching.
Goodson, 2015; McDermott et al., 2014; Osman, Tischler, & Schneider, 2016; Sixsmith & Gibson, 2007; Unadkat, Camic, & Vella-Burrows, 2016).

Themes

Overall, the thematic synthesis of qualitative literature resulted in four themes: Taking Part, Being Connected, Affirming Identity and Immersion “in the moment”. These themes were interpreted as overlapping, rather than distinct, but provided an emergent understanding about the personal benefits of musicaking for people with dementia. The following section will outline each theme in turn, supported by quotations taken from the research studies included in the review (see Table 2).

Theme 1: Taking Part

Music was viewed as an accessible medium where the ability to take part was not determined by cognitive abilities or any previous music training. Musicaking was enjoyed on an “emotional and sensory level rather than an intellectual level” (Sixsmith & Gibson, 2007, p. 134), with people at all “stages” of dementia (mild, moderate, advanced) enjoying the soothing and motivating nature of music, as seen in the following quote:

All participants discussed the stimulating effect of music and how playing instruments or listening to music instantly caught the attention of many residents who often appeared less aware or disinterested in other people or activities around them. (McDermott et al., 2014, p. 710)

People with dementia expressed pride and a sense of accomplishment at having taken part in a musicaking activity (Camic et al., 2013; Hara, 2013; McCabe et al., 2015; Osman et al., 2016; Tomaino, 1998). Through this encounter, people with dementia were also able to refresh skills that may have been lost over the progression of their condition and “learn something new” through exposure to music that may not have been in their personal repertoire (Camic et al., 2013; Hara, 2013; McCabe et al., 2015; McDermott et al., 2014; Unadkat et al., 2016). In turn, this exposure facilitated increased confidence and self-esteem, which was further heightened by the immediate, sensory feedback participants received through musicaking. Moreover, through musicaking, people with dementia were able to share in the experience as equals to those who did not live with the condition (Gardner, 1999; Göttell, Brown, & Ekman, 2009; Hammar, Emami, Engström, & Göttell, 2010; Hara, 2013; McCabe et al., 2015; Unadkat et al., 2016). This appeared to draw attention away from “the dementia” and onto “the person.” For example, care staff and family carers often appeared surprised that people with dementia were able to engage with music even after their abilities to verbally communicate had been significantly compromised (Gardner, 1999; Hammar et al., 2010; Hammar, Emami, Engström, & Göttell, 2011b; McDermott et al., 2014; Osman et al., 2016; Sixsmith & Gibson, 2007; Unadkat et al., 2016). Being perceived as an equal may have enhanced the person with dementia’s sense of identity through the acknowledgement that they were still able to make a meaningful contribution within a shared activity, as in this exchange:

Spouse: “Well, I can’t sing, you always sang didn’t you?”

Person with dementia: “Yes, I have to teach you! I didn’t half laugh at your efforts, it’s very funny, you are getting better though.” (Unadkat et al., 2016, p. 9)
<table>
<thead>
<tr>
<th>First author (Year)</th>
<th>Country</th>
<th>Participants</th>
<th>Musicking activity</th>
<th>Level of engagement</th>
<th>Methodology</th>
<th>Data collection methods</th>
<th>Analysis</th>
<th>Research questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Australia</td>
<td></td>
<td>5 spousal caregivers</td>
<td>Listening to pre-recorded music</td>
<td>Passive</td>
<td>Mixed-method</td>
<td>Semi-structured interviews Diary entries</td>
<td>Thematic analysis</td>
<td>To understand the benefits of music on the well-being of the person with dementia, from the perspective of the spousal caregiver</td>
</tr>
<tr>
<td>Canic (2013)</td>
<td>UK</td>
<td>10 people with dementia 10 family caregivers</td>
<td>Group singing</td>
<td>Active</td>
<td>Mixed-method</td>
<td>Semi-structured interviews with people with dementia and family caregivers</td>
<td>Thematic analysis</td>
<td>To examine whether participation in group singing impacted on the quality of life of both people with dementia and their family caregivers</td>
</tr>
<tr>
<td>Dassa (2014)</td>
<td>Israel</td>
<td>6 people with dementia</td>
<td>Group listening to pre-recorded music</td>
<td>Active</td>
<td>Qualitative</td>
<td>Observation</td>
<td>Qualitative content analysis</td>
<td>To explore the role of music in stimulating communication in people with dementia</td>
</tr>
<tr>
<td>Gardner* (1999)</td>
<td>USA</td>
<td>2 people with dementia 2 family caregivers</td>
<td>Individual music therapy</td>
<td>Combined</td>
<td>Qualitative</td>
<td>Interviews with family carers Observation</td>
<td>&quot;Inductive data analysis&quot; (p. 21)</td>
<td>To explore the impacts of long-term music therapy on the relationships between the person with dementia, their family caregiver and the music therapist</td>
</tr>
<tr>
<td>Göttell (2002)</td>
<td>Sweden</td>
<td>9 people with dementia 5 nurse caregivers</td>
<td>Caregiver singing Background pre-recorded music</td>
<td>Passive</td>
<td>Qualitative</td>
<td>Interviews with staff carers Observation</td>
<td>Phenomenologic-Hermeneutic method</td>
<td>To explore the use of background music versus caregiver singing during caregiving activities</td>
</tr>
<tr>
<td>Göttell (2009)</td>
<td>Sweden</td>
<td>9 people with dementia 5 nurse caregivers</td>
<td>Caregiver singing Background music</td>
<td>Passive</td>
<td>Qualitative</td>
<td>Observation</td>
<td>Qualitative content analysis</td>
<td>To examine the effects of background music versus caregiver singing on the emotions and moods of people with severe dementia</td>
</tr>
<tr>
<td>Hammar (2010)</td>
<td>Sweden</td>
<td>6 staff caregivers</td>
<td>Music Therapeutic Caregiving</td>
<td>Passive</td>
<td>Qualitative</td>
<td>Group interviews</td>
<td>Qualitative content analysis</td>
<td>To explore the reaction of people with dementia to Music Therapeutic Caregiving during morning care situations</td>
</tr>
<tr>
<td>Hammar (2011a)</td>
<td>Sweden</td>
<td>10 people with dementia 6 staff caregivers</td>
<td>Music Therapeutic Caregiving</td>
<td>Passive</td>
<td>Qualitative</td>
<td>Video observation</td>
<td>Qualitative content analysis</td>
<td>To explore verbal and non-verbal communication of people with dementia during morning care routines with Music Therapeutic Caregiving.</td>
</tr>
<tr>
<td>Hammar (2011b)</td>
<td>Sweden</td>
<td>6 staff caregivers</td>
<td>Music Therapy</td>
<td>Passive</td>
<td>Qualitative</td>
<td>Group interviews</td>
<td>Qualitative content analysis</td>
<td>To explore the differences in staff caregiver experiences with and without Music Therapeutic Caregiving during morning care situations</td>
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<tr>
<td>Hara* (2013)</td>
<td>UK</td>
<td>10 people with dementia**&lt;br&gt;10 and their carers**&lt;br&gt;10 volunteers**&lt;br&gt;1 singer group facilitator</td>
<td>Groupsinging</td>
<td>Active</td>
<td>Qualitative</td>
<td>Interviews Observations</td>
<td>Grounded theory analysis</td>
<td>To use ethnographic study to explore how music helps people with dementia and their caregivers</td>
</tr>
<tr>
<td>McCabe (2015)</td>
<td>UK</td>
<td>9 people with dementia&lt;br&gt;3 family caregivers</td>
<td>Creative musical project</td>
<td>Active</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
<td>To explore the experiences of people with dementia involved in a creative music project, and how the benefits of involvement evolve over time.</td>
</tr>
<tr>
<td>McDermott (2014)</td>
<td>UK</td>
<td>15 people with dementia&lt;br&gt;15 family carers&lt;br&gt;8 music therapists</td>
<td>Group music therapy</td>
<td>Active</td>
<td>Qualitative</td>
<td>Focus groups Interviews</td>
<td>General inductive approach</td>
<td>To understand the meaning and value of music for people living with dementia</td>
</tr>
<tr>
<td>Osman (2016)</td>
<td>UK</td>
<td>10 people with dementia&lt;br&gt;10 family carers</td>
<td>Singing for the Brain (Alzheimer’s Society)</td>
<td>Active</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>Thematic analysis</td>
<td>To explore the experiences of people with dementia and their carers attending a group singing activity.</td>
</tr>
<tr>
<td>Pavlicevic (2015)</td>
<td>UK</td>
<td>6 music therapists</td>
<td>Music Therapy</td>
<td>Active</td>
<td>Qualitative</td>
<td>Focus group</td>
<td>Interpreative phenomenological analysis</td>
<td>To reflect on the experiences of music therapists using music for the therapeutic benefit of people with dementia within care home settings</td>
</tr>
<tr>
<td>Skurnett (2007)</td>
<td>UK</td>
<td>26 people with dementia&lt;br&gt;family/staff caregivers**</td>
<td>Music in everyday life</td>
<td>Combined</td>
<td>Qualitative</td>
<td>Semi-structured interviews</td>
<td>Analysis guided by ‘conceptual model of wellbeing’ (p. 129) template</td>
<td>To explore the role of music in music-related activities in the everyday lives of people with dementia</td>
</tr>
</tbody>
</table>

(Continued)
<table>
<thead>
<tr>
<th>First author (Year)</th>
<th>Country</th>
<th>Participants</th>
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<th>Level of engagement</th>
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<th>Data collection methods</th>
<th>Analysis</th>
<th>Research questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>&quot;Olaison&quot; (1998)</td>
<td>USA</td>
<td>4 people with dementia</td>
<td>Individual music therapy</td>
<td>Passive</td>
<td>Qualitative</td>
<td>Video observation</td>
<td>Not reported</td>
<td>To explore the experiences of people with dementia when they engage with familiar music.</td>
</tr>
<tr>
<td>Lockett (2015)</td>
<td>Australia</td>
<td>7 family caregivers 23 staff caregivers</td>
<td>Group music therapy</td>
<td>Active</td>
<td>Qualitative</td>
<td>Reflexive practitioner journal Focus groups</td>
<td>Qualitative content analysis</td>
<td>To examine the benefit of music in reducing &quot;behaviours that challenge&quot;</td>
</tr>
<tr>
<td>Unakat (2016)</td>
<td>UK</td>
<td>17 people with dementia 17 family caregivers</td>
<td>Singing group</td>
<td>Active</td>
<td>Qualitative</td>
<td>Couple interviews</td>
<td>Grounded theory analysis</td>
<td>To understand the benefits of group singing for people with dementia.</td>
</tr>
</tbody>
</table>

*Thesis **Unable to determine precise participant numbers
Although musicking was seen as accessible, there were a number of barriers to taking part, with the most frequent being access to music. People with dementia may not have been able to bring to mind their enjoyment of music nor had choice in the way in which they engaged with music. For example, within care home environments, music was often engaged with through media such as the radio or CD players, or, alternatively, via pre-determined activity schedules. People with dementia in these situations had little control over when or how they engaged with music, or had to rely on others to make the decisions for them, as this illustration suggests:

For some people the problem lay in articulating their musical wishes and preferences to others. As a result, people with dementia tended to become increasingly dependent upon others in order to gain access to music or musical activity. Because of limits on their time and personal resources, carers were not always able to provide regular access to music. (Sixsmith & Gibson, 2007, p. 137)

Overall, although this theme highlights that music is universally accessible to everyone in the musicking space there appear to be barriers to taking part for people with dementia, especially within care home environments.

**Theme 2: Being Connected**

Musicking facilitated enhanced connection between people with dementia and their spouses, other family members, care staff, musicking facilitators (i.e. music therapists) and the environment in which the activity took place. The majority of studies in the review explored the use of music within a group setting and as a shared activity between people with dementia and their support networks (Camic et al., 2013; Dassa & Amir, 2014; Hara, 2013; McCabe et al., 2015; McDermott et al., 2014; Tuckett, Hodgkinson, Rouillon, Balil-Lozoya, & Parker, 2015; Unadkat et al., 2016). These music groups were viewed primarily as a social activity in which, over time, a supportive group culture could be developed whatever the encountered environment:

"When you see one of those care-home rooms with 20–30 chairs in a huge circle – generally speaking, I feel that that is the worst sort of setup for any socialising: any communication anything going on at all. But then this focus of the music, and what music enables, changed that." Music Therapist (Pavlicevic et al., 2015, p. 670)

This group culture, created through musicking, provided people with dementia with a sense of belonging and a sense of security (Camic et al., 2013; Dassa & Amir, 2014; Hammar et al., 2010; Hara, 2013; Osman et al., 2016; Pavlicevic et al., 2015; Tomaino, 1998; Unadkat et al., 2016). Moreover, such an initiative, and the shared enjoyment of musicking, also created a sense of togetherness between those with dementia and those supporting them. Furthermore, musicking provided a space in which the person with dementia was not dependent on others; in turn, this enhanced the quality of existing relationships with carers and facilitated positive interactions across a number of social and relational networks as these two extracts reveal:

The caregivers described the elements in the caring situation as uninterrupted and this time was described as a nice moment they shared with the [people with dementia], which made them feel close to them. (Hammar et al., 2011b, p. 105)
“Wherever you go and whatever group of people you’re in, singing seems to break down barriers and to open up sort of, not only companionship, but a sense of belonging, and that’s great”
Person with dementia (Osman et al., 2016, 5)

This sense of being connected was heightened by musicking as it helped people with dementia to connect with family members, music therapists and care staff on a level that did not require words (Baker, Grocke & Pachana, 2012; Gardner, 1999; McDermott et al., 2014; Sixsmith & Gibson, 2007; Unadkat et al., 2016). Furthermore, musicking facilitated enhanced eye contact and touch between the person with dementia and others, thus making connections across the musicking space (Gardner, 1999; Hammar et al., 2010; Hammar, Emami, Engström, & Göttell, 2011a; Hammar et al., 2011b; McDermott et al., 2014; Pavlicevic et al., 2015; Tomaino, 1998). Musicking also promoted non-verbal communication and this created a space in which new ways of meaningful communication could be explored, as below:

“... just being able to be together and enjoy and listen to something we both love is a benefit. [...] There were no words or anything... We didn’t need to talk. The music did enough.” Spouse of person living with dementia (Baker et al., 2012, p.14)

Overall, musicking provided an opportunity for people with dementia to connect to others and the environment around them, without the need for words. This connection enabled people with dementia to feel part of a group culture, which enhanced a sense of togetherness and a sense of security.

**Theme 3: Affirming Identity**

Within each study in the review, it was evident that each person with dementia had a musical identity and musical history. Personal preferences for certain pieces, or genres, of music were expressed both verbally and non-verbally, for example by foot tapping, conducting and smiling. Music was also bound to cultural and spiritual identities with many people with dementia connecting to religious music that was significant in their life. The expression of musical preferences, in combination with the memories that musicking evoked, resulted in care staff and music therapists actively seeking to understand the life history of the person with dementia (Hara, 2013; Tomaino, 1998). In turn, this enabled people with dementia to strengthen their sense of identity and promoted an understanding of the person that went far beyond a diagnostic label.

This strong affiliation between a person’s life history and their musical preferences resulted in the awakening of memories in people with dementia. For example, people with dementia were able to remember past events that were coupled with music, remember lyrics to songs and, in some cases, develop new memories of the musicking activities from week to week. All but one study (McCabe et al., 2015) drew on biographically relevant songs within group musicking activities. The use of familiar, biographically significant songs was twofold: firstly, people with dementia were able to reminisce about memories associated with these songs and affirm a sense of past-present identity; and secondly, the person’s confidence in their abilities was enhanced through an ability to remember lyrics and melodies.

The shared musical history of many group members allowed people to identify with others who had grown up in the same era. Musicking was therefore able to stimulate memories of times gone by, which people with dementia shared with others in the same space. This ability to reminisce as a group affirmed a collective identity as this quotation attests:
“... music and singing especially, brings people together, if you are singing then you are sharing in something no matter who you are beforehand because you are all going for it together.” Person with dementia (Unadkat et al., 2016, p. 8)

Furthermore, people with dementia were able to develop new musical tastes throughout the engagement with music activities. This would suggest that although musicking can be used as a tool to reminisce with a person with dementia, it is also important to understand that musical preferences evolve over time. Therefore, as the literature reveals, new musical experiences should be explored in order to expose the person with dementia to new and interesting musical experiences and consequently a new and changing identity as seen in the illustration below:

[…] one of the popular waltz tunes, “Irish eyes are smiling” started to be known as Arnold’s [person with dementia] favourite song. I observed the process of how it went from being “a song” to being “Arnold’s Song” (Hara, 2013, p. 155)

Overall, this theme highlights that music enables the person to connect with their past through personal musical preferences and a shared musical history with others. This enabled shared reminiscence, which affirmed a sense of personal and collective identity.

**Theme four: Immersion “in the moment”**

People with dementia appeared absorbed in musicking to the extent that they were “lost in its hearing” (Sixsmith & Gibson, 2007, p. 132), appearing happier, more “alive” and less agitated. Although these observable changes in well-being were described as immediate, doubts were expressed from care staff and family members about the lasting effects of musicking outside of that specific musicking space (McDermott et al., 2014; Sixsmith & Gibson, 2007; Tuckett et al., 2015). However, the positive impact that musicking had on the person with dementia “in the moment” was seen as being as important as any long-term effects on sociability and mood, for example, as these two slices of data attest:

Many therapists acknowledged they did not know how much staff or family carers noticed sustained communicability following music therapy sessions. Therapists generally seemed to regard meaningful connection with others and normal togetherness that happened during a session more crucial for the well-being of people with dementia than potential long-term effects of therapy (McDermott et al., 2014, p. 712)

The nature of dementia means that, for those with the condition, the benefit of the sessions is somewhat short-lived as the activity is forgotten in some cases; therefore, the intrinsic value of the sessions becomes most important (Osman et al., 2016, p. 7)

As well as improved mood and communication, music facilitated many embodied reactions which allowed people with dementia to express themselves and take part in the activity without the need for words. This embodied musical participation resulted in people with dementia being able to express musical preferences through their bodily movements, such as dancing and/or reaching out for instruments. It also empowered the person with dementia to express their enjoyment of musicking, whether this was expressed outwardly, such as by actively engaging with the music therapist, or more subtly, such as through foot tapping and swaying in time to the music (Gardner, 1999; Götel, Brown, & Ekman, 2002; Hammar et al., 2011a; Hara, 2013; Sixsmith & Gibson, 2007; Tomalino, 1998; Tuckett et al., 2015). Such actions enabled the person with dementia to enhance their sense of self and strengthen their relationships with others, as well as to perform embodied memories from the past.
experiences are shared below:

There were several sessions when Carmen [person with dementia] was very tired and displayed almost no response. On closer observation, however, I could see that her breathing was synchronised with the rhythm of the music. (Tomaino, 1998, p. 60)

The memory exercises, through singing familiar songs, were supported by the rhythm of the songs [...] these rhythms entrained their bodies, enabling an almost automatic participation with others (Hara, 2013, p. 223).

Overall, this theme highlights the benefits of musicking for the person with dementia "in the moment" allowing for a multi-sensory experience that enabled an exploration of sound and self.

Discussion

In recent years, there has been a move away from the view that music is a "curative" intervention for symptoms associated with dementia, and towards a view that music can enhance the well-being and quality of life of people with dementia (Sixsmith & Gibson, 2007). For this review, we conducted a comprehensive search of the qualitative literature surrounding the use of musicking with people with dementia. Overall, 18 studies were identified and a thematic synthesis of the qualitative findings revealed a number of emotional, psychological and social benefits for the person with dementia when engaging with music. These personal benefits were presented under four themes: Taking Part, Being Connected, Affirming Identity and Immersion "in the moment".

The first theme, Taking Part, was a common thread running through the literature, emphasising that musicking enables people with dementia to take part without having to rely solely on cognitive and/or linguistic capabilities. The accessibility of music also enabled people with dementia to take part in an activity that was failure-free, meaning they were viewed as equals within the musical space. This democratisation of the musicking space enabled the stigma associated with dementia to be challenged, with others involved in the activity able to see beyond the diagnostic "label" of dementia and to the person living with the condition (Batsch & Mittelman, 2012).

This theme also highlighted a number of barriers to musicking, such as control over when and how musicking was engaged with by the person with dementia. Many people with dementia, particularly when they enter a care home setting, may not have control over when and how they engage with music or other arts activities. Such activities may be viewed predominantly as entertainment, with care staff and residents anticipating scheduled activities at a set time on a certain day of the week (Basting et al., 2016). Perhaps thinking beyond music as a scheduled activity, and beginning to explore how musicking can become an integral part of people with dementia’s day-to-day lives and linked to the person’s biography, the barriers to taking part in musicking can be reduced. Seeking the views of people of dementia in the design of products which enhance access to music would further enhance the usability and acceptability of such technology (Brankaert, 2016).

The second theme Being Connected highlighted that musicking provided a space for the person with dementia to be connected: both to themselves, to other people and to the sensory environment. This sense of being connected enabled the person with dementia to feel a sense of security and a sense of belonging, thus providing an opportunity for them
to feel part of a community through the meaningful social interactions that musicking afforded (Nolan, Brown, Davies, Nolan, & Keady, 2006). As everyone was able to take part as equals, this enabled the person living with dementia to “connect with themselves, to music and then, perhaps ... to another person” (Pavlicevic et al., 2015, p. 668).

The third theme, Affirming Identity, explored the idea that musicking strengthened the sense of identity held by a person with dementia. People with dementia were able to express musical preferences, either verbally or non-verbally, but also developed new musical tastes and preferences across time. The singing of biographically significant music acted as a catalyst for memories for the person with dementia, allowing them to remember key life events that were interwoven with different pieces, or genres, of music. However, it was the sense of strengthening a sense of identity and creating a meaningful connection with others that appeared more important than the remembrance of particular life events.

The fourth theme, Immersion “in the moment”, highlights the value of embodied musical experiences within the present moment. Although the personal benefits of musicking may not have lasted outside of the musicking space, the immersive, multisensory experience of the moment was still valued greatly by family members, care staff and music therapists. In recent years, there has been a growing body of work that is seeking to understand the benefits of meaningful activity for people with dementia “in the moment” (Gridley, Brooks, Birks, Baxter, & Parker, 2016). Understanding of “in the moment” experiences, specifically “flow”, are also closely linked to the Positive Psychology movement (Csikszentmihalyi, 1997; Nakamura & Csikszentmihalyi, 2014) in which emphasis is placed not only past experiences, but also on the present moment and the future (Heffernon & Boniwell, 2011).

By placing the focus on music for reminiscence purposes alone, the importance of embodied, “in the moment” responses, can be overlooked (Killick, 2016). Musicking can, therefore be seen as a platform for “embodied selfhood” enabling the person with dementia to strengthen their sense of identity through their bodily agency (Kontos, Hycén, Brockmeier, & Lindemann, 2014). Only by shifting the focus of enquiry towards understanding “in the moment” experiences can we begin to understand the possibilities for music outside the remit of cognitive enhancement or as “symptom” reduction. Through further exploration of the musical bodies of people with dementia, we can begin to learn more about how music enables a person living with dementia to connect with those around them, and to interact with, the world around them (Phinney, Hycén, Lindemann, & Brockmeier, 2014).

This review has revealed that many music engagement programmes for people with dementia place a significant emphasis on the shared musical histories of people with dementia, but there are very few instances of the creation of new music with people with dementia. Of 18 studies, only McCabe et al. (2015) explored the composition of a new piece of music with people with dementia. Although reminiscence-based singing groups appear very beneficial, it is also important to consider how gaining creative control over a musicking project may facilitate enhanced engagement and a sense of agency for people with dementia. As one person with dementia in Unadkat et al.'s (2016) study expressed:

"all that looking back, it can be a bit mindless maybe, possibly if we were being active and creating something it would be more beneficial, like a sort of new learning for us". (p. 8)

Going forward it would seem necessary that, in practice, it is important to explore the use of music beyond simply being a tool for reminiscence purposes. By shifting the focus away from reminiscence and towards the “in the moment” experiences and the creative musical output of people with dementia, we may begin to understand the benefits of
musicking further. Highlighting the importance of “in the moment” creative engagement to those funding, facilitating and taking part in musicking programmes may also lead to more nuanced and participatory approaches to evaluation.

The secondary objective of this review was to understand the involvement of people with dementia in the research surrounding their musicking experiences. Within the identified studies there were relatively few examples of active participation in research by people with dementia. Many of the studies relied on observation, or reports from family members, care staff, and music therapists meaning the voices of people with dementia are largely absent from this research arena. The drive to involve people with dementia in research has significantly increased in recent years, with it no longer seen as being acceptable to rely on proxy accounts (McKeown, Clarke, Ingleton, & Repper, 2010). The qualitative literature surrounding the use of musicking in dementia studies needs to make a similar move towards enhanced inclusion of people with dementia in the conduct and presentation of future research (Gridley et al., 2016).

Conclusion
This review of the qualitative literature surrounding the personal benefits of musicking for people with the lived experience of dementia has provided an opportunity to examine the subjective emotional, psychological and social benefits. Whilst there are some good news stories in the review, it is perhaps fair to say that there is some distance to go to ensure the active participation of people with dementia in understanding, and translating, their own lived experiences. However, going forward, it is important to be able to communicate the “in the moment” experiences of people with dementia, and view the personal benefits of musicking as having impacts that extend to multiple stakeholders, and environments, at different points in time and in different ways. Measuring such impacts remains a significant challenge and a research agenda for the future.

Disclosure statement
No potential conflict of interest was reported by the authors.

Funding
This work was supported by the Economic and Social Research Council and Manchester Camerata.

ORCID
Robyn Dowlen http://orcid.org/0000-0003-2982-7039

References


McCabe, L, Greasley-Adams, C, & Goodson, K. (2015). 'What I want to do is get half a dozen of them and go and see Simon Cowell': Reflecting on participation and outcomes for people with dementia taking part in a creative musical project. *Dementia, 14*(1), 734–750. doi:10.1177/1471301213508128


## Appendix 2: Quality of studies

<table>
<thead>
<tr>
<th>Items</th>
<th>Study Number</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
</tr>
<tr>
<td><strong>Personal Characteristics</strong></td>
<td></td>
</tr>
<tr>
<td>Interviewer/facilitator identified</td>
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<tr>
<td>Credentials (e.g. PhD, MD etc.)</td>
<td>+</td>
</tr>
<tr>
<td>Occupation</td>
<td>-</td>
</tr>
<tr>
<td>Gender</td>
<td>+</td>
</tr>
<tr>
<td>Experience and training in qualitative research</td>
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</tr>
<tr>
<td><strong>Relationship with participants</strong></td>
<td></td>
</tr>
<tr>
<td>Relationship established</td>
<td>-</td>
</tr>
<tr>
<td>Participant knowledge of the researcher</td>
<td>-</td>
</tr>
<tr>
<td>Interviewer characteristics</td>
<td>-</td>
</tr>
<tr>
<td><strong>Theoretical framework</strong></td>
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</tr>
<tr>
<td>Methodological orientation and theory</td>
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</tr>
<tr>
<td><strong>Participant Selection</strong></td>
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</tr>
<tr>
<td>Selection strategy (e.g. snowball, purposive etc.)</td>
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</tr>
<tr>
<td>Method of approach/recruitment</td>
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<tr>
<td>Sample Size</td>
<td>+</td>
</tr>
<tr>
<td>Number/reasons for non-participation</td>
<td>-</td>
</tr>
<tr>
<td><strong>Setting</strong></td>
<td></td>
</tr>
<tr>
<td>Setting of data collection</td>
<td>-</td>
</tr>
<tr>
<td>Presence of non-participants</td>
<td>-</td>
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<tr>
<td>Description of the sample</td>
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</tr>
<tr>
<td>Data collection</td>
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</tr>
<tr>
<td>Repeat interviews/observations</td>
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</tr>
<tr>
<td>Audio/visual recording</td>
<td>+</td>
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<tr>
<td>Field notes</td>
<td>-</td>
</tr>
<tr>
<td>Duration</td>
<td>+</td>
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<tr>
<td>Data (or theoretical) saturation</td>
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<tr>
<td>Transcripts returned to participants</td>
<td>-</td>
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<tr>
<td><strong>Data Analysis</strong></td>
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<tr>
<td>Number of data coders</td>
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<tr>
<td>Description of coding tree</td>
<td>-</td>
</tr>
<tr>
<td>Derivation of themes/findings</td>
<td>-</td>
</tr>
<tr>
<td>Use of software</td>
<td>-</td>
</tr>
<tr>
<td>Participant feedback or member checking</td>
<td>-</td>
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<tr>
<td><strong>Reporting</strong></td>
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<tr>
<td>Quotations presented</td>
<td>+</td>
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<tr>
<td>Data and findings consistent</td>
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<tr>
<td>Clarity of major themes</td>
<td>+</td>
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<tr>
<td>Clarity of minor themes</td>
<td>-</td>
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<tr>
<td><strong>Ethics</strong></td>
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<td>Participant Information</td>
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<td>Informed Consent</td>
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<tr>
<td>Ethical Approval</td>
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<td><strong>Total</strong></td>
<td>13</td>
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</table>
# Appendix 3: Musical instrument inventory

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Image</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Castanets</td>
<td><img src="image1.jpg" alt="Castanets" /></td>
<td>Percussion instrument used in European music, most typically in Spanish and Portuguese music. The concave shells produce clicking sounds when hit together.</td>
</tr>
<tr>
<td>Cowbell</td>
<td><img src="image2.jpg" alt="Cowbell" /></td>
<td>Percussion instrument most typically used in salsa music as well as popular music. Produces a tinny sound when struck with a beater.</td>
</tr>
<tr>
<td>Egg Shakers</td>
<td><img src="image3.jpg" alt="Egg Shakers" /></td>
<td>Percussion instrument that makes noise when shaken. The oval shell contains loose objects, such as beads, in order to produce a shaking sound.</td>
</tr>
<tr>
<td>Glockenspiel</td>
<td><img src="image4.jpg" alt="Glockenspiel" /></td>
<td>Tuned percussion instrument with tuned notes arranged in a keyboard fashion in ascending order. Produces a bright metallic sound.</td>
</tr>
<tr>
<td>Hand Bells</td>
<td><img src="image5.jpg" alt="Hand Bells" /></td>
<td>A tuned percussive instrument, with each bell representing a different note on the musical scale. Played by pressing a button on the handle of the bell. Produces a light ringing sound.</td>
</tr>
</tbody>
</table>
Lyre

Stringed instrument originating from ancient Greece. Similar in appearance and sound to a small harp.

Maracas

Percussive instrument which produces a rattle once shaken. It is held by the handle and typically played as part of a pair.

Ocean Drum

Percussive instrument which is shaken from side to side in order to produce sounds of the sea. The drum is held by the frame and played horizontally by tilting the wrists which moves metal beads within the drum.

Snare Drum

Percussion instrument which produces a sharp, short sound when struck with a drum stick.

Tambourines

Percussion instrument which has a wooden or plastic frame with mettle jingles. Tambourines can be hit or shaken in order to produce different sounds.
<table>
<thead>
<tr>
<th>Instrument</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ukulele</td>
<td>Stringed instrument with four strings. Strings can be played individually or in combination to produce melody or chords.</td>
</tr>
<tr>
<td>Wood block</td>
<td>Percussion instrument made from a single piece of wood. Sound is produced by using a beater to hit the wooden block.</td>
</tr>
</tbody>
</table>
Appendix 4: Social Care Research Ethics Committee approval letter

Health Research Authority

Social Care REC
Ground Floor
36-40 London Road
London
SE1 8LU
Telephone: 0207 772 2305

24 January 2017

Ms Robyn Dowlen
PhD Student
University of Manchester
Division of Nursing, Midwifery and Social Work, The University of Manchester
Jean McFarlane Building
Oxford Road, Manchester
M13 9PL

Dear Ms Dowlen

Study title: "Music Matters": Developing an 'in the moment' multisensory music assessment tool with people living with dementia through a participatory design.

REC reference: 16/IEC08/0049
Protocol number: N/A
IRAS project ID: 212997

Thank you for your letter of 11 January 2017, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Vice-Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact hra.studyregistration@hra.net outlining the reasons for your request.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person

A Research Ethics Committee established by the Health Research Authority
who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).


Where a NHS organisation’s role in the study is limited to identifying and referring potential participants to research sites (“participant identification centre”), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publicly accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.study.registration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

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Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NIHR/HSC R&D office prior to the start of the study (see “Conditions of the favourable opinion” below).

Non-NHS sites

The Committee decided that the research did not require Site-Specific Assessment at non-NHS sites as it involves no clinical interventions and all study procedures at sites would be undertaken by the Chief Investigators' team and the Committee was satisfied that the risk to participants is likely to be negligible, and the study procedures will not significantly interfere with participants' freedom of action or privacy or be unduly invasive or restrictive.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<table>
<thead>
<tr>
<th>Document</th>
<th>Version</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Copies of advertisement materials for research participants</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Copies of advertisement materials for research participants [Cycle 3 recruitment poster]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Covering letter on headed paper [Cover letter]</td>
<td></td>
<td>17 November 2016</td>
</tr>
<tr>
<td>Covering letter on headed paper [Cover letter]</td>
<td></td>
<td>15 January 2017</td>
</tr>
<tr>
<td>Covering letter on headed paper [Cover letter]</td>
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<td>19 January 2017</td>
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<td>Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor insurance]</td>
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<tr>
<td>Interview schedules or topic guides for participants [Focus group topic guide]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Interview schedules or topic guides for participants [Cycle 3 telephone interview schedule]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Letters of invitation to participant [Cover letter for person living with dementia with the capacity to consent]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Letters of invitation to participant [Cover letter for person living with dementia who has capacity to consent]</td>
<td>Version 1</td>
<td>31 October 2016</td>
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A Research Ethics Committee established by the Health Research Authority
<table>
<thead>
<tr>
<th>Document Title</th>
<th>Version</th>
<th>Date</th>
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<tbody>
<tr>
<td>Other [Abuse protocol]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Other [Participant research diary]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Other [Risk assessment ]</td>
<td>Version 1</td>
<td>29 October 2016</td>
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<tr>
<td>Other [Visual cue card for video elicitation interviews]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Other [Structured capacity assessment form]</td>
<td>Version 1</td>
<td>31 October 2015</td>
</tr>
<tr>
<td>Other [Cycle 1. Family members and support workers. Expression of Interest Form.]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Other [Cycle 3. Healthcare, charity, or arts organisations. Expression of Interest Form.]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Other [Expression of interest - person living with dementia with capacity]</td>
<td>Version 1</td>
<td>31 October 2015</td>
</tr>
<tr>
<td>Other [Personal Consultee Expression of interest form]</td>
<td>Version 1</td>
<td>31 October 2015</td>
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<tr>
<td>Other [CV Caroline Swarbrick]</td>
<td>Version 1</td>
<td>21 November 2016</td>
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<tr>
<td>Other [Christine Milligan CV]</td>
<td>Version 1</td>
<td>21 November 2016</td>
</tr>
<tr>
<td>Participant consent form [Consent form for person living with dementia who has capacity to consent]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
<tr>
<td>Participant consent form [Consent form family members and support workers (videoing only)]</td>
<td>Version 1</td>
<td>31 October 2016</td>
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<tr>
<td>Participant consent form [Family members and support workers consent form]</td>
<td>Version 1</td>
<td>31 October 2016</td>
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<tr>
<td>Participant consent form [Healthcare, charity or arts organisations consent form]</td>
<td>Version 1</td>
<td>31 October 2016</td>
</tr>
</tbody>
</table>
Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/.

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

A Research Ethics Committee established by the Health Research Authority
With the Committee’s best wishes for the success of this project.

Yours sincerely

Ms Susan Harrison
Vice Chair

Email:nrescommittee.social-care@nhs.net

Enclosures:  "After ethical review – guidance for researchers"

Copy to: Ms Lynne Macrae

A Research Ethics Committee established by the Health Research Authority
Appendix 5: Recruitment flyer

RESEARCH VOLUNTEERS NEEDED

How do people with dementia experience music ‘in the moment’?

- Are you, or the person you care for, living with dementia?
- Are you, or the person you care for interested in taking part in Music in Mind?
- Are you also interested in taking part in dementia research?

We would like to work with you in order to learn about your experiences during music sessions. We would like to work together with you to design a new music assessment tool.

If you decide to take part you will receive a £20 Love2Shop voucher as thanks for your participation in the research.

For more information please contact Robyn Dowlen:

Email: robyn.dowlen@postgrad.manchester.ac.uk

Telephone: 0160 306 7732/0161 908 0042
# Appendix 6: Structured capacity assessment form

1. Is there an impairment of, or disturbance in, the functioning of the person’s mind or brain?
   - [ ] No  (should be deemed to have capacity; go to box 8)
   - [ ] Yes  (specify the disorder or condition)

2. Is person able to understand information relating to participating in the study?
   - [ ] Yes
   - [ ] No  Give evidence or examples:

3. Is person able to sufficiently retain information related to participating in the study?
   - [ ] Yes
   - [ ] No  Give evidence or examples:

4. Is person able to use and weigh up the information in relation to making this decision?
   - [ ] Yes
   - [ ] No  Give evidence or examples:

5. Is person able to communicate this specific decision by any means?
   - [ ] Yes
   - [ ] No  Give evidence or examples:

6. Additional evidence or information from other sources (e.g. other staff, family, friends, EPA/LPA, IMCA etc.):

7. Is it concluded that the person lacks capacity to make this specific decision at this time?
   - [ ] Yes  (follow study procedures for patients who lack capacity)
   - [ ] No   (go to box 10)

## Decision Taken

8. What is decision at this time?

10. Decision Maker (Print name):  
    Signature:  
    Date Decision Made:  
    Tel:  
    Email:
Appendix 7: Information sheet for people with dementia with capacity

Hello
My name is Robyn Dowlen

• I am a researcher from the University of Manchester

• I research how people living with dementia respond to music
I would like to talk to you about your experiences of taking part in Music in Mind.

On the following pages there is information that can help you decide whether you would like to talk to me about your experiences.

What will happen if I decide to take part?
1. Filming you

If it is ok with you, I would like to film you when you take part in the Music in Mind group.

I would like to video each Music in Mind session – I will ask your permission to film you every week.

I will stop the filming at any time if you would like it to stop

2. Talking to you about your experiences

I would like to meet with you 2 or 3 times to discuss your experiences during the project.

We will watch videos of the Music in Mind group and you can tell me about your thoughts and feelings about the project.

You can bring a friend or family member with you if you would like to.
3. Reflecting back

I would like your help in understanding what you and other people involved in the project have told me.

I would like to meet with you twice after Music in Mind has finished. I would like to show you what I have found out about the experiences of people in the group. I would like to hear your opinions on whether my interpretations are correct.

You can bring along a family member or friend to this if you would like to.

I would like to record our conversations so that I can remember our conversations when I listen back to them.

I will ask your permission before recording what we talk about.
If you do decide to take part...

I would like to record you telling me your decision to take part

You can do this in one of two ways

1. You can sign a ‘consent form’
2. We can film you saying your decision

You can change your mind

You can decide not to talk to me, even after agreeing to help me

You do not have to tell me why you do not want to speak to me

You will still be able to take part in Music in Mind even if you decide not to speak to me
My contact details

agogako 0161 306 7732
0161 226 8696

robyn.dowlen@manchester.ac.uk

University of Manchester
Division of Nursing, Midwifery
and Social Work, Room 6.332
Jean McFarlane Building
Oxford Road
Manchester M13 9PL

Thank you for your interest in my project
and taking the time to read this booklet

If you have any questions, please contact
me and we can talk more about the
research.
Appendix 8: Consent form for people with dementia with Capacity

IRAS Project ID: 212997

Your agreement to take part in the research: “Music Matters”: Understanding how you experience music ‘in the moment’

This booklet contains my agreement(s) for taking part in the research: “Music Matters”: Understanding how you experience music ‘in the moment’

Music Matters: Developing an ‘in the moment’ multisensory music assessment tool in collaboration with people living with dementia

I can confirm that I have had the chance to read and look at the participant information for this study

The information booklet was Version x and dated

I confirm that I have read and discussed the information booklet. (tick or cross the box).
I can confirm that I have had the chance to ask any questions that I have

(tick or cross the box)

I understand that taking part is voluntary and I can choose to stop at any time without giving a reason

I confirm my understanding of this (tick or cross the box):
I agree to being filmed while I am taking part in the music sessions

I confirm that I agree to be video recorded when I am taking part in the music sessions (tick or cross the box):

I agree to our interview and group work sessions to be audio recorded

I confirm that I agree to the audio recording (tick or cross the box):
I agree to quotes from things that I tell you being used in specialist magazines and reports as long as I cannot be identified and you use another name for me.

I confirm that I agree to this (tick or cross the box):

If you want to use images that show my face, then you would need to come and ask my permission again.

I agree to you contacting me again for this purpose.

I confirm that I agree to this (tick or cross the box):
I agree to take part in this study

This is my name and signature:
Name: .................................................................................................

Signed: ............................................................................................... 
Date: .....................................................................................................

This is Robyn Dowlen’s signature who took this agreement.

This is my name and signature:
Name: .................................................................................................

Signed: ............................................................................................... 
Date: .....................................................................................................

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Appendix 9: Information sheet for people with dementia without capacity

Understanding your experiences of taking part in Music in Mind

Participant Information

Music Matters: Developing an ‘in the moment’ multisensory music assessment tool in collaboration with people living with dementia through a participatory design. Accessible Information booklet for people living with dementia without capacity to consent. Version 4 [19.01.2017]

Hello

My name is Robyn Dowlen

- I am a researcher from the University of Manchester
- I research how people living with dementia respond to music
I would like to talk to you about your experiences of taking part in Music in Mind.

What will I need to do when I take part?
1. Filming you

I would like to film you when you take part in the Music in Mind group.

I would like to film you during each Music in Mind session across the 15 week project.

I will stop the filming at any time if you would like it to stop.

2. Talking to you about your experiences

I would like to meet with you 2 or 3 times to discuss your experiences during the project.

We will watch videos of the Music in Mind group and you can tell me about your thoughts and feelings about the project.

You can bring a friend or family member with you if you would like to.
3. Reflecting back

I would like your help in understanding what you and other people involved in the project have told me.

I would like to meet with you twice after Music in Mind has finished.

I would like to show you what I have found out about the experiences of people in the group.

I would like to hear your opinions on whether my interpretations are correct.

You can bring along a family member or friend to this if you would like to.

My contact details

0161 306 7732
0161 226 8696
robyn.dowlen@manchester.ac.uk

University of Manchester
Division of Nursing, Midwifery and Social Work, Room 6.332
Jean McFarlane Building
Oxford Road
Manchester M13 9PL
Thank you for your interest in my project and taking the time to read this booklet.

If you have any questions, please contact me and we can talk more about the research.
Appendix 10: Personal consultee information Sheet

Personal Consultee Information Sheet

Music Matters: Developing an ‘in the moment’ multisensory music assessment tool collaboratively with people living with dementia through a participatory design

Invitation

Your relative/friend is being invited to take part in a research project. To help to decide if s/he should join the study, we would like to ask your opinion as to whether or not they would want to be involved. Before you decide, it is important that you understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please consider any previous wishes and feelings that your relative/friend may have had regarding their participation in research. These should take precedence. Please feel free to ask us if there is anything that is not clear or if you would like more information.

If you decide your relative/friend would have no objection to taking part, we will ask you to read and sign a consultee declaration to document your opinion as to how your relative would have chosen to participate in the study. We will then give you a copy to keep. By signing the declaration, this allows us to approach your relative/friend. If they do not wish to answer any questions, we will not continue with the study. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative would not wish to take part, it will not affect the standard of care they receive in any way.

What is the purpose of the study?

The purpose of the study is to develop a new way of measuring the impact of music on people living with dementia. We want to work with people with dementia in order to ensure that this tool is meaningful to them and reflective of their experience. We
hope that this research will lead to the development of a measurement tool that can strengthen the evidence-base for the use of music in the context of dementia care.

Why has my relative/friend been chosen?

Your relative/friend has been invited to take part in this study because we are including people who are involved in Manchester Camerata’s Music in Mind project.

Does my relative/friend have to take part?

No. We are asking you to decide whether or not you are happy for your relative/friend to be approached to take part in this study. You should only agree for your relative/friend to be approached if you think they would not have refused to take part. If you do decide that you would like them to be approached, you will be asked to sign a consultee declaration form. If you agree for them to take part, but for any reason they do not wish to answer questions at the time when we approach them, we will not continue with the study. If you do not want your relative/friend to take part, or you want them to drop out of the study at anytime this will not affect the medical care that they receive in any way. You do not have to give any reason for not wanting them to take part.

What will the project involve if I choose to take part?

We would like to video your relative while they take part in Manchester Camerata’s Music in Mind project. We would like to use the video that we collect to stimulate a discussion between ourselves and your relative regarding their experiences of the project. We would therefore like to meet with your relative twice for no more than 45 minutes to discuss the videos with them. After the project has ended we would like to invite your relative to give us feedback on the data we have collected, to make sure that it is reflective of their experiences. In order to gain feedback from your relative, we would like to visit them in their home, or the community centre in which Music in Mind took place, for no longer than 60 minutes.

What will happen to the data once it has been collected?

The video footage of each session will be watched and edited by the research team. These videos will then be used to stimulate discussions with people living with dementia as part of interviews. The videos will also be used to stimulate discussion with members of the Focus Group.

The researcher will audio record the interviews and the feedback sessions with the person living with dementia who you support. Audio data will be backed up on a
University of Manchester computer, and the original recording will be deleted off the recording device. The audio data from the interviews and feedback sessions will be transcribed by a University of Manchester approved service. Once the researcher receives the transcript of the interview or feedback session, they will remove any identifying information from the transcripts. Once transcripts have been anonymised, the researcher will delete the sound file of the interviews and feedback sessions.

**How long will the data be stored for?**

The anonymised data and consent forms will be stored for 10 years, but items such as your contact details will be deleted as soon as they are no longer needed. Video data will be kept for 5 years after the completion of the research project and then deleted off of the university computer system. No personal information will be attached to the videos, with videos being labelled only with participant numbers or pseudonyms.

The University of Manchester (data controller) will be responsible for the personal data collected during this study.

**What will happen to the findings of this research study?**

The findings of the study will be presented to researchers and health and social care professionals, and will be published in scientific journals. The findings of the study will include anonymised quotes from the people living with dementia involved in the research. The researcher will send you a copy of any quotes that have been said by your relative in order to gain your permission to use them. The researcher may also select video from the Music in Mind sessions to be used when presenting findings. The researcher will send you a copy of the video that they wish to use, and you can give your permission if you are happy to do this. The researcher will be able to obscure the face of your relative in the footage so that you are not identifiable. The findings of the study will also be presented in a report written by the researcher so that you can see what has been discovered as a result of the research.

**Are there any possible risks to my relative/friend taking part?**

The interviews and discussions are not expected to cause any direct harm. If at any point your relative/friend experiences any psychological or emotional discomfort whilst answering questions then the researcher will allow time to rest or stop the study altogether.

**What are the possible benefits of my relative/friend taking part?**

There are no direct benefits to anyone taking part in this study. Nonetheless the findings from this research will help enhance our understanding of why music is
beneficial to people living with dementia in the hope that a more meaningful and accurate music assessment tool can be developed. By providing personal viewpoints, people living with dementia can have a direct impact on funding for dementia care using an evidence-based approach.

*Will my relative/friend’s information stay confidential?*

Yes. All information collected about your relative/friend during the course of the research will be kept strictly confidential. Any identifying information will be made anonymous and this information will be collected, stored, handled and processed by Robyn Dowlen, a PhD student at the University of Manchester.

Everything reported remains confidential unless your relative/friend tells us something that indicates that they or someone else is at risk of harm. In the event of this, we may need to disclose information about your relative / friend without your advice to protect them or others around them. If possible, we will discuss this with you before making such disclosures.

Individuals from the University of Manchester or regulatory authorities may need to look at the data collected during this study to make sure the project is being carried out as planned. This might include your or the person you support’s personal data but, anyone accessing the data will have a strict duty of confidentiality to you as a research participant.

*Who is organising and funding the research?*

The study is being funded by the Economic and Social Research Council (ESRC). It is being organised by the University of Manchester, Lancaster University and Manchester Camerata.

*Who has reviewed the study?*

This study has been reviewed and given favourable opinion by the National Social Care Research Ethics Committee (Ref: 16/IEC08/0049). Approval does not guarantee that you will not come to any harm if you take part. However, approval means that the Committee is satisfied that your rights will be respected, that any risks have been reduced to a minimum and balanced against possible benefits, and that you have been given sufficient information on which to make an informed decision about whether to take part or not.

*What if I have any comments?*
If you have any questions or concerns that the researcher cannot answer or if you have any comments about the study, you can ask the Chief Investigator of the study Professor John Keady. He will do his best to answer your questions.

Professor John Keady
Professor of Mental Health Nursing and Older people
University of Manchester
Jean McFarlane Building
University Place
Oxford Road
Manchester
M13 9PL
Tel: 01613067854/ Email: john.keady@manchester.ac.uk

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact April Lockyer, Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674 or 275 2046.

What should I do now?

If, having read this Information Sheet, you believe that the person with dementia that you support would like to take part in the study, please either return the Expression of Interest Reply Slip (attached) in the prepaid envelope, or contact the research team in person, by email or phone. We will get back in touch with you.

Contact details:

Email: robyn.dowlen@postgrad.manchester.ac.uk/ Telephone: 0161 306 7732/ 0161 226 8696

Thank you for the time you have taken today to read about our study.
Appendix 11: Personal consultee agreement form

Music Matters: Developing an ‘in the moment’ multisensory music assessment tool in collaboration with people living with dementia through a participatory design

Personal Consultee Declaration Form

Participant ID: ______________

1. I can confirm that I have read and understood the personal consultee information sheet dated insert date (version xx) for the above study and have had the opportunity to consider the information

2. I can confirm that I have had the opportunity to ask questions about the study and that these questions have been answered satisfactorily

3. In my opinion, the person I care for, as named below, when they had capacity, would have agreed to join the proposed study. By signing this form, I am agreeing for my relative/friend to be approached to take part

4. I understand that the participation of the person I care for is voluntary and they are free to withdraw at any time. If they do decide to withdraw, or if I decide their withdrawal is appropriate and in their best interests, they/I do not have to give a reason and their involvement in Music in Mind will not be affected.

5. In my opinion, the person I care for, as named below, when they had capacity would have no objection to taking part in the study.

6. In my opinion, the person I care for, as named below, when they had capacity, would have been happy to be video recorded as part of the study

7. In my opinion, the person I care for, as named below, would have been happy to be interviewed.

8. In my opinion, the person I care for, as named below, would have been happy to be audio recorded
9. I give my permission for the researcher, Robyn Dowlen, to approach the person I care for to discuss their involvement in the research

Please sign below

Name of Participant: ________________________________________________
Name and date of birth of the person I care for _____________________________
Signature: _______________________________ Date: _____________

Name of Researcher: _________________________________________________
Signature: _______________________________ Date: _____________
Appendix 12: Abuse protocol

Abuse Protocol

Should a case(s) of physical, emotional, sexual, financial, discriminatory, institutional abuse or neglect be disclosed during an elicitation interview or discussion group:

1. The researcher will directly acknowledge the disclosure and will give the participant the opportunity to talk about the disclosure should he/she wish to do so. However, the researcher will not press for information nor ask the participant to describe the disclosure. It is paramount that the participant controls the information he/she wishes to share without prompting.

2. If the researcher considers the participant to be in immediate danger, the researcher will contact the Manchester City Council Adult Social Care Contact Centre for guidance.

3. If the researcher considers the participant not to be in immediate danger, but still at risk, the researcher will immediately contact their supervisory team, including members of the Manchester Camerata, in order to discuss the course of action.

Should a case(s) of physical, emotional, sexual, financial, discriminatory, institutional abuse or neglect be observed by the researcher when reviewing the video footage before the video elicitation interviews:

1. The researcher will contact the chief investigator immediately.

2. The researcher will document the incident including the date and time of the incident, as well as the type of abuse that has been observed.

3. The researcher will contact Lucy Geddes, the Safeguarding Lead for Manchester Camerata.

4. The researcher will contact the manager of the community centre to report the incident.

5. The researcher will preserve any evidence -- i.e. will not destroy or disturb any articles that could be used as evidence.

Actions:
- The researcher will report the event to the Chief Investigator immediately.
- The researcher will record the event/s via a fieldwork diary, complete with date, time and description of what took place.
Appendix 13: Distress protocol

Distress Protocol

The safety and well-being of those involved in the study are paramount. Patience and empathy of the researcher is required.

Any participant with dementia who does not have capacity and shows distress at any point during the research process will be withdrawn immediately from the study and will not be re-enrolled.

Should any participant indicate that they are experiencing high levels of stress or shows signs of distress (i.e. uncontrolled crying, shaking etc.) during the video recording of Music in Mind sessions the following procedure will be taken:

1. The researcher will immediately stop the video recording of the session
2. The interview will cease immediately and the video or audio recording will be stopped.
3. The researcher will ask the participant if they would like to share their feelings or whether they wanted to discuss anything that may have been concerning them. The researcher will be sensitive to the fact the participant may need time alone and will therefore respond to the situation as appropriate.
4. The researcher will offer the participant a drink of water, if appropriate.
5. The researcher will ask the participant whether they would like the researcher to contact a person of their choice.
6. The researcher will ask the participant how he / she is feeling. Dependent on the cause of the distress, the researcher will explore the participants’ support network and offer to supply contact details of relevant organisations, if necessary.
7. If the participant is happy to resume being video recorded during the session, the researcher will continue the recording. If they are not happy to resume being recorded, the researcher will ensure the participant is stable and will remove the camera from view.

Should any participant indicate they are experiencing high levels of stress or shows signs of distress (i.e. uncontrolled crying, shaking etc.) during the elicitation interviews the following procedure will be taken:

1. The interview will cease immediately and the video or audio recording will be stopped.
2. The researcher will ask the participant if they would like to share their feelings or whether they wanted to discuss anything that may have been concerning them. The researcher will be sensitive to the fact the participant may need time alone and will therefore respond to the situation as appropriate.

3. The researcher will offer the participant a drink of water, if appropriate.

4. The researcher will ask the participant whether they would like the researcher to contact a person of their choice.

5. The researcher will ask the participant how he/she is feeling. Dependent on the cause of the distress, the researcher will explore the participants’ support network and offer to supply contact details of relevant organisations, if necessary.

6. If the participant wishes to continue the interview, the interview will resume. If not, the researcher will make sure that the participant is stable and ensure that it is appropriate to leave.

Should any participant indicate they are experiencing high levels of stress or shows signs of distress (i.e. uncontrolled crying, shaking etc.) during discussion/focus groups the following procedure will be taken:

1. The focus group will be stopped immediately and all recording will cease.
2. The participant will be asked if they would like to leave the room.
3. The participant will be asked if they wish to share their feelings or if they have anything they wish to discuss.
4. The researcher will offer the participant a drink of water, if appropriate.
5. If the participant remains distressed, the researcher will offer to contact a person of the participants’ choice.
6. The researcher will ask the participant how he/she is feeling. Dependent on the cause of the distress, the researcher will explore the participants’ support network and offer to supply contact details of relevant organisations if necessary. In the case where individuals are recruited via external organisations, the individual may be highlighted to the referring organisation for additional support. The individual would be informed of this beforehand.
7. If the participant wishes to continue with the focus group, then the focus group will resume. If not, the researcher will make sure the individual has suitable transport home.

Actions:
- The researcher will report the event to the Chief Investigator.
- The researcher will record the event/s via a fieldwork diary, complete with date, time and description of the occurrence.
Appendix 14: Supervisor biographies

Professor John Keady (The University of Manchester)
John Keady is Professor of Mental Health Nursing and Older People at the University of Manchester. He holds a joint post with the NHS and has held a number of positions working alongside people living with dementia and their families for over 30 years.

https://www.research.manchester.ac.uk/portal/john.keady.html

Dr Caroline Swarbrick (The University of Manchester)
Caroline Swarbrick is a co-investigator on the £5million ESRC/NIHR-funded Neighbourhoods and Dementia study. Caroline leads work programme 1, which involves working with co-researchers who are living with a diagnosis of dementia.

https://www.research.manchester.ac.uk/portal/caroline.swarbrick.html

Professor Christine Milligan (Lancaster University)
Christine Milligan is the co-director of the Lancaster University Centre for Ageing Research. Christine’s area of expertise is surrounding health and geographical perspectives of ageing. Christine has recently been involved in a joint research project with the Duke’s Theatre in Lancaster exploring the use of theatre to explore how the arts can better understand the lives of those living with dementia.

http://www.lancaster.ac.uk/fhm/dhr/people/christine-milligan

Nick Ponsillo (University of Chester)
Nick is currently Director of Philip Barker Centre for Creative Learning at The University of Chester, exploring practical approaches to the use of creative learning and creativity across the life course alongside the Arts and Culture sector to address growing inequalities in our society. Prior to his current role Nick was Head of Manchester Camerata in the Community (2010-2016), studied music at The University of Huddersfield, has worked as a part-time university lecturer, performer and as a scagliola worker for Hayles and Howe.

Lucy Geddes (Manchester Camerata)
Lucy Geddes MusB (Hons) DipABRSM, is a Manchester-based musician and Head of Camerata in the Community at Manchester Camerata. She is responsible for the creation and development of the orchestra's musical activities with communities across the North West, reaching over 24,000 people of all ages per year. Outside of Manchester Camerata, she plays professionally as a pianist and clarinetist in the British Army Reserves, and is an accompanist.
### Appendix 15: Measurable qualities of ‘in the moment’ musical experience

<table>
<thead>
<tr>
<th>Measurable Quality</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Living a Life Story Through Music</strong></td>
<td><strong>Life History</strong></td>
</tr>
<tr>
<td>Profession</td>
<td>The profession held by the person living with dementia.</td>
</tr>
<tr>
<td>Significant Relationships</td>
<td>Relationships that have been significant in the person living with dementia’s life (e.g. spouse, parents, children, friends etc.)</td>
</tr>
<tr>
<td>Cultural Identity</td>
<td>Information regarding group membership relating to nationality, ethnicity, social class etc.</td>
</tr>
<tr>
<td>Hobbies and Interests</td>
<td>Activities engaged with for leisure purposes (e.g. sport, art, literature etc.)</td>
</tr>
<tr>
<td><strong>Musical History</strong></td>
<td></td>
</tr>
<tr>
<td>Music of Cultural Significance</td>
<td>Music that has a shared component with other people who have had shared experiences due to demographic factors such as age, gender, culture etc.</td>
</tr>
<tr>
<td>Favourite Music</td>
<td>The particular songs or musical styles that resonate most with the individual.</td>
</tr>
<tr>
<td>Musical Experience</td>
<td>The interactions the person has had with musical instruments or choirs. Whether the person has had any formal musical training.</td>
</tr>
<tr>
<td>Music of Biographical Significance</td>
<td>Music that has played a role in significant life events such as birthdays, religious holidays, religious ceremonies etc.</td>
</tr>
<tr>
<td><strong>Being ‘In the Moment’ with Music</strong></td>
<td><strong>Musical Preferences</strong></td>
</tr>
<tr>
<td>Instrument Choice</td>
<td>The person living with dementia chooses an instrument for themselves.</td>
</tr>
<tr>
<td>Favoured Instrument</td>
<td>The person living with dementia engages with the same instrument(s) over an extended period of time, whether this is during one session, or over a number of sessions.</td>
</tr>
<tr>
<td>New Instrument Preferences</td>
<td>The person living with dementia develops new instrument preferences through engaging with novel instruments.</td>
</tr>
<tr>
<td>Preferred Musical Style</td>
<td>The person living with dementia responds to a particular musical style by sitting forward in their seat, dancing or playing their instrument more than for other musical styles.</td>
</tr>
<tr>
<td>Harmonic Preference</td>
<td>The person living with dementia responds to a particular harmonic structure, responding through sitting forward in their seat, playing their instrument or using their voice, or dancing.</td>
</tr>
<tr>
<td>Rhythmic Preference</td>
<td>The person living with dementia responds to a particular rhythmic beat, responding through sitting forward in their</td>
</tr>
</tbody>
</table>
The person living with dementia responds to a particular melody, which may have personal significance to them, responding through sitting forward in their seat, playing their instrument or using their voice, or dancing.

**Musicianship**

<table>
<thead>
<tr>
<th>Skill</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Melodic Preference</td>
<td>The person living with dementia responds to a particular melody, which may have personal significance to them, responding through sitting forward in their seat, playing their instrument or using their voice, or dancing.</td>
</tr>
<tr>
<td>Rhythmic Abilities</td>
<td>The person living with dementia is able to keep in time with the musical beat.</td>
</tr>
<tr>
<td>Tempo Manipulation</td>
<td>The person living with dementia is able to change the tempo by speeding it up, or slowing it down.</td>
</tr>
<tr>
<td>Improvisational skill</td>
<td>The person living with dementia is able to improvise around an accompaniment, showing evidence of a novel musical contribution.</td>
</tr>
<tr>
<td>Instrument Exploration</td>
<td>The person living with dementia explores the different sounds that can be produced by an instrument. This exploration may contain unconventional means of playing the instrument (e.g. using the rim of a drum to produce a different sound to the skin of a drum).</td>
</tr>
<tr>
<td>Musical Leadership</td>
<td>The person living with dementia is able to lead the group in musicking, whether this is through conducting, or gesturing to encourage the involvement of others.</td>
</tr>
<tr>
<td>Musical Dynamics</td>
<td>The person living with dementia uses musical dynamics (loud vs. soft) in order to convey emotion through their playing.</td>
</tr>
<tr>
<td>Playfulness</td>
<td>The person living with dementia engages with their instrument or another group member in a way that is light-hearted and fun.</td>
</tr>
<tr>
<td>Comedic Gesture</td>
<td>The person living with dementia uses gesture to express a comedic idea, such as wiping their forehead to express ‘fatigue’ after a particularly long improvisation.</td>
</tr>
<tr>
<td>Joint Performance</td>
<td>The person living with dementia tells a story through their performance with another person. Each person in the performance takes on the role of a character which is expressed through altering facial expression and gait.</td>
</tr>
<tr>
<td>Exaggerated Facial Expression</td>
<td>The person living with dementia adopts exaggerated facial expression, often to convey comedy, such as looking aghast or curious.</td>
</tr>
<tr>
<td>Sustained Concentration</td>
<td>The person living with dementia has a sustained moment of concentration. They are completely focused on the instrument they are playing and not on external factors to this experience.</td>
</tr>
<tr>
<td>Returning to Flow</td>
<td>The person living with dementia returns to a flow state after the flow of the moment has broken. They return to playing their instrument with complete concentration.</td>
</tr>
<tr>
<td>Being in the Musical Spotlight</td>
<td>The focus of the room is on the person living with dementia. Group members orient their bodies towards the person living with dementia, listening to and watching their musical contributions intently.</td>
</tr>
</tbody>
</table>

**The Musical Body**
<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clapping</td>
<td>The person living with dementia rhythmically taps their hands creating audible sound.</td>
</tr>
<tr>
<td>Tapping Feet</td>
<td>The person living with dementia rhythmically taps their feet creating audible sound.</td>
</tr>
<tr>
<td>Thigh Tapping</td>
<td>The person living with dementia rhythmically taps their thighs creating audible sound.</td>
</tr>
<tr>
<td>Vocalization</td>
<td>The person living with dementia uses their voice to make sounds (other than singing), such as humming, clicking and whistling.</td>
</tr>
<tr>
<td>Singing</td>
<td>The person living with dementia sings along with a melody or improvises a melody line with lyrics.</td>
</tr>
<tr>
<td>Body Tapping</td>
<td>The person living with dementia taps their instrument on different parts of their body to produce rhythm.</td>
</tr>
<tr>
<td>Seated Dance</td>
<td>The person living with dementia dances in their seat, moving their body in time to the musical beat.</td>
</tr>
<tr>
<td>Standing Dance</td>
<td>The person living with dementia dances out of their seat, with or without the support of another person.</td>
</tr>
<tr>
<td>Dancing Together</td>
<td>The person living with dementia dances with another person, whether this is seated or standing.</td>
</tr>
</tbody>
</table>

**Connecting Through Music**

<table>
<thead>
<tr>
<th>Activity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Swaying</td>
<td>The person living with dementia sways in time to the musical beat.</td>
</tr>
<tr>
<td>Synchronised Swaying</td>
<td>The person living with dementia sways in time with one or more people.</td>
</tr>
<tr>
<td>Body Mimicry</td>
<td>The person living with dementia mimics the body movements of another person, such as gesture and facial expression.</td>
</tr>
<tr>
<td>Musical Mimicry</td>
<td>The person living with dementia mimics musical phrases offered up by others, such as melodic or rhythmic musical phrases.</td>
</tr>
<tr>
<td>Initiating Musical Conversation</td>
<td>The person living with dementia starts a musical conversation with another person.</td>
</tr>
<tr>
<td>Sustained Musical Conversation</td>
<td>The musical conversation between a person living with dementia and another individual lasts over an extended period of time, usually longer than four bars of musical accompaniment.</td>
</tr>
<tr>
<td>Responding to Musical Contributions of Others</td>
<td>The person living with dementia notices a musical idea provided by another person and responds with their own musical idea, which begins a musical conversation.</td>
</tr>
<tr>
<td>Sound Matching</td>
<td>The person living with dementia produces a sound that matches the contributions of another group member, which begins a musical conversation.</td>
</tr>
<tr>
<td>Laughter</td>
<td>The person living with dementia is seen to be laughing.</td>
</tr>
<tr>
<td>Smiling</td>
<td>The person living with dementia is seen to be smiling.</td>
</tr>
<tr>
<td>Reflective Emotion</td>
<td>The person living with dementia cries, or expresses sadness as a result of hearing a personally significant song or piece of music.</td>
</tr>
</tbody>
</table>

**Musical Ripples into Everyday Life**

**Home**
<table>
<thead>
<tr>
<th>Alterations to Home Environment</th>
<th>The person living with dementia, or their family carer, brings music into the home such as through the purchase of musical equipment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-Living the Moment</td>
<td>The person living with dementia sings songs related to the music programme or reminisces about their time in the programme.</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td></td>
</tr>
<tr>
<td>Engaging with Cultural Institutions</td>
<td>The person living with dementia engages with other arts institutions within their community, such as art galleries and music venues.</td>
</tr>
<tr>
<td>Sharing Musical Stories</td>
<td>The person living with dementia shares their experience of taking part in the music programme whether this is in more formal settings, or sharing with family and friends.</td>
</tr>
</tbody>
</table>
Appendix 16: Updated reflexivity exercise

<table>
<thead>
<tr>
<th>Factor</th>
<th>Potential influence</th>
<th>Actual influence</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am white-British and middle class</td>
<td>Many of the areas in Manchester which participants will drawn from are deprived areas in which there is a lot of poverty. The fact that I am from a white, middle-class background may influence the rapport that I am able to develop with participants as they may not be as trusting of someone who has not come from the same background as them, or may take more time to warm up to me.</td>
<td>Having been from a white-British, middle class background I made many assumptions about the group members. For example, in planning the research I overestimated the verbal and computer literacy of the group members. More than one carer told me that they found it really difficult to read all the information on both the personal consultee information sheet and their own participant information sheet. In the future I think it would be important for me to consult with a Public and Patient Involvement group in order to make sure that my own assumptions do not discriminate against those who want to take part in the research.</td>
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<tr>
<td>I am a trained musician</td>
<td>My background as a musician may have an influence in a number of ways. It is possible that being involved in the group will allow me to experience some of the same sensory experiences as group members, but I also have to consider how my own musical training might influence my role in the group. It is important to remember that I am a researcher in this context and not a project practitioner. My role in the group is to take part and observe rather than engage any members of the group using any music-therapeutic techniques I have been exposed to in the past.</td>
<td>My musical background influenced both my role in the group and the data collection and analysis processes. I found myself being a middle ground in musical knowledge between the group members and the project practitioners. I often found it difficult to describe musical processes, relying on my limited musical vocabulary, but this also helped me to understand how difficult it was to convey complex musical experiences. I also felt that my musical ear influenced my analysis of the data, as I may have been more likely to pick out certain rhythms or melodies more easily than a researcher with an untrained musical ear. I also was very aware when musical contributions were out of key or out of time with the musical accompaniment, perhaps drawing my attention to if a contribution was out of place, neglecting the importance of creativity and control within the <em>Music in Mind</em> setting.</td>
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<td>I have an undergraduate and Master’s degree in psychology</td>
<td>Both degree programmes I was enrolled upon for undergraduate and master’s levels had a focus on quantitative and clinical research. Although I have developed a new way of thinking about how music influences people living with dementia through a positive psychological lens, there may still be a tendency for me to view participants as ‘patients’ who have symptoms.</td>
<td>I worked very hard to challenge some of the preconceptions that I had about people living with dementia that had come from my undergraduate and Master’s degrees. I made sure to consider the language I was using when talking about the research, taking the emphasis away from using language more intertwined with a biomedical approach such as ‘patients’ and using ‘people living with dementia’ instead. I do not think that this influenced my data collection or data analysis, but my change in perspective came as a result of my first and second years’ training on the PhD programme, having explored literature pertaining to personhood, citizenship and embodiment.</td>
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<td>I am the granddaughter of someone who lived with dementia</td>
<td>My grandmother had dementia, though at the time I was not aware of her diagnosis as I was in my early adolescence. I therefore need to ensure that I am listening to the experiences of the group members rather than interpreting their experience through the lens of the experience I had with my grandmother.</td>
<td>I do not believe that my own experience of dementia influenced my interactions and interpretations of the data to a great extent. The fact that each individual had their own significant experiences with music highlighted the differences between each individual in the group, showing me that each individual’s experience of dementia was different.</td>
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<tr>
<td>I am in my mid-twenties and female</td>
<td>It is very likely that I will be younger than any of those involved in the programme including the people living with dementia, family carers and project practitioners. I need to consider whether my age and gender may influence the quality of the data that is collected as it may be that participants might not take me seriously as a researcher, especially if they have children or grandchildren my age.</td>
<td>Although I was worried that my age would result in group members not taking me seriously, this did not happen. The influence my age had was on the understanding of shared musical repertoires that most of the group members had, but I was too young to have been exposed to. This mean that I had to go back to the group members or project practitioners for clarification on a given melody to ensure I had the details correct. I think this made me more inquisitive as I had to actively seek the answers to my musical questions, which were not easily answered using a search engine.</td>
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I am not a clinician and had not worked with people living with dementia before in a research context.

I have not worked in any clinical settings and so I need to consider how my lack of clinical knowledge may influence the data collection process. I wonder whether I might feel uncomfortable in asking people about their diagnoses (a condition of ethical recruitment of participants into the study) or miss out on key language relating to services that were accessed by participants.

My experience before the PhD was focussed in research understanding factors associated with Autism Spectrum Disorder, with the majority of the projects being with children rather than adults. I do not want to come across as patronising in any way with the people living with dementia involved in the project but I am concerned that my lack of experience in speaking with those with communication difficulties may impact the rapport I have with research participants living with dementia.

Reflecting back, asking about dementia diagnoses was something that I was not all that confident in discussing. Clarifying a diagnosis often led to an in-depth conversation about the person’s diagnosis journey, which was often very negative. I was particularly upset when I heard about Phillip’s diagnosis as he had not been granted the paper work to receive benefits and so he and Esther lived in extreme poverty whilst fighting for Phillip’s right to remain in the country and receive the benefits he was entitled to. I think this story was particularly shocking for me as I had not heard stories like this previously as I had not interacted with many people living with dementia prior to this study.

<table>
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<th>Unexpected factors</th>
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<td>I have a complicated history with religion, having been religious until age 15 but then deciding I did not believe</td>
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did not believe in what she believed in. At times, I think this affected the rapport that I had with Mary, and made me close up during interviews when Mary would change the topic of conversation to evangelise to me.

I can be a shy and unconfident person at times

These personal characteristics made me question myself throughout the programme. I struggled to make telephone calls to arrange interviews as I was aware of how busy some of the group members were, and did not want to make them feel as if the research was a burden to them.

The research was an intense and tiring project that left me feeling strained

In the middle of the project I became very strained balancing attending the *Music in Mind* sessions, conducting interviews and reviewing footage. My observational notes from the middle of the project are a lot shorter than those at the beginning and end, perhaps being representative of how tired I felt during this time in the programme. It was a challenging but rewarding 15-week programme, but I think at times the quality of some of the data was compromised by how I felt.
Appendix 17: Dissemination activities

**Peer Reviewed Articles – Published**


**International Conference Presentations**


**National Conference Presentations**


**University Presentations**


**Dowlen, R.** (May, 2017) The development of an ‘in the moment’ multisensory music assessment tool for people living with dementia. Presented at the Manchester Institute
for Collaborative Research on Aging PhD Network meeting, University of Manchester.

**Dowlen, R.** (June 2017) Music Matters:. Presented at Dementia@Manchester 4th Annual Showcase

**External Presentations**


**Dowlen R** (October 2015) Music Matters: Developing an ‘in the moment’ multisensory music assessment tool in collaboration with people living with dementia. Presented at ‘Music in the Third Age’ at the Royal Northern College of Music, Manchester, UK

**Public Dissemination**

**University of Manchester 3 Minute Thesis Finalist (June, 2018)** - I competed with 11 other individuals in the university-wide 3 Minute Thesis competition.

**Being in the Moment with Music (November 2017):** A workshop as part of the ESRC Festival of Social Science

This workshop explored Manchester Camerata’s Music in Mind programme for people living with dementia. I led and organised the event which brought together academics from the University of Manchester, Music in Mind practitioners and people living with dementia to explore the benefits of music for people living with dementia. The workshop focussed on enabling audience members to understand how social science research can aid in our understanding of the experiences of people living with dementia. The 40 workshop attendees included people living with dementia and their family members, activities coordinators, staff from the Alzheimer’s Society and local dementia charities.