

**Going to the museum together:  
The impact of including carers in museum programmes for people with  
dementia**

Submitted by Debbie Kinsey to the University of Exeter  
as a thesis for the degree of  
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Signature: .....

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Firstly, I would like to thank the people with dementia, carers, and the museums and their staff who participated in this research. I am grateful for the time they took to speak to me about their experiences, and for allowing me to participate in the programmes with them. This thesis is dedicated to them. The year following my evaluation work has been incredibly challenging for people with dementia and carers, who have lost access to formal support services such as respite, and informal support services such as the museum programmes investigated in this thesis. Many have become much more isolated during the pandemic. It has also been challenging for museum staff, some of whom are facing redundancy due to the financial pressures of museum closure. I know of at least one programme included in this thesis which has permanently ended due to these pressures. My thoughts and solidarity have been with everyone struggling this year.

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## Abstract

Many people with dementia and carers receive support through the third sector, including through cultural arts interventions which aim to provide a meaningful, shared experience. Museums are one venue offering these interventions, including non-remembrance-based programmes. Although there has been some research on the impact of museum programmes, it has tended to focus on positive outcomes. The impact of including carers in these programmes is also not well understood, which means it is not possible to say for which dyads they work, or do not work, or how to best support dyads in this setting.

This thesis aimed to explore how including carers in museum programmes for people with dementia has an impact on the person with dementia, the carer, and the relationship between them, using a realist approach to develop theory. Theories were first developed through a realist review of the literature, and then tested in an evaluation at six museum sites, which included participant-observation of sessions and interviews. From these theories, a generalisable conceptual platform was developed on the core processes involved when carers are included.

This research highlighted that the inclusion of carers has positive impacts, such as shared respite and opening up the museum, and negative impacts, such as highlighting losses and excess disability. The developed programme theories and conceptual platform considered how these outcomes may be generated. This resulted in a number of implications for further research, policy, and practice. The findings may also be applicable beyond museum programmes, and further research could use the theories and platform to consider how including carers may have an impact in other kinds of programmes for people with dementia, and in programmes for other kinds of dyads.

This thesis suggests the inclusion of carers is not a neutral act, and careful consideration needs to go into how to support people with dementia and carers given the variety of positive and negative processes which can occur. Alongside making venues and programmes more dementia-friendly, there must also be a consideration of how they can become more carer-friendly.

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## Preface – positioning and pathways

"A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions"

(Malterud, 2001; p483)

This preface to the PhD thesis considers what I brought to the research – my prior experiences and preconceptions about caring, dementia, illness – and how a PhD can impact the way research is conducted. Although these ideas will be examined in detail in chapter 8, it is important to briefly consider them here. Often, discussions about reflexivity only occur at the end of the write-up of a piece of research, particularly around the impact on data analysis. However, as Malterud states, your personal positioning also impacts the questions you ask in the first place, how you ask them, and what you pick out as being the key ideas. There is no such thing as completely objective research (e.g. Braun & Clarke, 2019; Maxwell, 2012), and you therefore need to know a researcher's positionality *before* the research, as well as the impact during, to consider how a person's characteristics or preconceptions may have had an impact. This preface will briefly consider what I believe may have been my preconceptions prior to beginning the research (although this also relies on how I judge what is an 'important' preconception for this research). I will also use this preface to discuss how the research formed, and changed, during the PhD. Chapter 8, at the end of this thesis, will include more detailed discussions about reflexivity, definitions, and the ways my positioning may have impacted this research.

Museums are well-known cultural venues so most people have some personal conceptualisation of what they are like or what happens in them, whether they have ever been to one or not. I enjoy going to art galleries and feel comfortable in them. I enjoy talking with others about their interpretations of the artwork and usually feel comfortable giving my own opinion, even where it differs from the other person. However, I also view some museums as 'stuffy' and 'boring', and prefer more modern or abstract art exhibits. Additionally, I was generally unaware of the different kinds of wellbeing and outreach programmes museums run, and of the specific type of programme I examined in this PhD. At the start of this research, I therefore

believed that there was value or enjoyment in discussing your views of artwork with others, but also that there was individual preference in the type of museum or artwork that people enjoyed. I was also aware that I am a white, educated British woman, so my comfort in museum spaces may be related to those privileges, as those aspects of my identity are represented in that space, so I needed to be mindful that others may not feel that same comfort – both in being in the space and in feeling able to share their opinions, especially where they are in disagreement with others.

I have some experience of care work, which means I had some preconceived ideas about caring from the perspective of having been a care worker. I worked as a paid carer for two and half years, although with adults with severe learning disabilities rather than dementia. During my PhD, I also had one-off days of caring for family members, and witnessed the impact of a close family member increasingly having more of a caring role for another. As these family caring experiences occurred during the work, rather than prior, they will be discussed in the reflexivity section in Chapter 8. At the outset of focusing my research on the impact of carers, I reflected on my experience of caregiving and what it was that I believed about it. I felt care work was both the best and the worst job I had – the hours were long, the organisation was often understaffed, it was physically demanding and often stressful, but I absolutely loved spending time with the residents, particularly when it was in fun activities rather than basic care tasks. These outings were challenging, and at the time could be stressful when the person was unpredictable, but the memories of them are some of my favourites. For example, watching a horror movie with a woman who had an excellent cackle at all the scariest parts, terrifying the other film-goers in the dark cinema. Towards the end of my time as a carer, I was able to do these fun activities with people less and less as the organisation increasingly relied on inexperienced agency staff and I had to focus mainly on basic caring tasks. I enjoyed my job much less. Although the resident was always the focus in outside activities, and the activities always felt they were for them and not for or about me, it was these shared moments and connections that remained with me, and that I valued. I valued it professionally, as supporting the residents to live a life, and personally.

I then trained as a clinical psychologist. I worked mainly with children and families, but received training in dementia assessment and worked in an older people's service for six months. My experience of dementia at the outset of this research was

from the perspective of a clinician, not of a lived experience of having dementia or caring for someone with dementia. My work as a researcher just prior to the PhD was health research with older people and co-creation methods. This meant I worked in a team which included those working with people with dementia and their carers. We had discussions over lunch or tea about their work, so I had some awareness of the dementia rights movement and dementia advocacy prior to beginning this PhD. I came into this research believing people with dementia should be met on their own terms and treated as individuals rather than making assumptions due to the diagnosis of dementia. However, I had not given as much thought to the needs of family carers who supported them.

Beyond a family member in what I now know, but only suspected then, to be in the early stages of dementia, and a friend who was coping with her mother being in the final stages, I had limited personal experience of dementia prior to the research. I was also thirty-three when I began this PhD, much younger than most people with dementia and their family carers. However, I am a person with a chronic illness, which will impact how I view the value of illness-related groups and programmes. My condition is very different to dementia, and I do not have a carer, but, like dementia, it was acquired in adulthood and I had to learn to adapt to it. I am personally invested and interested in the idea of 'living as well as you can' with a condition. What does it mean to 'live as well as you can'? How can you be supported to do that? Does it mean different things to different people? I therefore came to the research with my ideas about 'living well' being based in disability and generalising them to non-disabled people, rather than thinking about 'living well' generally and applying that to an illness/caring context. As carers became the focus of my research, my thinking about these questions as applied to this research shifted from being located in the person with dementia, to also how they were relevant to the person caring for them.

The context of the research as being a PhD thesis should also be considered as part of the positioning of the research. PhD research is assessed and has particular time and budget constraints, and particular milestones that must be reached. Although all academic research has some constraints, that this work will be assessed in a very different way to other academic research changes the research. I could not help but consider throughout that I needed to write a thesis and that I would need to justify my work orally in a viva. PhD work is also individual, rather than in a team, which has

implications for analysis work, as I needed to find other ways of ensuring I considered other explanations or perspectives. This will be discussed further in Chapter 8.

This PhD was a project I applied to undertake, rather than one I developed myself. The advertised project was an investigation of how museum programmes for people with dementia worked, using realist methodology, with some partnership established with the local museum who ran such a programme. In my first few months of the PhD, reading existing research, I realised that there was already some theoretical work on how these programmes worked (Camic, Baker, & Tischler, 2016) and on how visual art programmes may work for people with dementia (Windle, Gregory, et al., 2018). Although the research was limited, I decided to change my focus and made a list of various different perspectives and ideas connected to these programmes. I became interested in the impact of including carers after reading MacPherson, Bird, Anderson, Davis, and Blair's (2009) paper which discussed the idea of excess disability in the museum sessions, caused by carers intervening unnecessarily on the person with dementia's behalf. I realised I had found very little else on the potential impact of including carers, aside from some positive outcomes carers experienced. I also knew that many, if not most, programmes for people with dementia in all kinds of settings included carers to some extent, so I was surprised that there was little research about the possible effect of this. I thought that the impact of including carers would be interesting and valuable to study within the museum programmes, but that the results may also have relevance for other programmes. I became interested in the questions that arose about the impact of including carers, and the opportunity to use the study of one particular type of programme to consider the issues and applications more widely.

I had not heard of 'realist methodology' prior to applying for the PhD, but found the paradigm fit with both my personal view as a researcher, and was suitable for the process-based question I developed. As my PhD research was my own, rather than part of a larger project, I did have scope to change the proposed methodology if I wished.

As is often the case with PhD work, and all research to some extent, my initial plans had to change a number of times over the course of my PhD. My initial research plan is summarised in Figure 1. I had intended to develop theory through a realist review, test this in an evaluation of museum programmes, refine the theory further with stakeholders, and then test some of the generalisable aspects of theory in a different kind of programme, such as a singing group.

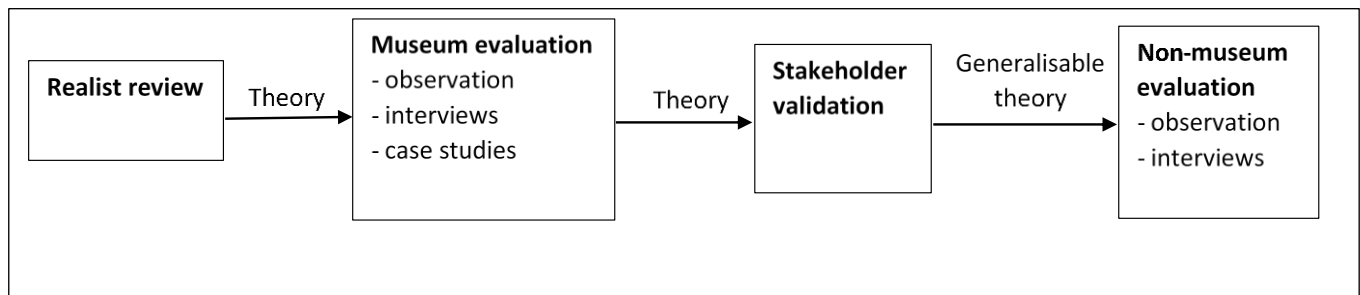


Figure 1. Initial PhD plan

This plan was intended to be flexible, with the option to drop the non-museum evaluation if needed. During the museum evaluation, I had a number of problems with recruitment (which will be examined further in Chapters 4 and 8). I therefore decided to extend the evaluation to a full year, and drop the non-museum evaluation. As I was unable to conduct many interviews with people with dementia or carers during the museum evaluation, this became the main focus of the stakeholder study, and would have included people who attended sessions and those who had not. Unfortunately, when I was due to start this work, the Covid-19 pandemic reached the UK. The museum programmes were no longer running, and the other groups I had intended to recruit from, such as memory cafes, were no longer meeting. The people I met on the museum programmes were usually not online, so converting this part of the research to an online study was not possible. I also felt the tone and meaning of some of my questions would be too different in the context of a pandemic. For example, being asked “what do you like to do together”, or asking the carer questions related to respite, is a very different thing when you are unable to leave the house, do your usual activities, or receive support from professional carers and services. I have seen some research that adapted by asking participants to consider how they felt prior to, and during, the pandemic context, but that could be very challenging for people with dementia. Due to the way my PhD was funded, I was unable to extend my deadlines, and a six-month extension would likely have made

little difference in any case given the probable timescales of groups of higher risk people meeting again. I therefore decided I also needed to drop the stakeholder study, and focus on the data I did have and the available literature. My final PhD research thus changed to the structure illustrated in Figure 2, and is what will unfold over this thesis:

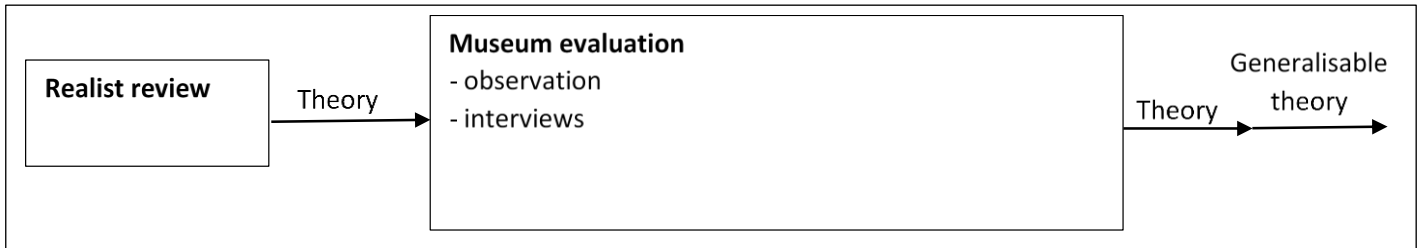


Figure 2. Final PhD structure

The perspective of this research is therefore a combination of my personal experiences (with care work, dementia, and chronic illness), and the context in which the work took place (that it was a PhD and finished during a pandemic). These things are not separate from the questions posed and conclusions suggested, but are part of the evidence about how they were posed and suggested. I use first-person throughout this thesis, not only because it is grammatically clearer to write in this way, but because it continually makes me as a researcher overt, which makes the positionality I discuss here more overt. The research did not conduct itself. I conducted the research. Reflexivity will be considered in much greater depth in Chapter 8 at the end of this thesis. However, although these discussions bookend the research itself, my positionality and its impact was, in reality, considered and interwoven throughout the research process.

There are many different kinds of carers, including spouses, friends, children, care home workers, and community respite workers. Although the terms ‘formal’ and ‘informal’ are often used in literature and policy to differentiate between paid workers and family/friends who act as carers, I think the casualness of the term ‘informal’ can obscure the huge amount of time and effort those carers spend caring. For the purposes of this thesis, the term ‘professional carer’ will be used to describe all types of paid carers (where caring is their paid job), and the term ‘family carer’ will be used to describe informal carers such as spouses, children, and friends. However, I would like to acknowledge that not all family carers self-identity as ‘carer’, particularly spouses who see their caring role as an extension of their role as husband or wife (Larkin, Henwood, & Milne, 2018). The term ‘person with dementia’ will also be used



throughout, and will not be abbreviated to PwD (Alzheimer's Society, 2018). It is also worth noting that this thesis refers to 'museum programmes for people with dementia' because this is the way the programmes are framed by the museums themselves, and most existing research, even though most aim to include carers on equal basis.

Chapter 1 will examine and discuss literature related to this thesis, including caregiving in dementia, the relational impact of dementia, and cultural arts programmes for people with dementia and their carers. Chapter 2 discusses the realist methodological framework for this research. Chapter 3 describes a realist review of the literature, developing initial programme theories about the impact of including carers to be tested in the evaluation. Chapter 4 describes the conceptualisation for the evaluation, data collection methods and procedures, ethics, and analysis. The results of the evaluation are presented over two chapters. Chapter 5 considers findings not apparent in the review, and Chapter 6 examines how evaluation evidence supported, or did not support, the theories developed in the literature review. Chapter 7 uses the programme theories developed in Chapters 5 and 6 to create a reusable conceptual platform of the core processes involved when carers are included in museum programmes for people with dementia. Chapter 8 considers the strengths and limitations of this research; how the findings may have implications for research, policy, and practice; and how my positionality may have shaped the research. Chapter 8 concludes with how the thesis makes an original contribution to research and ways it may be disseminated.

## Chapter 1 – Introduction

### 1.1 Introduction

This chapter situates the thesis within existing literature. I begin by describing dementia (section 1.2) and professional and family caregiving in dementia (section 1.3). I then discuss the relational impact of dementia (section 1.4), including the impact of the dyadic relationship on individuals' experiences of dementia, identity, and social exclusion. I outline the formal support for people with dementia and their carers (section 1.5), including mixed evidence for relationally-embedded support, and how there is increasing reliance on third sector support, with a particular focus on cultural arts interventions (section 1.6). I focus further on non-remembrance museum programmes and the evidence for their impact and how they may work (section 1.7). Within this section, I highlight two studies which suggest a negative impact of including carers in these programmes, and the little research on this, and other potential negative outcomes, in museum settings. Finally, I summarise the existing literature as a rationale for the thesis aims (section 1.8).

### 1.2 Dementia

Dementia is a syndrome in that it is a set of symptoms that can have different underlying disease processes (Calvo et al., 2003). Dementia is characterised by progressive cognitive decline in areas such as memory, executive functioning, and/or language, and an associated impact on the person's functional abilities in activities of daily living (World Health Organization, 2018). There are a number of different types of dementia, related to differing underlying conditions. The most common is Alzheimer's disease, with around 62% of dementia caused by Alzheimer's, followed by vascular dementia (17%), mixed dementia (10%), Lewy body dementia (4%), frontotemporal dementia (2%), Parkinson's dementia (2%), and other conditions, such as Creutzfeldt–Jakob disease and Huntingdon's disease, together causing around 3% of dementias (Prince et al., 2014). Although all dementias include progressive cognitive decline, different types can have different primary symptoms related to the underlying causal condition. For example, memory difficulties, particularly with shorter-term memory, are usually the first symptom of Alzheimer's disease, due to the disease impacting the medial temporal lobe and the hippocampus (National Collaborating Centre for Mental Health, 2011). In contrast,

frontotemporal dementia primarily impacts the frontal and temporal lobes, so early difficulties may be in language, behaviour, or changes in personality which may mean it is initially misdiagnosed as psychiatric or psychological condition (Bang, Spina, & Miller, 2015; World Health Organization, 2018). These differing underlying conditions can also cause differing progression of the dementia. For example, both Alzheimer's and frontotemporal dementia may cause a relatively steady decline in cognitive function, but vascular dementia may have a stepwise deterioration due to discrete vascular events such as mini-strokes (National Collaborating Centre for Mental Health, 2011). Regardless of the type of dementia and its accompanying symptoms, it is progressive and currently not curable, though there are a number of pharmacological, psychological, and environmental interventions which aim to help manage specific symptoms (Livingston et al., 2017).

Dementia most often occurs in people over the age of 65 (Livingston et al., 2017). As a greater number of people are living into older age, the number of people living with dementia in the UK is predicted to increase by 80% from 885,000 in 2019, to 1.6 million in 2040 (Wittenberg, Hu, Barraza-Araiza, & Rehill, 2019). However, dementia is not limited to those in older age, and there are over 40,000 people in the UK who developed dementia under the age of 65, which is also called 'early-onset' dementia (Prince et al., 2014).

### 1.3 Caregiving in dementia

As dementia impacts functional abilities, a person with dementia may need support or care from another. The type and amount of care a person needs is dependent on their symptoms and the progression of their dementia, any co-morbid conditions, and their personality (World Health Organization, 2012). Support may range from prompting about tasks, to managing finances, to full assistance with personal care such as bathing, dressing, and eating. Though an individual's needs will vary, as dementia varies for individuals, generally the amount of care they need will increase as their dementia progresses (Lewis et al., 2014; Wimo et al., 2013). Care may be 'informal' and provided by family and friends (unpaid), or 'formal' and provided by paid carers in a care home or in the person's own home (World Health Organization, 2012). As stated in the Preface to this thesis, all informal carers will be called 'family carers' (regardless of whether they are friend or family) and all formal carers will be called 'professional carers'.

Estimates of the proportion of people with dementia being supported at home, and the proportion of people living in care homes, varies. Some suggest two-thirds of people with dementia live in their own homes (Department of Health, 2009), whereas others suggest the proportion of people with dementia living in care homes is much higher than currently estimated due to dementia not being recognised and diagnosed in those who enter a non-specialist care home prior to developing the condition (Macdonald & Cooper, 2007; MacDonald & Carpenter, 2003).

Government policy aims to support people to live in their own homes for as long as possible. For example, the Prime Minister's Challenge on Dementia 2020 Implementation Plan (Department of Health, 2016) often describes one of the aims of interventions as “delaying the admission to residential care” (e.g. p40). This is also illustrated by what the government funds – only a minority of care homes (9% in 2005) are managed by local government, with most run by for-profit private companies (Macdonald & Cooper, 2007), and most government-funded social care support is centred on home-care support and respite (National Collaborating Centre for Mental Health, 2011). The available support for people with dementia and their carers will be discussed further in section 1.5. Government policy also aligns with the view of a majority of people who would want to live in their own home with dementia (Alzheimer's Society, 2016).

Much like family carers for all kinds of conditions, family carers of people with dementia are most likely to be the person's spouse and female (World Health Organization, 2012). Of those cared for by family carers, around 67.5% of people with dementia are cared for by a spouse, 25.9% by a child, and 6.6% by other family members or friends (Wimo et al., 2013). It is difficult to estimate how many hours a week family carers spend providing care, as they may be doing more than one task at once, or find it difficult to separate normal household tasks from informal caring tasks when they have taken on more household tasks from the person with dementia (van den Berg & Spauwen, 2006). Schneider et al. (2002) studied a small sample of 132 people with dementia and their carers in south London. They estimated that family carers spend an average of around 44 hours per week on caring tasks, but this rose to around 75 hours when the carer lived with the person with dementia. It is also difficult to estimate the cost of unpaid care in terms of the number of hours carers provide care, the impact on their ability to attend paid employment, and the

impact on their leisure time, and how to quantify these things (Hoefman, Van Exel, & Brouwer, 2013; Wimo et al., 2013). However, it has been estimated that family caregiving accounts for about 40% (or £13.9 billion) of the total cost of dementia care in the UK (Wittenberg et al., 2019).

Social care, or formal professional care, includes residential homes, professional carers supporting people with dementia to live in the community, and short-term respite care. Social care is means-tested, so people pay for part, or all, of their social care dependent on their financial situation (National Collaborating Centre for Mental Health, 2011).

There are an estimated 11,300 care homes in the UK (Competition & Markets Authority, 2017), with the majority managed by the private sector (Macdonald & Cooper, 2007). Since 1996, the number of available beds has steadily declined (Macdonald & Cooper, 2007), but the proportion of people who require residential care is likely to rise as the number of people with dementia (and so the numbers with severe dementia) increases in the future (Wittenberg et al., 2019). Though the sector has been growing as the population ages, turnover rates of professional care workers are relatively high, at 24.3% in 2016 (Independent Age, 2016), which may be related to negative public perceptions about this work (Shury & Gunstone, 2012). Despite often limited formal training (Ballard, et al. 2000), professional carers are expected to prioritise person-centred care (Department of Health, 2001), though this concept can be poorly defined with different meanings for different people (Brooker, 2003). Person-centred care will be discussed in more depth in section 1.4.1.

#### 1.4 Relational impact of dementia

Caregiving is a relational practice (Larkin et al., 2018), which means each person in the caregiving dyad indirectly and directly influences the other, and means dementia not only impacts the person with dementia, but also the person who cares for them (e.g. Moon & Adams, 2013; Ward-Griffin, Oudshoorn, Clark, & Bol, 2007). This section will consider how the dyadic relationship impacts experiences of dementia, how dementia impacts the relationship, and specific impacts such as on identity and social life.

#### 1.4.1 Impact of the relationship on experience of dementia

Though there is a lack of quantitative evidence on the role of relationships in outcomes for the person with dementia such as hospitalisation and quality of life (Edwards et al., 2018), there is some qualitative evidence and conceptual modelling of the role of the caring relationship on the experience of dementia for both the carer and the person with dementia. As stated earlier, caregiving is a relational practice (Larkin et al., 2018), which means it cannot be separated from the dyad's experiences of each other in the past, present, or anticipated future (Poirier & Ayres, 2002, cited in Ward-Griffin, Oudshoorn, Clark, & Bol, 2007).

One of the most influential early models of the relationship's impact on the person with dementia's experience is that of personhood and person-centred care (Kitwood, 1997). Kitwood's (1997) approach focuses on the individual with dementia within a relationship. According to his work, 'personhood' is "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; p8). He described a person with dementia's personhood and wellbeing as the interplay between the neurological process of their dementia, and their psycho-social environment. In other words, a person with dementia's wellbeing is not just about how their dementia impacts them, but how others respond to them – it is a relational process. He therefore emphasised a 'person-centred' care approach, to differentiate personhood-focussed ways of caring for people with dementia from medically framed approaches (Brooker, 2003). However, Kitwood's personhood model has been criticised for a lack of attention to reciprocity. This approach solely focuses on personhood as something that is *done to* the person with dementia, rather than the person with dementia explicitly also being an active social actor in the relationship who can reciprocate and influence the other (Bartlett & O'Connor, 2007).

Though personhood is applicable to all carer types, it has particular prominence in professional caregiving. Person-centred care is one of the key standards of care in the UK National Service Framework for Older People (Department of Health, 2001), and in guidelines for the training of professional carers (National Collaborating Centre for Mental Health, 2011). However, despite its prominence, 'person-centred care' is often poorly defined and can have different meanings for different people (Brooker, 2003). Brooker (2003; p216) identified four elements of person-centred

care in dementia using the acronym 'VIPS': "Valuing people with dementia and those who care for them (V); 2) Treating people as individuals (I); 3) Looking at the world from the perspective of the person with dementia (P); 4) A positive social environment in which the person living with dementia can experience relative wellbeing (S)". However, this model has been criticised for being personal opinion rather than empirically based (Edvardsson, Fetherstonhaugh, & Nay, 2010). Edvardsson et al (2010) interviewed professional carers, people with dementia, and family members in order to describe person-centred care based on their participants' perceptions and meanings. They suggested that person-centred care was about promoting a continuation of self and normality through knowing the person, welcoming family, providing meaningful activities, being in a personalised environment, and experiencing flexibility and continuity. This framework, like Kitwood's (1997) original conception of personhood, focuses on the what the professional carer provides, but not on the reciprocal relationship between the person with dementia and the carer.

A lack of focus on the emotional processes and attachment within professional caregiving may be linked with findings that professional caregivers can fear becoming too attached to residents, and resist interventions promoting emotional closeness (Rapaport et al., 2017). All carers must grapple with an ethical difficulty of balancing a person with dementia's autonomy with their safety, but professional carers must also deal with a sometime tension between these 'in-situ' ethical dilemmas, professional codes of conduct, and the regulatory rules of their particular place of work (Lundberg, 2018). This may also link with a reluctance (and lack of theoretical modelling) to consider personal, emotional connections in their professional role.

There has been much more research on the impact of familial caregiving relationships. Although different dyad types (such as spousal or adult-child) are likely to face different socio-relational challenges (Rausch, Caljouw, & Van Der Ploeg, 2017), most models of familial caregiving relationships in dementia are general, rather than about a specific dyad type. However there are some exceptions, for example Ward-Griffin et al (2007) specifically examined mother/adult-daughter caring relationships in dementia, and Lewis et al (2005) modelled spousal relationships. Many models consider how the caregiving relationship impacts carer

stress or burden. The Stress Process Model (SPM) proposes that four domains (background and context of caregiving stress, stressors, mediators of stress, and carer outcomes) explain the process of stress for carers, with social support and the carer's coping strategies as the main mediators of the relationship between stress and wellbeing (Pearlin, Mullan, Semple, & Skaff, 1990). This model has also been adapted to explain the stress process for the person with dementia (Judge, Menne, & Whitlatch, 2010). However, the SPM does not include how the dyadic relationship could also be a mediator (Leung, Orgeta, & Orrell, 2017); in other words, how the relationship may impact the process of carer stress and experience of caring in dementia. Leung et al (2017) revised the SPM to include the importance of dyadic interpersonal reactions as a potential mediator of carers' experiences of stress in dementia. This aligns with other research which suggests the dyadic relationship has an impact on the carer's (and person with dementia's) experience. Ablitt, Jones, and Muers (2009) found that the dyad's relationship prior to dementia had an impact on the dyad's current coping with, and experience of, dementia. Though they found most carers who had a good prior relationship with the person with dementia experienced less distress, there were some for whom a good prior relationship was linked with higher levels of distress, due to the loss of this close relationship. They also found the prior relationship affected the carer's approach to their caring role, and how they shaped the caring relationship. This current caring relationship, in turn, impacted the level of stress experienced by the person with dementia (Ablitt et al., 2009). This is echoed by Fauth et al (2012), who found that prior closeness in the dyadic relationship was associated with better mental health of carers immediately after diagnosis of dementia. However, they also followed dyads longitudinally, and found that higher levels of closeness worsened the carer's mental health over time, and a greater loss in closeness before and after diagnosis of dementia predicted improvements in carer wellbeing over time (Fauth et al., 2012). This shifting of the relationship may explain the different findings for different dyads in Ablitt et al's (2009) work, and highlights the need to understand caring relationships as changeable rather than static. This fluidity of the caring relationship is not only about change (or not) from a prior relationship, but also how the dyad adapts to dementia. It is not just the dyad's prior relationship or existing relationship skills which can have an impact on their experience of, and coping with, dementia, but also the active role they take in adapting and maintaining their wellbeing within the relationship



(Conway, Watson, Tatangelo, & McCabe, 2018; Martin, Peter-Wight, Braun, Hornung, & Scholz, 2009).

#### 1.4.2 Impact of dementia on the experience of the relationship

The symptoms of dementia can have an impact on the relationship, particularly as dementia progresses, such as a decline in communication, though this is not the same thing as a decline in affection or emotional warmth or feelings of 'togetherness' (Ablitt et al., 2009; Wadham, Simpson, Rust, & Murray, 2016). As suggested by the previous section, dementia can have an impact on the dyadic relationship due to the shift to 'carer' and 'cared-for'. For example, for couples, there is a shift in responsibilities, with carers taking on more tasks, such as housework, in the home, as well as caring tasks, which can lead some to feel overwhelmed and distressed (Holdsworth & McCabe, 2018). This shift in the balance of responsibilities alongside caring tasks led some spousal carers to describe their relationship as a shift to 'parent-child', rather than a partnership, which also negatively impacted areas of the relationship such as intimacy and sexuality (Holdsworth & McCabe, 2018). However, this idea of imbalance is not supported by all research. For example, Hellström, Nolan and Lundh (2007) describe both individuals within a couple actively working to maintain reciprocity and appreciation and a sense of 'couplehood', much like research in the previous section on dyads actively adapting to maintain their wellbeing within the relationship (Conway et al., 2018; Martin et al., 2009).

Impacts on the relationship are also not solely related to the symptoms of dementia. The way the carer appraises how those symptoms impact the identity of the person with dementia, as being the same/different, influences how the carer perceives the relationship and responds (Riley, Evans, & Oyebode, 2016). The intertwined issue of perceptions of identity and relationships will be considered in the following section.

#### 1.4.3 Identity

'Identity' is generally referred to in psychology and sociology as a person's conception of themselves, and as something that can change over time due to life changes such as becoming a parent, changing jobs, or religious conversion (Lesser, 2006). It has been specifically conceptualised and investigated in a number of different ways within dementia research, such as the self as narrative, socially constructed, or embodied (Caddell & Clare, 2010). One model of understanding identity is as a form of social representation which "mediates the relationship

between the individual and the social world” as a way of positioning the individual in their social environment, communicating their positioning, and developing relationships with others (Chrysochoou, 2003; p237). In other words, identity can be relational and social. The identities of ‘carer’ and ‘cared-for’ can only exist in relationship to another.

As considered in the previous section, dementia can have an impact on how individuals in a family dyad perceive and understand their relationship, such as some carers feeling their relationship no longer has a partnership dynamic but that of a parent and child (Holdsworth & McCabe, 2018). These changes in ‘relationship identity’ in dementia have mainly been investigated in spousal dyads, and work has highlighted how couples work to maintain their ‘couplehood’ and relationship identity outside of the roles of ‘carer’ and ‘cared-for’ (e.g. Colquhoun & Moses, 2017; Wadham, Simpson, Rust, & Murray, 2016). This also links with how individuals in the dyad choose to label themselves. As discussed in the Preface to this thesis, some do not call themselves a ‘carer’ as this can challenge the dyad’s relationship identity of ‘couple’ and the individual’s conception of caring as simply an extension of their role as spouse (Larkin et al., 2018). It has been argued that support services’ framing of their support as to the ‘carer’ can undermine not only the individual’s sense of identity as ‘husband’ or ‘wife’, but also the couple’s relationship identity (Wadham et al., 2016).

Family carers can experience a ‘role engulfment’, in which the number of caregiving responsibilities and tasks leaves little time for other activities, and a subsequent loss of personal identities other than ‘carer’ (Eifert, Adams, Dudley, & Perko, 2015). Similarly, people with dementia have reported that losses in professional and social roles, combined with others treating them as ‘incapable’ due to their diagnosis, threatened their sense of personal identity (Beard & Fox, 2008).

For family dyads, and people with dementia in professional caring dyads, both individual and dyadic identities can therefore be challenged and changed by dementia.

#### 1.4.4 Shrinking social world

Dementia can lead to a ‘shrinking social world’ for both family carers and people with dementia in terms of the places they feel comfortable going and their level of social

participation (Duggan, Blackman, Martyr, & Van Schaik, 2008; Nay et al., 2015). In other words, family carers and people with dementia occupy a smaller geographical space and have fewer social connections as dementia progresses. This can be for a number of reasons such as the symptoms of dementia (e.g. Livingston et al., 2017) or a lack of understanding from others (Lilly, Richards, & Buckwalter, 2003).

#### 1.5 Formal support for people with dementia and carers

Despite a policy focus on early diagnosis of dementia (Department of Health, 2001), post-diagnostic support is often inadequate (Watts, Cheston, Moniz-Cook, Burley, & Guss, 2014). Medical professionals, people with dementia, and carers have all highlighted that many people receive little further support once diagnosed (Dodd et al., 2014). Formal support systems through social care and the NHS can also be difficult to navigate due to local variation, inadequate information, and inadequate financial support (Department of Health and Social Care, 2018b; National Collaborating Centre for Mental Health, 2011). Additionally, despite well-documented potential negative impacts of family caregiving in dementia (e.g. Livingston et al., 2017), in some areas only a third of carers are asked if they need any help (Orrell, Cooper, & Braithwaite, 2006), and there is a lack of a comprehensive theoretical framework and means of clinically assessing carers' needs (Bangerter, Griffin, Zarit, & Havyer, 2019).

The formal support for people with dementia includes pharmacological approaches to alleviate symptoms, such as cholinesterase inhibitors to improve cognitive symptoms in Alzheimer's disease (Raina et al., 2008). However this treatment is not curative and guidelines also recommend non-pharmacological support (Department of Health, 2001). Within NHS settings this may take the form of psychological treatment for anxiety or depression, occupational therapy, or cognitive training, for example (Watts et al., 2014). As discussed earlier, policy (and funding of provision) is centred on supporting people with dementia to live in their own homes for as long as possible, and therefore also for family carers to remain in their caring role for as long as possible (e.g. Department of Health, 2016). Policy on supporting family carers prioritises providing and improving respite services (Department of Health and Social Care, 2018a; National Collaborating Centre for Mental Health, 2011). Respite is defined within policy as a physical break from caregiving, with the aim that this will enable the carer to remain in their role for longer (Maayan & Lee, 2014). However,

many carers define 'respite' differently than policy, and focus on respite as a psychological, rather than a physical, break, which may contribute to the relatively low uptake of formal respite services (O' Shea, Timmons, O' Shea, Fox, & Irving, 2019). Chappell, Reid, and Dow (2001) proposed conceptualising respite as an outcome experienced by carers, not a service, and interviewed carers about their subjective meanings of 'respite'. No carers defined respite as service provision, but instead described respite as 'external' (a separation from caregiving) and 'internal' (a break while remaining within the caregiving situation). External respite can include activities like visiting friends without the person they care for, and internal respite can include doing an enjoyable activity with the person they care for that is outside of their usual routine such as a picnic. This suggests that some carers could be supported to experience respite while being with the person with dementia they support.

Research has highlighted a need for relationally-embedded support. Personhood is framed in relational terms, which suggests support for the person with dementia's personhood should be relational (Kitwood, 1997). As discussed in sections 1.4.1 and 1.4.2, the dyadic relationship is of importance in the experience of dementia for both carers and people with dementia. As identity and relationship quality has been linked to the wellbeing of both the carer and the person with dementia, dyadic interventions may be beneficial (Ablitt et al., 2009; Conway et al., 2018; Moon & Adams, 2013). For example, spousal couples work to maintain their relationship identity and 'couplehood' (e.g. Colquhoun & Moses, 2017; Wadham, Simpson, Rust, & Murray, 2016). If what spousal couples are trying to maintain and prioritise is their relationship (Wadham et al., 2016), then interventions which include the dyad, rather than the individual, may be more acceptable and effective for some (Martin et al., 2009). Some interventions to support family carers, such as those to support their caregiving knowledge and skill, may be more effective if the person with dementia is also involved (Brodaty, Green, & Koschera, 2003).

However, governmental policy on support focuses on the individuals, with support for carers and people with dementia often considered separately, rather than the dyadic context and dyadic relationship as a whole (Larkin et al., 2018; Martin et al., 2009). Additionally, relationally-embedded support may not be beneficial for all dyads. For example, Fauth et al (2012) suggested that some family carers may need to detach

emotionally from the person they support in order to protect their own mental health, so, for those carers, relational interventions which aim to support closeness in their relationship may have a negative impact. This issue is not limited to family carers – as discussed in section 1.4.1, some professional carers resist interventions promoting closeness with the person they support. There is also some mixed evidence for a dyadic approach to reminiscence therapy, which is a common intervention in healthcare settings. For example, Melunsky et al (2015) found that, whilst some carers perceived a positive impact, such as enjoying having a shared experience with the person with dementia and more things to talk about, others felt a negative impact, such as a lack of physical respite or not being able to maintain positive changes they saw in the person with dementia in the group once they were home. Relationally-embedded interventions may therefore be appropriate for some dyads, but not all, and it is important to understand for whom they may have benefit, and for whom they may have a negative impact.

#### 1.6 Cultural arts interventions

Alongside formal sources of support, people with dementia and carers can also receive support from the third sector, with the health sector often signposting or advising people to use these informal services (Dodd et al., 2014). These third sector organisations are increasing their role, which may be in part due to increasing pressures on the NHS and social care services (Chatterjee, Camic, Lockyer, & Thomson, 2017). This role is becoming more formalised through social prescribing. Social prescribing is the prescribing of non-medical or social activities to support a person's wellbeing (Husk et al., 2020). There are different models, but usually a person is referred to a link worker who meets with them to discuss their wants and needs to co-produce a 'social prescription'. The link worker then refers them on to a suitable local group or source of support, such as arts groups or running clubs (Fixsen, Seers, Polley, & Robins, 2020). Social prescribing is now a key component NHS England's Universal Personalised Care Strategy (NHS England, 2019b). Full funding is being provided to GP surgeries for link workers (NHS England, 2019a), which the NHS states "legitimises community-based activities and support alongside medical treatment as part of personalised care" (NHS England, 2019b). The aim is for at least 900,000 people to be referred to social prescribing by 2023/24 (NHS England, 2019b).

'Cultural arts interventions' have been defined and categorised in a number of ways (Schneider, 2018). They include literary arts, such as creative writing; performing arts, such as music or dance; and visual arts, such as creating artwork or visiting galleries (Young, Camic, & Tischler, 2016). Some have also argued that, although there is less research focused on it, manual arts and crafts such as gardening and cooking should also be included under the umbrella of 'cultural arts' (Schneider, 2018). In contrast to medical approaches which aim to act on specific symptoms in a specific manner, the primary aim of cultural arts interventions is meaningful experience (De Medeiros & Basting, 2014). Cultural arts interventions also differ from art therapy. Art therapy uses the arts within a psycho-therapeutic relationship to treat or ameliorate particular difficulties, whereas these interventions are about meaning and engagement without a specific focus on the physical or psychological condition or symptom treatment (Zeilig, Killick, & Fox, 2014). 'Meaningful experiences' have been described as a key component of person-centred care, within which people with dementia are able to reciprocate in the dyadic relationship and maintain their personal identity (Edvardsson et al., 2010).

There is growing interest in cultural arts work with people with dementia and their carers, particularly as creativity is not dependent on memory (Schneider, 2018). Recent reviews have suggested potential benefits for people with dementia include communication, wellbeing, social connection, and cognitive function (De Medeiros & Basting, 2014; Young et al., 2016; Zeilig et al., 2014). Benefits have also been suggested for family and professional carers who participate with the person with dementia, in terms of their own enjoyment and wellbeing, and in seeing the person they care for having a good experience (e.g. Schneider, 2018). This links to broader research on the cultural arts which suggests they can improve feelings of social connection and wellbeing, and open up cultural spaces for marginalised groups (Daykin et al., 2020; Mental Health Foundation, 2011), which may be important given the 'shrinking social world' people with dementia and their carers face (section 1.4.4).

Research in the cultural arts in dementia has been criticised for methodological limitations such as small sample sizes, lack of control groups, and lack of standardised measurement (Beard, 2012; De Medeiros & Basting, 2014). However, 'high quality' research may be different in cultural arts research than in medical

research. Firstly, there may not be standard means of adequately measuring outcomes. For example, there is no standard measure of ‘meaningful experience’, and what is ‘meaningful’ to a person is extremely individual (De Medeiros & Basting, 2014). Secondly, there can be a bias in judgements of interventions which prioritises medicalised outcomes over subjective experiences such as meaning and enjoyment (Beard, 2012). The difference between the ‘objective’ and ‘subjective’ is also apparent in other kinds of intervention research, for example a tension between what is evidenced as being an effective (and cost-effective) intervention for carers, and what carers subjectively value (Larkin et al., 2018). Thirdly, linked to subjective value, there should not always be an expectation that interventions for people with dementia and their carers should have a long-term benefit beyond the session itself (Woods et al., 2016). A cultural arts intervention does not need to have a measurable long-term clinical benefit to have worth. Enjoyment ‘in the moment’ is valuable in itself. Research into cultural arts interventions is moving away from focusing solely on outcomes, to considering underlying mechanisms and processes of *how* they work and for whom (Daykin et al., 2020; De Medeiros & Basting, 2014; Windle, Gregory, et al., 2018).

### 1.7 Museum programmes

Museums are one venue offering cultural arts interventions. This section will first define what a ‘museum’ is, and then discuss specific museum programmes for people with dementia and their carers, including current research.

#### 1.7.1 Definitions

The definition of ‘museum’ has recently been a contentious issue. The current definition by the UK’s Museums Association is that “museums enable people to explore collections for inspiration, learning and enjoyment. They are institutions that collect, safeguard and make accessible artefacts and specimens, which they hold in trust for society.” (Museums Association, n.d.). Similarly, the International Council of Museums’ (ICOM) definition is that “a museum is a non-profit, permanent institution in the service of society and its development, open to the public, which acquires, conserves, researches, communicates and exhibits the tangible and intangible heritage of humanity and its environment for the purposes of education, study and enjoyment.” (International Council of Museums, 2019). However, in 2019, ICOM proposed a new definition:

“Museums are democratising, inclusive and polyphonic spaces for critical dialogue about the pasts and the futures. Acknowledging and addressing the conflicts and challenges of the present, they hold artefacts and specimens in trust for society, safeguard diverse memories for future generations and guarantee equal rights and equal access to heritage for all people. Museums are not for profit. They are participatory and transparent, and work in active partnership with and for diverse communities to collect, preserve, research, interpret, exhibit, and enhance understandings of the world, aiming to contribute to human dignity and social justice, global equality and planetary wellbeing.” (International Council of Museums, 2019).

This definition has not yet been accepted, as the vote on the change was postponed due to opposition from some members about consultation and ‘politicisation’ of the museum sector (Grincheva, 2020). The proposed new definition, and to a lesser extent the current definitions, of museums means they are not only places where object or art collections are housed, but places within the context of society and a community. The proposed new definition particularly emphasises values and an active engagement with people and issues, rather than a passive, indifferent, or ‘neutral’ stance (O’Neill, 2019). Despite the controversy over the definition, this active engagement is work museums have been doing for a number of years, including trying to reach and include those who may not previously have engaged with museums (Burdett, 2004), and using exhibitions to create dialogues about wider issues such as climate change (Swim, Geiger, Fraser, & Pletcher, 2017).

For the purposes of this thesis, the term ‘museum’ will be used to include art galleries, heritage sites, and ‘traditional’ museums (buildings/institutions which exhibit objects and artefacts for the public).

#### 1.7.2 Museums as sites for wellbeing programmes

The role of museums has been linked to a potential therapeutic role (Camic & Chatterjee, 2013; L. H. Silverman, 2010). Silverman (2002) described a number of ways the museum environment can act as a therapeutic agent. One of these is the social roles that are possible to museum participants, with the museum reinforcing both personal identity and connections to others. This may be due to participants creating new social identities through shared experiences at the museum, or participants making and re-making their identities through giving personal meanings



to museum objects (Newman & McLean, 2006). Participants may also reframe their identities through improved self-esteem from creative activities, or re-connect with old identities through reminiscence using museum objects or artwork (Chatterjee & Noble, 2013). Some research has suggested the museum setting itself being valued or 'special', in turn makes the participants themselves feel valued, particularly when they are in a marginalised group (Camic et al., 2016; Roberts, Camic, & Springham, 2011). Wellbeing programmes in museums may also reduce feelings of social isolation (e.g. Flatt et al., 2015), improve confidence (Morse et al., 2015), and enable carers to see older people they support in a new way (Roe et al., 2016).

A number of museums offer programmes that specifically work with people with health issues, such as those with mental health difficulties, cancer, and carers, with the aim of improving wellbeing, offering support, and/or providing education (Camic & Chatterjee, 2013). The museum as a non-medicalised, public space (Camic & Chatterjee, 2013), where the focus is not on the health issue (Roberts et al., 2011), may also support outcomes in this setting.

1.7.3 Non-reminiscence museum programmes for people with dementia and their carers  
Museums have been increasingly working with people with dementia and their carers. Some museums offer reminiscence-based programmes, in which participants discuss museum objects, reminisce, and share stories (Chatterjee & Noble, 2013). Reminiscence therapy is also commonly offered in healthcare settings (Woods et al., 2016). However, reminiscence may be challenging for some people with dementia due to the emphasis on memory and recall (Roe et al., 2016), or for those with distressing early memories (Bohlmeijer, Roemer, Cuijpers, & Smit, 2007).

In 2006, New York's Museum of Modern Art (MoMA) developed a non-reminiscence programme for people with dementia and their carers named 'Meet Me at MoMA' (Rosenberg, Parsa, Humble, & McGee, 2009). The Meet Me programme included a monthly tour of four to five artworks, related to a theme, with groups of around eight dyads. The tour was focused on a discussion of the artworks, between the facilitator and the group, with the emphasis on the participants' own observations and interpretations, and the connections between different views and historical points (Rosenberg et al., 2009). The programme aimed for people with dementia and carers to participate equally, and for participants to have a shared, enjoyable experience, with no emphasis on dementia (the guidelines for facilitators specifically

states “never mention Alzheimer’s”; Rosenberg et al., 2009; p122). Research on the Meet Me programme suggested a positive impact on mood for both the person with dementia and the carer, improved feelings of self-worth in the person with dementia, and a positive shared experience which validated their relationship identity, such as spousal or parent/adult-child (Mittelman & Epstein, 2009).

This thesis will focus on these non-remembrance programmes, and hereafter uses the term ‘museum programmes’ to refer to this type of programme only.

Other museums have since developed their own programmes, with adaptations such as including different activities like object-handling and art-making. Studies evaluating individual programmes have found similar impacts to MoMA’s Meet Me programme, such as social enjoyment (e.g. MacPherson, Bird, Anderson, Davis, & Blair, 2009), improved mood (e.g. Eekelaar, Camic, & Springham, 2012), and stress relief (e.g. Lamar & Luke, 2016). As well as assessing impact, some studies have also attempted to model *how* these programmes have an impact. Camic, Baker, and Tischler (2016) studied a programme which involved an hour of art-viewing followed by an hour of art-making. They observed sessions and interviewed the people with dementia, carers, and facilitators who participated, and used grounded theory to develop a model of how the programme worked. Their model is illustrated in Figure 3:

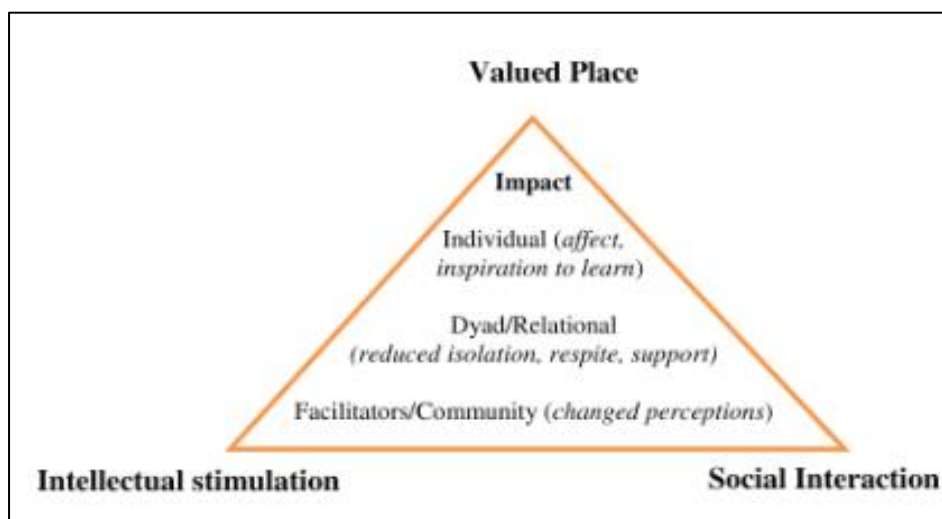


Figure 3. Model of how an art gallery intervention affects individuals with dementia and their caregivers; Camic et al (2016)

Camic et al (2016; p1038) describe their model as follows:

“The special, valued and different context of the gallery setting enabled an intellectually stimulating learning experience to take place for both the person with a dementia and their caregiver; this stimulation contributed to feelings of engagement and a growing sense of competency. The intervention stimulated social interaction and positive affect, which, in turn, enabled a sense of respite in caregivers’ daily lives. The shared experience was often a new way of being with one another and caregivers saw something different in the cared for person, which positively affected the caring relationship. The effect or impact can be considered divided into effects at an individual, relational, and community level. Both those with dementia and caregivers experienced positive affect changes (individual level) but also described positive effects of social interaction (relational level). ... Facilitators and other museum staff, along with caregivers, noted changes in their perceptions toward people with dementia, which possibly could be considered indicative of the potential for community and societal changes in attitudes toward dementia.”

In this way, the programme had individual impacts, such as a sense of respite for carers, within a dyadic programme, as well as relational impacts, and the relational and individual were intertwined.

Similarly, Burnside, Knecht, Hopley, and Logsdon (2017) used a grounded theory approach and interviewed participants to evaluate a programme which included both tours and art-making, attended by both family and professional carers. In contrast to Camic et al (2016), Burnside et al (2017) included antecedents, or what the dyad brought to the programme, as well as the process within the programme (see Figure 4). Despite this difference, Burnside et al (2017) described many similar processes

to Camic et al (2016), such as shared enjoyment and socialisation, and both individual and relational impacts.

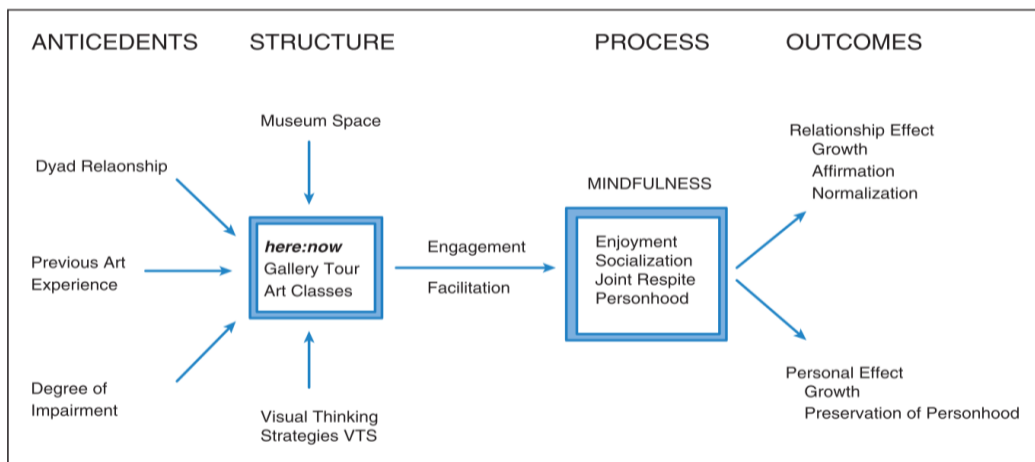


Figure 4. Conceptual model of museum programmes; Burnside et al (2017)

Both Camic et al (2016) and Burnside et al (2017) include the idea of participants experiencing respite through the programme. This supports Chappell, Reid, and Dow’s (2001) conceptualisation of respite as being something that can be experienced by carers while remaining in the caregiving situation. Camic et al (2016; p1037) described respite purely in terms of the carer – as an opportunity for them to have a break from “everyday care obligations”. However, Burnside et al’s (2017) framing was of ‘joint respite’, experienced by both the carer and the person with dementia. This form of respite was defined as a break, together, from dementia and caring roles, with a change in focus of the dyadic relationship away from ‘dementia’. This may link with previous discussions in this chapter about relationship identity. Programmes aim to treat individuals equally, regardless of their caring role, and activities are facilitated in such a way that emphasises the validity of different subjective perspectives on artworks (Rosenberg et al., 2009). This may help to reduce any perceived power imbalances (Roberts et al., 2011), and enable a sense of mutuality which may be important in removing carer/cared-for roles (Ablitt et al., 2009). The session may then act as an activity the dyad shares outside of caring roles (shared respite), which also helps the dyad to strengthen and maintain their relationship identity as, for example, spouses, rather than ‘carer’ and ‘cared-for’ (Boylstein & Hayes, 2012; Hellström et al., 2007). In other words, dyads are able to

have a shared experience as husband and wife, or two friends, rather than as a carer and a person with dementia, and this helps to strengthen their relationship identity.

While most studies evaluating museum programmes focus on positive outcomes, two reported negative outcomes related to the inclusion of carers. MacPherson et al (2009) evaluated a six-week art-viewing museum programme. They found that professional carers created 'excess disability' in the participants with dementia in that the carers answered for, and did tasks for, the person that they were able to do themselves once the carers had been asked to sit out of sight. Excess disability is "the discrepancy which exists when the person's functional incapacity is greater than that warranted by the actual impairment" (Brody, Kleban, Lawton, & Silverman, 1971, p124), i.e., excess disability is disability or loss of ability caused by something other than the dementia itself. This can be caused by a carer doing too much for the person with dementia. In a case study of a couple ('Mr and Mrs R'), Sabat (1994) found that Mrs R demonstrated much more ability in a day centre she attended than at home. For example, Mr R said Mrs R was unable to follow instructions at home, but day centre staff said she could as long as a combination of verbal instructions and gestures were used (Mr R stated he did not use gestures when giving instructions). The ability of Mrs R to follow directions, for example, was not solely dependent on her dementia but on the way information was presented to her by whomever was supporting her. Sabat (1994) linked this with Kitwood's (1997) ideas around personhood in dementia. Kitwood described a person with dementia's wellbeing and functioning as the interplay between the neurological process of their dementia and their psycho-social environment. He termed negative aspects of the environment as 'malignant social psychology', which included behaviours of carers such as not allowing the person to use abilities they have or forcing a person to do something which denies the desires of the person themselves. This malignant social psychology could thus result in excess disability, as the actions of carers could create functional impairment, such as whether Mrs R could or could not follow instructions (Sabat, 1994).

Excess disability has also been linked to a negative impact on identity. People with dementia have reported feeling that others treated them as incompetent or incapable, despite having autonomy prior to their diagnosis, and that this combined

with losses in their social and professional roles to make them feel their identity was threatened and consequently had to be consciously negotiated to be maintained (Beard & Fox, 2008). In excess disability terms – if carers treat the person as though they are not capable, for example by doing tasks for them that they could otherwise do themselves, this could make the person with dementia feel they are not capable or make them question their identity as a capable person. Excess disability, caused by the inclusion of carers, could therefore prevent some people with dementia from engaging fully in the museum session, potentially impacting their outcomes.

On the basis of MacPherson et al's (2009) findings, a recent large-scale evaluation of visual arts programmes, including those in a museum setting, made the participation of carers optional (Windle, Joling, et al., 2018). Windle, Joling, et al (2018; p13) noted that “the presence of [professional carers] and [family] carers on occasion required careful management by the artist-facilitators”, but did not give further detail on to what extent facilitators needed to intervene, how, or what impact it had.

The museum-based research does not consider whether there may also be a potential negative impact on carers themselves due to their inclusion. As discussed in section 1.5, research on other kinds of interventions has suggested there can be a negative impact of dyadic interventions on the carer, such as increased stress (e.g. Melunsky et al., 2015; Woods et al., 2016) or a negative impact of interventions promoting closeness when what the carer needs is to detach emotionally (Fauth et al., 2012).

Studies of cultural arts programmes in general have also been criticised for a focus on positive outcomes without acknowledging potential negative effects (Daykin et al., 2020). Much of the research on museum programmes has also focused on family, rather than professional, carers, or not differentiated between dyad types in their analysis. This may be important given the different experiences of different dyad types (Rausch et al., 2017).

#### 1.8 Thesis aims and overall research question

In summary, this chapter has detailed how dementia can have a relational impact – impacting both the person with dementia and the carer, as well as the relationship between them. The formal support available to carers and people with dementia can

be limited, under-funded, and difficult to navigate, with common means of support such as respite underutilised, which may be linked with a misalignment between carer and policy conceptualisations of respite. Many dyads therefore receive support through the third sector, which is becoming more formalised through social prescribing. Cultural arts interventions are increasingly being offered to people with dementia and their carers, with the aim of providing a meaningful, shared experience, linked to maintenance of individual and relationship identity. Museums are one of the venues providing cultural arts interventions, including a particular type of non-remembrance-based programme which is focussed on a shared, equal, enjoyable experience.

Though there has been some research on the impact of museum programmes (e.g. Eekelaar, Camic, & Springham, 2012; Roe et al., 2016), and on how they may work (Burnside et al., 2017; Camic et al., 2016), the impact of including carers is not well understood. This means it is not possible to say for which dyads they work, or do not work, or how to best support dyads to mitigate possible negative impacts in a museum setting. As the majority of programmes include carers, and research suggests dyadic interventions may not benefit all, it is important not to overlook the impact of including them.

However, the focus needs to be on more than simply *what is* the impact of including carers, but on *how* including carers has an impact. A focus on underlying processes and mechanisms may not only strengthen the research base for cultural arts programmes (De Medeiros & Basting, 2014), but also support broader implementation through understanding what works in different settings and for different people (Windle, Gregory, et al., 2018).

This thesis therefore has an overarching research question of:

“How does including carers in museum programmes impact the person with dementia, the carer, and the relationship between them?”

### 1.9 Conclusion

This chapter outlined the background research to this thesis, which led to the overall research aim of investigating how including carers in museum programmes may have an impact. The next chapter will outline the methodological approach used to investigate this question. The remainder of this thesis details a realist review of the

literature, an evaluation of museum programmes, and a synthesis of the results of these in order to understand the impact of including carers.



## Chapter 2 – Methodological framework

### 2.1 Introduction

This chapter outlines the realist methodological framework for this thesis. Firstly, the distinction between ‘methodology’ and ‘methods’ is defined. I will then discuss realism as a methodological framework, including ontology and epistemology. A separate section is devoted to realist understandings of causation so that the idea of the context-mechanism-outcome configuration and its component parts can be considered in more detail. The chapter concludes with a discussion of realist evaluation as methodology rather than method, and the rationale for adopting a realist approach.

### 2.2 Methodology

There is a difference between research ‘methodology’ and research ‘methods’. Research methods are the techniques used in the conduct of research, such as data collection techniques and analysis methods (Kothari, 2004). Methodology, however, is the underlying philosophy for the research – the rationale and broader strategy for how the research will be conducted (Howell, 2012). In other words, the methodology is the overarching framework or ‘lens’ through which the research is conducted, and the methods are the tools used to conduct the research.

This chapter will outline the methodological framework used for this thesis, which has directly informed the methods used in both the literature review (Chapter 3) and the evaluation (Chapter 4).

### 2.3 Realist ontology and epistemology

Research is essentially about understanding reality through “the systematic investigation into, and study of, materials and sources in order to establish facts and reach new conclusions” (Stevenson, 2010; p1510). However, the exact nature of ‘reality’ is not universally agreed, which has fundamental implications for how research is conducted (Howell, 2012). A researcher’s ontological positioning is the assumptions that a researcher makes about the nature of reality; their epistemological positioning is the assumptions about how to discover knowledge about that reality. Though this positioning is often not made explicit in published research, it is implicit in how research questions are framed and how data is collected (Howell, 2012).

### 2.3.1 Realism

This thesis uses a realist methodological framework. Realism sits between positivism (that there is a real, external world that can be observed and measured objectively) and constructivism (that reality and its meaning is continually being constructed by individuals) (Wong, Westhorp, Pawson, & Greenhalgh, 2013). Realist ontology asserts that there is a 'real world' independent of our perceptions of it (Sayer, 2010). If reality is independent of mind, evidence of that reality is limited by our ability to perceive or measure it, which implies that knowledge cannot be 'objective' as it is never independent of a particular viewpoint. However, this is not the same as a constructionist view of multiple realities independently constructed by individuals, but instead means that knowledge is partial and there are multiple perspectives on reality rather than a single 'correct' view (Maxwell, 2012). In this way, a realist research paradigm has a realist ontology (a 'real world' exists independent of mind), and a constructivist epistemology (our knowledge of reality is constructed from a specific perspective) (Maxwell, 2012).

As well as knowledge being partial, there are four other key ideas to consider about a realist framework which will have an impact on the conduct of research: the mental as 'real', stratified reality, emergence, and how these link with causation. The first three of these will be discussed here, whilst the realist understanding of causation will be discussed in greater depth in section 2.4.

Within realism, mental processes (such as beliefs, ideas, and intentions) are seen as equally real as physical processes and objects in that they have real effects and are as important in causal explanation (Bhaskar, 2008). These processes may be more difficult or impossible to directly observe, but may be inferred indirectly, for example, from verbal behaviour (Maxwell, 2012). For realist research, this means a person's perspective and their situation are both real and separate phenomena that causally interact (Maxwell, 2012). It also means my perspective as a researcher is a construction of reality rather than an 'objective truth', but is also a 'real object' in that my perspective has real effects on the conduct and findings of the research.

Realist ontology also proposes that reality is 'stratified'. There are two meanings for 'stratified reality' within realism – the philosophical construct of reality, and the nature of systems (Wong, Westhorp, et al., 2013). Bhaskar (2008) argued that there are three layers of reality: the empirical (that which can be observed or measured), the

actual (that which exists, regardless of whether it is observable), and the real (which includes the empirical and the actual, but also that which causes things to be the way they are, possibility, and potential). Within the 'real', causes and potential can be dormant, even within physical objects (Jagosh, 2018a). For example, in a presentation on this, Jagosh (2018) used an illustration of possibility within a chair. He suggested the potential or possibility of a chair to offer support lies in the physical object of the chair itself, rather than the meaning ascribed to it. If the chairs in a meeting room are nailed to the floor, facing in the wrong direction, the context means a different potentiality of support for the meeting is activated than if they are facing each other. This possibility/potentiality is activated, therefore, in different contexts (Jagosh, 2018a). The three levels of stratified reality are also embedded within each other. As described by Westhorp (2018; p44) – "Everything that is 'empirical' must by definition be actual and incorporate its own causal forces and processes. That which is 'actual' may not be empirically observed or even observable, but necessarily involves real causal forces. Causal forces are real whether or not they are generating actual (or empirical) outcomes and whether or not they can be observed." This first, philosophical, meaning of stratified reality suggests that there is a distinction between what exists and what we can know, or between what can be observed and what may be the causal mechanisms behind it (Bhaskar, 2008; Wong, Westhorp, et al., 2013). It also suggests causal processes of 'potentiality' can be dormant or activated by context (Jagosh, 2018a).

Stratified reality in terms of the nature of systems proposes that all systems are nested within other systems (Wong, Westhorp, et al., 2013). The different levels of a system (such as the individual, the group, their workplace, and workplace culture) have autonomy from one another, and have different effects, but are connected. For example, people's actions are shaped by their social structures, but those structures are also shaped over time by people's actions (Wong, Westhorp, et al., 2013). Archer (1995) terms the interplay and interconnection between levels of a system, 'morphogenesis', and it is this which leads to emergent properties. Emergence means that the whole (e.g. the overall system or set of nested systems) has properties which cannot be reduced to the sum of its parts (Elder-Vass, 2005). The implications of this for research are that change is perpetual and driven by all aspects of a system, which means causation can be upwards and downwards

between levels of a system, and programmes, for example, cannot be considered in isolation from the societal and cultural systems within which they sit (Pawson & Tilley, 1997; Wong, Westhorp, et al., 2013).

#### 2.4 Causation in realism

Realism's view that reality is stratified, that causation can be upwards or downwards within systems, and that there is a distinction between what can be observed and what may be the causal mechanisms behind it, has an implication for the realist understanding of causation.

A successionist or 'regularity' view of causation is that we cannot directly have knowledge of underlying causes beyond observing regular association between variables ('constant conjunction') and inferring a causal connection (Westhorp, 2018). Successionist explanation of cause includes determining what these associations are and estimating the significance of the particular cause for the particular outcome, such as through linear regression models to determine the size of influence various causal variables have on an outcome (Pawson, 2008; Westhorp, 2018).

Conversely, a realist approach, linked to conceptions of stratified reality, understands causation as generative rather than successionist. This understanding of causation posits that outcomes are generated by underlying processes or mechanisms, at a different level of the system (Pawson, 2008). As discussed in the previous section, these underlying mechanisms are context-dependant. This is understood to mean that mechanism and context are intertwined – context cannot be controlled for as it is a fundamental part of the causal process (Sayer, 2000). Realist explanation of cause is centred on using mechanisms and contexts to explain outcomes (Pawson, 2008). This means that rather than successionist questions of "does X lead to Y", realist research asks "what is it about X that leads to Y" or "how does X lead to Y" (Jagosh, 2018a).

As causation is context-dependant, realist work also has an underlying assumption that there will be variation in outcome and process due to variation in context. However, a lack of universal regularity does not mean there is no pattern at all to outcome or process (Wong, Westhorp, et al., 2013). Instead, realist work assumes

'demi-regularity', or semi-predictable outcomes or causal pathways, due to variations in context or setting (Jagosh et al., 2012).

#### 2.4.1 Context-mechanism-outcome configurations (CMOs)

Within realism, outcomes are caused generatively by context-dependant mechanisms. Pawson and Tilley (1997), in what they term their 'scientific realism' approach, suggest a heuristic of 'context + mechanism = outcome', or CMO. CMO configurations are used to explain the causal processes behind outcomes and outcome patterns. There are different ways CMOs have been conceptualised. These will be discussed in section 2.4.5, but, first, the individual elements of a CMO will be considered.

#### 2.4.2 Mechanism

'Mechanism' has been used and defined in a number of different ways in research (Mahoney, 2001). From a realist perspective, mechanisms are "underlying entities, processes, or structures which operate in particular contexts to generate outcomes of interest" (Astbury & Leeuw, 2010; p368). Within Bhaskar's (2008) conception of a stratified reality, mechanisms are in the domain of the 'real', and so may often be unobservable or 'hidden' as they are not necessarily also in the domain of the 'empirical' (and so must be inferred from what is observable, such as verbal behaviour). Because of this distinction between the ontological (what mechanisms exist) and the empirical (what mechanisms we can perceive), research design aims to close the gap between the two (Williams, 2018). However, proposed mechanisms can only be approximations or models of the 'real' mechanisms as they may only be partially perceived (Williams, 2018).

Pawson and Tilley (1997), who proposed the CMO heuristic, were interested in programme evaluation. They argued that programmes work by changing the decisions of the participants (discussed further in section 2.5), and thus defined 'mechanism' as comprising the resources offered by the programme and the participant's reasoning in response to those resources (Pawson & Tilley, 1997). The mechanism resources are not the same as the service or programme strategy itself, but are what the strategy creates (Dalkin, Greenhalgh, Jones, Cunningham, & Lhussier, 2015). For example, a programme strategy may be a health-information leaflet; the resource is what the leaflet offers, which may be information, social interaction with the leaflet giver, or a signal that the issue is important. In this

example, the mechanism reasoning may be how the recipient uses the information in the leaflet.

Pawson and Tilley's (1997) definition of mechanism as resource and reasoning is commonly used in realist research. However, this explanation is only at the level of human reasoning, and, within a stratified reality, other types of mechanisms may be apparent at different levels of the system (Westhorp, 2018). For example, Bhaskar (2008) discusses the power and resources of social structures as mechanisms, and Westhorp (2018) proposes a number of different conceptualisations of mechanisms at different levels of systems. Westhorp (2018) uses the example of how 'learning' can be described at different system levels, such as neurological processes or group-learning processes, and how different mechanisms will be identified at each of these different levels. The meaning and definition of 'mechanism' for a particular piece of research is therefore dependant on what the research is investigating (Dalkin et al., 2015). However, as systems operate on multiple levels and programmes may be trying to create outcomes at different levels, investigation or consideration of mechanisms at different levels may be needed (Westhorp, 2018), such as including both the reasoning of individuals in museum programmes, and the societal structures of support for carers.

As discussed in the introduction to section 2.4, context and mechanism are intertwined within realist understandings of generative causation (Sayer, 2000). This means that mechanisms are not absolute laws, but are context-dependant (Maxwell, 2012). Context will be defined and discussed further in the following section.

Finally, mechanisms may not be straightforward or linear. For example, mechanisms can be linked and multiple (Wong, Westhorp, et al., 2013), or may have a temporal element, such as changing over time due to repeated action (Westhorp, 2018). These ideas will be considered when discussing different conceptualisations of CMOs in section 2.4.5.

### 2.4.3 Context

The idea that outcomes can be different in different contexts is not exclusive to realism. As discussed previously, the realist explanation for this phenomenon is that context is part of the causal process, and is intertwined with causal mechanism (Sayer, 2000). In realist terms, context is "any condition that triggers and/or modifies

the behaviour of a mechanism” (Jagosh et al., 2012; p317). The definition of context is therefore quite broad and may refer to environmental factors, such as whether a programme takes place in a rural or urban location, socio-demographic factors, such as the age of participants, or wider cultural and political factors, such as policy or cultural norms, along with other individual characteristics such as beliefs and personal history. However, despite this broad definition, realist research does not attempt to simply list all of the infinite potential contexts which may have an impact (Wong, Westhorp, et al., 2013). Much like there being different constructs of mechanism dependant on the focus of the investigation (Dalkin et al., 2015), realist research is focused on “how a particular context acts on a specific programme mechanism to produce outcomes”(Wong et al., 2013; p9). In other words, the types and levels of context considered, and the construct of mechanism used, is dependent on the specific focus of the research. These are inter-connected, as the construct of mechanism used will be dependent at which ‘level’ of the system, and what context, is being investigated, and vice versa. For example, using Westhorp’s (2018) illustration of how ‘learning’ can be described at different levels of the system, if the research is investigating a group learning approach, the context of existing neurological connections within the brain of an individual would likely not be included, but the contexts of an individual’s anxiety about speaking in a group, or the organisational structure within which the group takes place, may be. However, if the focus of the research is on how learning in a group does or does not impact neuron activation, then the existing neurological connections may be an appropriate context to include, whereas organisational structure of the institution may not.

#### 2.4.4 Outcome

As in other research paradigms, outcomes in realist research are defined as “short, medium, and long-term changes resulting from an intervention” (Punton, Vogel, & Lloyd, 2016; p2). Importantly, outcomes may be either intended or unintended, which may be linked to intended and unintended mechanisms (Wong, Westhorp, et al., 2013). For example, Pawson and Tilley (1997) illustrated the realist approach through an example of an investigation into the impact of CCTV in car parks on car crime and suggest a number of possible mechanisms and outcomes. The presence of the CCTV may deter potential thieves as they do not want to risk being caught on the cameras, and so car crime is reduced (intended mechanism and outcome).

However, this may also cause thieves to increase their activity elsewhere, increasing car crime in other areas (unintended mechanism and outcome). Unintended outcomes are not necessarily negative, however, simply those which a programme or intervention designer did not consider. For example, the CCTV may remind drivers their cars may be vulnerable, so they take greater care to lock their cars and remove visible possessions, decreasing opportunistic theft and overall car crime rates (Pawson & Tilley, 1997).

#### 2.4.5 Understandings of CMOs

As discussed earlier, Pawson and Tilley (1997) proposed a heuristic of 'context + mechanism(resource & reasoning) = outcome', or CMO. In other words, in a particular context, a particular mechanism will be triggered, which generates a particular outcome. Elements of a programme are not inherently a context, a mechanism, or an outcome, and instead the role of a particular element is related to its function in explanation (Pawson & Manzano-Santaella, 2012). For example, 'shared respite' may be an outcome in one CMO configuration, but a context in another, as its function in explanation may be different for different theories. This means analysis in realist work must assess contexts, mechanisms, and outcomes in configuration, rather than as separate 'lists' of Cs, Ms, and Os (Pawson & Manzano-Santaella, 2012).

This idea also links to emergent and temporal analysis. The 'C + M = O' heuristic suggests a contained, linear narrative, which can obscure what is in reality a more complex interaction (Maxwell, 2012). For example, causal processes are not necessarily instantaneous, but may take place over a longer timescale (Westthorp, 2018). In their evaluation of community-based participatory research, Jagosh et al (2015) discuss the idea of a 'ripple effect' of linked CMOs. In this emergent analysis, the outcome of one phase of the participatory project became a context for the next phase, such as trust being built (or not built) in an early phase of the project (outcome), becoming the context for how and whether the participatory project proceeded in the next phase (Jagosh et al., 2015).

Another way in which causation may be more complex is through the idea of 'leveraging'. This has two components: firstly, whether the mechanism resources have enough leverage to overcome barriers in the context; and secondly, whether the mechanism is leveraging pre-existing resources in the context (Jagosh, 2017). In



terms of the first component, there may be a number of barriers within the context, such as mistrust or lack of financial resources. In a programme, an example may be whether the way in which information is presented in a workshop (mechanism) has enough leverage to overcome the participants' mistrust of the presenter (barrier in the context). The second component of leveraging links to work by Westthorp (2018), in which she argues that it is important to understand *how* the context impacts programme mechanisms, and how *mechanisms within the context* may enable or disable mechanisms related to the programme. For example, the social status of the trainer, such as whether they are a peer trainer or a manager (context resource), may impact how a training programme is delivered or perceived, and so impact the mechanisms around whether and how the participants learn. If the context is under-theorised and an evaluation does not take account of these issues, then a programme may be run elsewhere with differing outcomes, without any knowledge of why that is the case. It may be that elements of the context need to be re-theorised as an intervention component, such as a particular competency or social status of the trainer needing to become part of the specific programme structure or procedure, for example that the training must be delivered by a peer trainer (Jagosh, 2017).

Dalkin et al (2015) have suggested that the concept of mechanisms 'firing' or being 'triggered' can be difficult to apply to human reasoning and decision-making because it is rarely an 'on/off' switch. They suggest that the reasoning component of a mechanism in a CMO configuration may instead be better conceptualised as a 'dimmer switch' in some cases, in which there is a continuum of activation to account for the varying levels of intensity a person can feel, for example, confident or mistrustful, and that this leads to varying degrees of outcomes. Dalkin et al (2015) illustrate this using their own research on the use of palliative care registers for non-cancer patients, describing how the anxiety of the health professional (mechanism) was on a continuum, developed over time as the patient's illness progressed, and related to how much experience that professional had. This was not an 'anxiety versus no anxiety' activation of the mechanism, but a continuum that had an impact on the number of non-cancer patients registered for palliative care (outcome).

Pawson and Tilley's (1997) conception of 'C + M (resources and reasoning) = O' is commonly used in realist research. However, disaggregating and naming what in a programme is a 'context' or what is a 'mechanism' is often challenging (e.g. Marchal,

Kegels, & Van Belle, 2018). Dalkin et al (2015) proposed a revised version of Pawson and Tilley's (1997) heuristic, in which the mechanism's resources and reasoning are disaggregated. In their conception, an intervention resource is introduced into an existing context, which alters the reasoning or behaviour of the participants, and leads to the outcome. Rather than 'C + M (resources and reasoning) = O', they therefore suggest a heuristic of 'M(resources) + C → M(reasoning) = O'. They suggest this heuristic encourages researchers to consider both the resources and the reasoning aspects of a mechanism; highlights that resources are introduced into an existing context; and helps to clarify the distinction between mechanism and context of different programme elements (Dalkin et al., 2015).

## 2.5 Realist evaluation

This section considers how the previous discussions of ontology, epistemology, and causation apply to programme evaluation specifically.

Realist evaluation is not a *method* of evaluation, but a *methodology* in that it is underpinned by realist philosophy, rather than a particular set of evaluation tools (Westhorp, 2018; Wong et al., 2016). Given the philosophical issues discussed thus far in this chapter, a realist framework has a number of implications for programme evaluation. Firstly, given a realist paradigm of realist ontology and constructivist epistemology (Maxwell, 2012), knowledge can only be partial. This not only means that one evaluation cannot encompass all possible elements of a programme, but that the researcher(s) perspective has an impact on the knowledge that is generated. This also links to broader ideas around reflexivity and research as context-bound related to the researcher's positionality (Berger, 2015). My positionality as relates to this research is discussed in depth in Chapter 8.

Secondly, a realist ontology assumes that mental processes, such as a person's reasoning, social structures, or culture, are 'real' and have real effects, and are as important as physical processes (Bhaskar, 2008). This means these processes need to be considered in evaluation and analysis of cause. As described in the previous section on CMO configurations, part of the 'mechanism' within realist understandings of causation is the participant's reasoning or behaviour in response to the resources offered by the programme (Pawson & Tilley, 1997).

Thirdly, realism asserts that causation, through mechanisms, is context-dependant, and this context is part of the causal process itself so cannot be controlled for or disaggregated (Sayer, 2000). This means programmes will not work in the same way for all people, or in all circumstances, due to differing contexts (Pawson & Tilley, 1997). Realist evaluation must therefore take context into account, but cannot 'control for' context by attempting to remove it, as this would change the causal processes. This is linked to the previous discussions of stratified reality and how programmes cannot be considered in isolation from the systems in which they sit (such as society and culture), because systems interconnect (Wong, Westhorp, et al., 2013).

Finally, the idea of context-dependant mechanisms means that mechanisms are not inherent to the programme itself, but to the interaction between the programme and the context of, for example, the participants, setting, or workplace culture (Wong, Westhorp, et al., 2013). This means, again, programmes may be expected to work differently in different settings or with different participants. It also linked to the realist understanding that causation is generative, rather than seeking a constant conjunction of variables or determination of effect size (Westhorp, 2018). As programmes are expected to work differently in different circumstances, and realist ontology does not understand causation as being the constant conjunction of variables, realist evaluation cannot discount one participant having a different outcome than others as an 'outlier'. Instead, this difference is equally valid (because that is what occurred for that participant), and indicates a different causal pathway, and may be a source of a potential alternate theory on how the programme works for particular participants or in particular settings. The strength of evidence in realist evaluation is also therefore not necessarily related to the *amount* of evidence.

Realist evaluation, as developed by Pawson and Tilley (1997) aims to understand how a programme works, for whom, in what circumstances, and why. It is a theory-driven approach which aims to open the 'black box' of an intervention to identify causal processes (Astbury & Leeuw, 2010), in realist terms how the interaction between mechanisms and contexts leads to outcomes (Wong et al., 2016). The product of realist work is therefore evidence-based explanatory theory (often CMO configurations) on the causal processes within a programme, related to the research focus. Within realist evaluation, programmes themselves are considered 'theories

incarnate', which means that a programme is designed and implemented in a particular way due to a belief or theory that doing so will generate particular outcomes, regardless of whether those theories are correct (Pawson & Tilley, 1997). These theories may be implicit, and part of realist evaluation work is making those theories explicit in order to understand how a programme is intended to work, and how it does (or does not) work in practice (Wong et al., 2016).

'Theory' has a number of specific meanings within realist evaluation. Different types of theory within realist evaluation are defined by Wong et al. (2013) as:

- Initial rough theories: These are the initial ideas about how the programme may work, or not work. This is used to guide the beginning of a realist evaluation or literature synthesis.
- Programme theories: These are theories about how a programme is expected to work or what it is expected to do. CMO configurations are a particular way of expressing programme theories.
- Middle-range theories: Middle-range theory is detailed enough to apply to the specific programme under evaluation, but is also general enough to apply to other programmes or the same programme within different settings. Many refined CMO configurations at the end of an evaluation are aimed to be at this middle-range level of abstraction.
- Substantive theories: These are existing, established theories within a discipline, such as 'cognitive development' or 'partnership synergy'. Substantive theories may also be at the middle-range of abstraction.

These definitions will be used, and referred to, during this thesis.

#### 2.5.1 Rationale for adopting realist evaluation approach for this thesis

As discussed in the Preface, this PhD was advertised as a realist research project. However, as this research was my own, and not part of a larger project, I did have scope to change the methodological approach if I felt another would be more appropriate. I decided to use a realist approach for a number of reasons. Firstly, realist approaches are designed to answer explanatory questions – rather than whether something works, it asks how, why, and in what circumstances (Pawson & Tilley, 1997), which was a better fit with the explanatory aims of the research. I was interested in *how* including carers has an impact, rather than simply if they do.

Secondly, the approach includes an underlying assumption that programmes will not work for everyone at all times or in all circumstances, and the research aimed to consider both positive and negative impacts, and did not assume these would be the same for all participants. Thirdly, the product of realist literature reviews is evidence-based theory in answer to the research questions. Little existing research explicitly examined the impact of including carers, and this approach aims to identify underlying theories which may not be explicit. Finally, the realist focus on context fits with my personal views on ontology and epistemology as I have historically been professionally interested (as a clinical psychologist) in systemic approaches which consider an individual's context (discussed further in the section on reflexivity in Chapter 8).

## 2.6 Conclusion

This chapter has outlined the realist methodological framework for this thesis, how this framework impacts the conduct of research, and the rationale for adopting this framework to answer my research questions. Issues discussed in this chapter are linked to the methods of the literature review (Chapter 3), the evaluation methods (Chapter 4), and the development of a reusable conceptual platform (Chapter 7). The concept of partial knowledge is also linked to the section on reflexivity in Chapter 8.

## Chapter 3 – Realist review

### 3.1 Introduction

This chapter details a realist review of the literature which examines how including carers in museum programmes may have an impact. It is structured using the RAMESES publishing standards for realist reviews (Wong, Greenhalgh, Westhorp, Buckingham, & Pawson, 2013).

A shorter version of this chapter has been published as a journal article:

Kinsey, D., Lang, I., Orr, N., Anderson, R., & Parker, D. (2019). The impact of including carers in museum programmes for people with dementia: a realist review. *Arts & Health*, DOI: 10.1080/17533015.2019.1700536

As additional authors are listed in the paper, it is worth highlighting their relative contributions so it is clear what of this work was my own. All papers in the first stage search (discussed in section 3.4.2), were assessed for inclusion by me and by Daisy Parker. The remainder of documents were assessed only by me. I discussed and received feedback on my proposed aims and methods with my supervisors (Ian Lang, Noreen Orr, and Rob Anderson), and they provided feedback on the paper draft. I developed the research question and methods, synthesised the data, developed the programme theories, and used these to develop secondary research questions for the evaluation which followed the review.

### 3.2 Review questions

Considering the current literature discussed in Chapter 1, this review aimed to explore the following questions:

Main review question:

1. How does including carers in museum programmes for people with dementia impact the person with dementia, the carer, and the relationship between them?

Secondary questions:

- a. Is this different for different levels of impairment, for family vs professional carers, or for types of museum activities (such as art-making or art-viewing)?

- b. Do the impacts extend beyond the 'moment' of the group, or are they only or mainly experienced while at the museum?

### 3.3 Realist review

As discussed in Chapter 2, a realist framework was chosen for this thesis, including the literature review. A 'realist' review is a review of the literature which takes a realist approach. This means it is theory-led, and aims to understand the underlying mechanisms of how a programme, or class of programmes, works (Pawson, 2006b). As well as being the overarching methodology for this thesis, a realist approach to the literature review was chosen for a number of reasons. Firstly, a realist synthesis is designed to answer explanatory questions – rather than whether something works, it asks how, why, and in what circumstances (Pawson, Greenhalgh, Jarvey, & Walshe, 2005), which is a better fit with the review aims than approaches which focus on outcomes such as effect sizes, for example. Secondly, the approach includes an underlying assumption that programmes will not work for everyone at all times or in all circumstances, and this review aimed to consider both positive and negative impacts. Finally, a key difference between realist and conventional systematic reviews is the product of realist reviews is evidence-based theory in answer to the research questions (Pawson, 2006b). Little research explicitly examines the impact of including carers, and the realist approach aims to identify underlying theories which may not be explicit in existing research.

### 3.4 Methods

The methods section is structured following Pawson's (2006b) steps for realist reviews and through consulting the RAMSES publication standards (Wong, Greenhalgh, et al., 2013). Though this is described in stages, the process as a whole is iterative. The protocol for this review was registered on PROSPERO (ID: CRD42018092399), and no changes were made to the process detailed in the protocol.

#### 3.4.1 Developing initial theories

The initial rough theory to guide the review was developed through spending time as a participant and volunteer on a programme at a local museum and informal stakeholder conversations with staff, volunteers, and artist-facilitators at three museums. Additionally, an initial informal scoping of the literature was undertaken to find existing research and theories on how the inclusion of carers may impact on

outcomes. This scoping was not intended to be exhaustive, but rather to 'map the territory' (Pawson, 2006b) and explore the extent of research in this area. This initial scoping was combined with the informal stakeholder discussions and experience on the programme to create the initial theory to frame the review. The initial theory included eight statements, given below. These statements are not framed in realist terminology, but rather as a set of potential ideas.

1. Having a good/enjoyable experience on the programme means the museum becomes a 'safe'/familiar public place that the dyad can access outside the programme which increases sense of community involvement and reduces social isolation.
2. Good facilitation, no memory required, and activities pitched at the right level means people with dementia are able to contribute equally with people without dementia (and possibly more than the carer expected). The carer then gains a different view of dementia and the individual person with dementia's abilities (and impacts on interaction outside of the group?).
3. Good facilitation and environment means the carer sees the person outside of dementia. They experience a respite from 'dementia life' and individual caring roles (carer vs cared for).
4. Dementia not being mentioned (but activities accessible) means that the dyad enjoy an activity together that is not about dementia, which contributes to a respite from "dementia life".
5. The respite from caring roles means they bond as a couple/dyad separate from dementia, which strengthens their relationship outside of the group.
6. Poor facilitation (and dynamics of dyad?) means the carer does tasks for and answers for the person with dementia that they could do themselves, which means the person with dementia is unable to fully participate so cannot gain positive experiences/outcomes (e.g. cognitive stimulation), the carer and person with dementia's negative views of dementia (and the person with dementia's abilities) are reinforced, and the dyad has no respite from "dementia life" and roles. Creates excess disability for the person with dementia.



7. Poor facilitation means carers dominate conversations, which means people with dementia do not have a sense of belonging in the group and cannot gain potential positive outcomes.
8. The carer expects the person with dementia to 'perform' to past standard, which does not happen. Carer is disappointed or focussed on abilities lost and comparing the person with dementia to their 'old self'. This leads the carer (and person with dementia) to have a heightened sense of loss. This may be most prominent in art-making activities due to there being a more concrete end product vs process (when main focus of all sessions is essentially process / enjoying the moment, not end products).

#### 3.4.2 Search strategy

The search strategy was iterative; as relevant studies were located, initial theories were refined and refuted and new theories created, which in turn led to new areas of literature to examine.

Searching was conducted in stages. The first stage was a broad search of museum programmes and people with dementia in electronic databases including Web of Knowledge, Medline, and PsycInfo using the keywords (museum\* OR "art gallery" OR galler\*) AND (dementia OR Alzheimer's OR "Alzheimer's Disease" OR "mild cognitive impairment" OR MCI). Forward and backward citation searching of included papers was conducted, as well as contacting the authors of included studies for any additional reports or unpublished supplementary material related to the study. A grey literature search was conducted through posting on email network lists related to the arts in dementia or museums for in-house evaluations, searching museums' websites for reports, and searching ProQuest for dissertations.

After synthesising evidence from the included studies from this first search, gaps in programme theory development were identified. This led to one further iteration of searching – outcomes for the person with where the carer was not included, to compare with outcomes for the person with dementia when the carer was included.

Realist reviewing includes scope for including documents related to elements of theory, such as contexts or mechanisms, rather than only those examining the specific programme under investigation. I decided not to complete a further formal search on other participatory arts programmes for people with dementia, as a

scoping search indicated that this literature base did not provide evidence for additional contexts or mechanisms beyond those in the included documents, nor add to theory gaps. Scoping searches on the impact of dyadic relationship dynamics in dementia on outcomes also indicated a lack of specific evidence relevant to development of this review's theories, so it was included as part of the discussion rather than as data of the review. As highlighted in Chapter 1, research into other types of interventions has suggested some negative impacts of including carers. These were also not included in the review as, again, they did not provide evidence for additional contexts or mechanisms beyond those in the included documents. Therefore, this review only included research related to museum programmes as I felt there was enough data within those studies to adequately theorise, and because the theories would be subsequently tested in an evaluation (so I was not solely reliant on the evidence from the literature to develop them).

#### 3.4.3 Inclusion and quality appraisal

Documents were included if they had relevance to the research questions.

Specifically:

1. The programme explicitly included people with dementia, as the way programmes are organised and facilitated may differ significantly for people without cognitive impairment or acquired progressive illness.
2. It included outcomes or processes related to the impact of including carers in museum programmes for people with dementia.
3. The programme, or part of, took place in a museum, art gallery, or similar setting
4. It was written in English
5. Dissertations were included if they met the above criteria and provided insights additional to those in any published articles derived from the work which may also be included

Consistent with a realist framework, there were no inclusion criteria based on study methodology, to avoid missing pertinent information and evidence.

All papers in the first stage 'museums and dementia' search were assessed for inclusion by two reviewers independently (DK and DP) and any discrepancies discussed and agreed upon. There were two discrepancies – both papers which

Parker had initially excluded but I included. She had excluded them on the basis of the papers' outcomes of interest seeming irrelevant from the abstract, but we agreed they did fall under the inclusion criteria for full-text review (and there was subsequent relevant information for inclusion). The remainder of the documents were assessed by me only.

Quality appraisal in realist review is not based on a hierarchy of research methods (such as randomised control trial versus case study), but is judged on relevance and rigour of evidence within studies. According to the RAMESES guidelines (Wong, Westhorp, Pawson, & Greenhalgh, 2013, p9) this is defined as:

- “Relevance - whether it can contribute to theory building and/or testing; and
- Rigor - whether the method used to generate that particular piece of data is credible and trustworthy”.

The RAMESES guidelines do not recommend using a strict checklist to assess methodological quality given a wide range of documents may be included in a realist synthesis, and because parts, rather than the whole, of a paper may be included. Additionally, each fragment of evidence is considered within the synthesis as a whole, rather than in isolation. In this way, relevant data that has lower trustworthiness may be supported by other data with a higher degree of trustworthiness (for example a theory put forward in a discussion section of a paper may be supported by empirical data in another paper). The quality of the review as a whole is based on this trustworthiness of the data, but also on the coherence of the programme theories developed. ‘Coherence’ is judged by explanatory breadth, simplicity, and analogy (fitting with existing knowledge and substantive theory; Wong, 2018). To seek other perspectives and test the coherence of my theories, I attended an advanced four-day realist training event, which included presenting my developing theories and workshopping them within group discussions.

Realist understanding of causation is generative, rather than seeking a constant conjunction of variables or a determination of effect size, for example (Westhorp, 2018). This means theories could be supported by one study, for example, and one study offering a differing conclusion would not be considered an ‘outlier’ but as a source of a potential alternate theory. The strength of evidence therefore was not

necessarily related to the *amount* of evidence, such as the number of studies demonstrating a particular ‘constant conjunction’ of variables.

Appraisal of document quality therefore occurred in parallel with the synthesis, and was related to the relevance and rigour of the section being used in the context of how it is used (Pawson, 2006a).

#### 3.4.4 Data extraction

Included documents were imported into NVivo 11 and coded for contribution to theory in relation to the research questions. Nodes were not created in advance. Instead, documents were coded thematically with the question of ‘what is the impact of including carers’ in mind, for example for outcomes such as “seeing the person with dementia in a new way”, or for proposed programme theory. Each document was reviewed at least three times to ensure any new themes found in other papers could be assessed, and that evidence was not missed. This process enabled the identification of a number of themes which linked to evidence in sections of included documents.

#### 3.4.5 Data synthesis

The aim of the synthesis was to develop evidence-based and refined theory in relation to the research questions, and identify gaps in the literature related to the theory. Data were synthesised using a realist framework and thus was iterative and ongoing throughout the review. The stage one search was synthesised as a whole, the programme theories refined, gaps identified, and then the next stage search planned. Subsequently included documents were then added to the synthesis, and previous conclusions considered in the light of the new evidence.

The analytic strategy was inductive (creating theory from the data), deductive (testing theory with the data), and retroductive. In realist work, retroduction is the process of inferring or identifying underlying causal mechanisms (Sayer, 2000). As described in Chapter 2, mechanisms may not be observable, as they may not be in the domain of the empirical within a stratified reality (Bhaskar, 2008). This means some hidden mechanisms must be theorised and tested (retroduction). Retroduction is closely linked with abduction – abduction is the creative thinking which directs attention, and retroduction is the specific theorising and testing of mechanisms based on that directed attention (Jagosh, 2020).

As described in section 3.4.4, included documents were coded with the question ‘what is the impact of including carers’ in mind. For each code, a code sheet was created which included all extracts related to that code. I annotated these code documents with theorising on whole, or part, CMO configurations, and for how different extracts and code sheets may link together. These annotations were then used to develop programme theories. An example of an annotated code document is given in Appendix 1. Patterns of causal mechanisms, contexts, and outcomes were identified across included papers, and, as per Pawson (2006b), evidence was juxtaposed, adjudicated, reconciled, consolidated, and situated, in order to refine and develop programme theory (see Table 1 for definitions). This was completed both within and across code sheets, but always within the context of the particular document to ensure contexts, mechanisms, and outcomes were assessed in configuration (Pawson & Manzano-Santaella, 2012). For example, ‘shared respite’ may be an outcome in one configuration but a context in another, as its function in explanation (and so what role in the CMO configuration it has) may be different for different parts of the theory or for different CMOs.

*Table 1. Realist synthesis terms (adapted from Pearson et al., 2015, p2)*

Juxtapose	To place two or more things (evidence fragments) together, especially in order to suggest a link between them or emphasise the contrast between them
Adjudicate	To make a judgement about methodological quality or applicability in this instance and account for this judgement based on findings from the use of the critical appraisal tool or an explicit argument about why a piece of evidence was not applicable
Reconcile	To make two or more apparently conflicting things (evidence fragments) consistent or compatible
Consolidate	To bring together. In realist synthesis, ‘to bring together into a more coherent whole’
Situate	To place something (a piece or pieces of evidence) in a context or set of circumstances and show the connections (between it/them and other evidence fragments)

This was not a linear process, but involved moving back and forth between the level of individual data extracts, code sheets as a whole, complete documents, and programme theories. Iteratively examining the data at these different levels was a

way of integrating categorising and connecting analytic strategies in realist research (Maxwell, 2012). Categorising strategies are similarity-based, and consider the ways data are similar or different, such as through coding. Connecting strategies are contiguity-based, and consider how data interact and are physically and/or mentally associated with each other (such as a chain of events and/or thoughts). Maxwell (2012) argues that these two approaches can be used effectively in combination, not as a linear process of first categorising and then connecting data, but as an iterative process that moves between the two. He also argues for the importance of using connecting strategies at the level of the data as well as at the level of the categories, so that the connecting analysis considers the context and connections which may not have been included in the categorising analyses.

Reflections on the process of analysis and reasons for decisions made were also recorded in my research diary and used as a means for reflexive practice. This is discussed further in Chapter 8.

### 3.5 Search results

#### a) First stage search – museum programmes and dementia

Searching electronic databases yielded 54 unique citations. Titles and abstracts were reviewed against the inclusion criteria, and 33 citations were reviewed as full text. Following the full text review, 13 papers were included. Forward and backward citation searching led to the inclusion of a further seven documents, and searching ProQuest led to two relevant dissertations (one masters and one doctoral). All but one of the included authors responded to emailed requests, but this led to no further relevant reports, and no additional relevant reports were found through museum email lists or websites. In total, 22 documents were included in the review from the stage one search.

#### b) Second search – people with dementia's outcomes when carers are not involved in the programme

Using the search results from the stage 1 search, eleven citations were reviewed as full text. Of those, three papers describing museum programmes for people with dementia that did not include carers were identified, which included one document (a journal article) not included after the stage 1 search.

### 3.5.1 Included documents

In total 23 documents, reporting on 21 separate studies, were included (eighteen journal articles, three non-peer-reviewed reports, and two dissertations). The included documents are summarised in Appendix 2, including brief details about study design and the activities within the museum session under evaluation. A flow diagram of the search process is given in Figure 5.

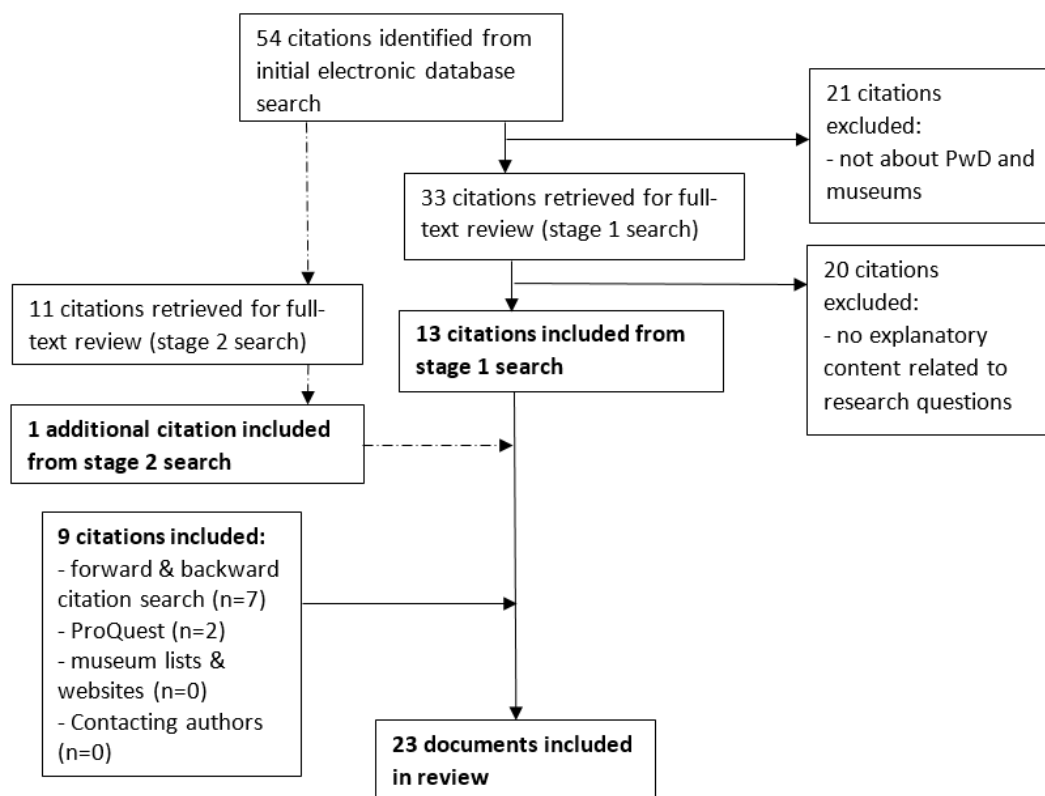


Figure 5. Search and inclusion flow diagram

### 3.5.2 Document quality

As stated in the inclusion and quality appraisal section (3.4.3), a document can be included in the review if it has relevance to the research questions, regardless of methodology, but the rigour of those documents is considered as part of the synthesis. The included documents in this review all reported on an evaluation of a museum programme for people with dementia, though none explicitly aimed to examine how including carers had impact on the person with dementia. Lamar (2015), and Lamar and Luke (2016), examined the impact of the programme on the carers, and other studies include relationship outcomes, but the impact of including carers was not a specific aim. Camic, Hulbert, and Kimmel (2017), did not include carers in their programme in order to assess the impact of *not* including them, which

implicitly suggests examining the impact of including them. No studies used realist terminology to consider the mechanisms of how including carers may have an impact, but the majority theorised their results in an explanatory manner which included implications for including carers. Those that did not theorise in this way included outcome data which implied an impact of including carers, such as relationship outcomes.

The majority of documents were published in peer-reviewed journals, but five were unpublished or published without peer review (Baker, 2014; Gaugler, Mojsilov, & Gerber, 2010; Gould, 2013; Lamar, 2015; Mittelman & Epstein, 2009), though two of these later became peer-reviewed articles that were also included in the synthesis (Baker, 2014; Lamar, 2015). Three documents did not provide enough information, either in their method or results sections, to enable a comprehensive assessment of their rigour (Clarke-Vivier, Lyford, & Thomson, 2017; Gaugler et al., 2010; Hazzan et al., 2016). Additionally, five did not include recognised methods of quantitative or qualitative data analysis for some or all of their data (Gaugler et al., 2010; Gould, 2013; Livingston, Fiterman Persin, & Del Signore, 2016; Mittelman & Epstein, 2009; Schall, Tesky, Adams, & Pantel, 2017). However, as previously stated, this does not preclude the documents being included as it is the fragment of evidence, rather the document as a whole, that is assessed, and it is considered within the synthesis and evidence base as a whole, rather than in isolation (Pawson, 2006a).

### 3.6 Results

The synthesis resulted in sixteen programme theory statements within four themes. These are presented below with supporting evidence. Unless the mechanism could not be separated into resource and reasoning, the theory statements use Dalkin et al's (2015) method of structuring CMO configurations whereby the mechanism's resource (M/res) is introduced into a context (C), which together change the participants' reasoning or behaviour (M/rea), leading to the outcome (O). Elements of the statements which were not apparent in the included literature but have been theorised are presented in italics for transparency.

#### 3.6.1 Theme 1: Seeing the person with dementia in a new way and relationship-building

The carer '*seeing the person with dementia in a new way*' as an outcome was supported for family carers (Clarke-Vivier et al., 2017; Johnson, Culverwell, Hulbert, Robertson, & Camic, 2017; Mittelman & Epstein, 2009), professional carers (Roe et



al., 2016), and in programmes with mixed or unspecified carer types (Baker, 2014; Burnside et al., 2017; Camic et al., 2016; Gould, 2013; Hazzan et al., 2016; Humphrey et al., 2017; Lamar, 2015; Lamar & Luke, 2016; Mangione, 2013). However, one study (Lamar, 2015) reported some carers specifically stated that the programme did not change how they saw the person with dementia, due to having long relationships.

'Building relationships' as an outcome was supported for family carers (Clarke-Vivier et al., 2017; Eekelaar et al., 2012; Gaugler et al., 2010; Mittelman & Epstein, 2009; Schall et al., 2017), professional carers (Roe et al., 2016), and in programmes with mixed or unspecified carer types (Baker, 2014; Burnside et al., 2017; Camic et al., 2016; Camic, Tischler, & Pearman, 2014; Gould, 2013; Hazzan et al., 2016; Humphrey et al., 2017; Lamar, 2015; Lamar & Luke, 2016; Livingston et al., 2016; Mangione, 2013). One study (Lamar, 2015; Lamar & Luke, 2016) reported that some participants stated the programme had no effect on their relationship.

*Theory statement (a)*

**When the facilitation enables the person with dementia to 'maximise capacity' to participate (M/res) and *the carer's expectations of the person with dementia are low (C)* and/or others in the group highlight the person with dementia's capabilities (C), the carer perceives the person with dementia to have achieved competency (M/rea), so the carer sees the person with dementia in a new way (O), which also helps to build their relationship (O).**

Baker (2014) explicitly theorised that the carer perceiving the person with dementia to have achieved a sense of 'competency' was the mechanism for the carer seeing them in a new way, though did not use the terminology of 'mechanism'. On the basis of participant and facilitator interviews, Baker (2014) (and Camic, 2016, based on Baker) suggest sharing an engaging experience in a stimulating environment, and the carer seeing the person with dementia making competent contributions, allows the carer to see the person with dementia in a new way. Other studies also support this theorising. Mangione (2013) included quotes from carers discussing seeing their partners with dementia making astute or insightful contributions and describing themselves as marvelling or feeling emotionally overwhelmed at the experience.

Similarly, Lamar (2015) included quotes from carers about learning something new about the person with dementia, and reported that in some cases the emergence of the artistic side of the person with dementia led the carer to see the person with dementia as more 'capable' than before. Johnson et al. (2017) included in their introduction the idea that carers gained new understanding of the person with dementia's abilities. Baker (2014) also included comments by facilitators suggesting a carer was able to see her partner in a new way through seeing his contribution through others' perspectives.

*...some CPs [care partners] (n=8) saw abilities within the person with dementia that they thought were already lost. One CP said, "Dementia has a way of conflicting with communication. But this was like, kind of like, opening up another avenue and it made me realise that there are still a lot of switches on in there." Another said, "Appreciation for abilities that I might have thought previously were lost...it's nice to see a new insight."*

*Lamar (2015) – p25 – results section*

*Facilitators (and carers) expressed new perspectives which appeared to be related to the opportunity to share an engaging experience with individuals with dementia and witness them making competent contributions in an intellectually challenging setting. The intellectual aspect interacted with the group environment to offer an opportunity for individuals with dementia to be seen differently.*

*Baker (2014) – p29 – discussion section*

However, no studies reported on whether these effects (both the carers' new perceptions and resulting building of the dyad's relationship) were maintained long-term. None of the studies suggested what it is about the context of the dyad which generated the mechanism. I have theorised here that the carer having lower expectations of what the person with dementia was capable of than they were actually able to achieve was the context. However, this is likely inadequate and will be examined further in the discussion.

*Theory statement (b)*

**Professional carers only have a relationship with the person with dementia in a work context (C) but take part in a shared activity outside**

**of the work context (M/res) and are able to get to know the person beyond dementia (M/rea), which builds their relationship (O).**

Following interviews and observation, Roe et al. (2016) described how the programme enabled care staff to see the person they cared for in a social, rather than care, context, and also gave staff new things to discuss with residents which helped them to bond. The interviews were held one month after the end of the programme, which suggested at least short-term effects. However, this was the only study in the review which included participants without dementia as well as people with dementia without differentiation, so the results are only suggestive of applicability to dyads including people with dementia.

*'...It gives them things to talk about with residents and it helps them bond with the residents – builds relationships. The staff saw the residents in a different context and in a different light. Not seeing the person in a care context but in a social context, staff do not always see them in “other” environment contexts.'*  
(project worker).

*Roe et al (2016) – p550 – results section*

*Theory statement (c)*

**Where dyads have little opportunity for meaningful/leisurely activity (C), sharing a meaningful experience on an equal basis (M/res), means they have meaningful communications and interactions (M/rea), which helps the carer to see the person with dementia in a new way (O) and build their relationship (O).**

Eekelaar et al. (2012) theorised the stimulating activity and environment allowed for meaningful communications. Burnside et al. (2017) defined their outcome of 'relationship growth' as being related to meaningful experience, and, similarly, Lamar (2015) and Camic et al. (2016) both suggested the shared experience builds the relationship. Lamar (2015) and Clarke-Vivier et al. (2017) discussed the art product itself opening up dyad communication, and helping the carer to learn or see something new about the person with dementia. Clarke-Vivier et al. (2017) and Lamar and Luke (2016) both linked this 'seeing/learning something new' with relationship-building.

*In the current study, the shared experience of the person with dementia and family carer, in an aesthetically stimulating activity and environment, allowed for meaningful communication and understanding to occur, be it through making art, discussing paintings in the gallery, or having the opportunity to socialize during the sessions.*

*Eekelaar et al (2012) – p270 – discussion section*

*Theory statement (d)*

***In dyads where the carer is unsure about how best to support the person with dementia or is struggling with communication (C), modelling by the facilitators (M/res) means carers learn new ways to interact with the person with dementia and new strategies (M/rea), which builds relationships through improved communication and a focus on process rather than product (O).***

Six papers discussed carers learning new ways of interacting with the person with dementia. Humphrey et al. (2017), Hazzan et al. (2016) and Lamar (2015) gave examples of carers reporting using skills modelled by the facilitators in other, unrelated, situations, such as helping the person with dementia eat, and to focus on the process of activities rather than the end product. Camic et al. (2016) and Mittelman and Epstein (2006) both reported at least one carer in their programmes who intended to make changes in the way they interacted with their partner at home. Mangione (2013) included one quote from a physician working with the programme about how it opened up new ways of coping and reacting to behavioural difficulties, which may also be linked with this modelling by facilitators. However, none of the studies had enough long-term follow-up to determine if this effect was lasting, or if those with intentions to interact in different ways actually did so.

*One care partner wrote that she was able to better help her husband eat after learning how to help him with painting; another spouse commented that she learned strategies that improved her ability to interact with her husband.*

*Hazzan et al (2016) – p6 – results section*

*“I feel like this is wind beneath our sails now...given me some direction with my sister...I didn’t think I’d take to this but I do. I can see its value. I keep notes and I am making changes at home.” (carer)*

*Camic et al (2016) – p1038 – results section*

*Theory statement (e)*

**Where the person with dementia is anxious about new activities (C), the carer reassuring or taking part in a shared activity (M/res) helps the person with dementia to feel comfortable/able to take part (M/rea), so the person with dementia is able to participate without anxiety (O).**

One study (Hazzan et al., 2016) suggested carers being involved helped people with dementia to engage with the programme through the reassurance of their presence.

*Participants seemed to engage in an activity because their care partners (mainly spousal family care partners) were present and also engaged in the activity.*

*Hazzan et al (2016) – p5 – results section*

3.6.2 Theme 2: Shared respite

Shared respite as an outcome was supported for family carers (Eekelaar et al., 2012; Flatt et al., 2015; Johnson et al., 2017; McGuigan, Legget, & Horsburgh, 2015), professional carers (Roe et al., 2016), and in programmes with mixed or unspecified types of carers (Baker, 2014; Burnside et al., 2017; Camic et al., 2016, 2014; Hazzan et al., 2016; Lamar, 2015; Lamar & Luke, 2016). One study (Baker, 2014) reported that respite had not been experienced for one carer, in contrast to others in the same study.

*Theory statement (f)*

**Where the dyad’s home interactions are mainly around caring (C), enabling facilitation in a non-medical setting in which the carer has no caring responsibilities (M/res) means the dyad can enjoy the activity together on an equal basis (M/rea), which leads to the dyad experiencing shared respite from dementia roles/life (O), which also helps to strengthen their relationship (O).**

The carer not having caring responsibilities as a context was suggested by five papers reporting on three studies (Baker, 2014; Camic et al., 2016; Lamar, 2015; Lamar & Luke, 2016; McGuigan et al., 2015). Four of these (Baker, 2014; Camic et al., 2016; Lamar, 2015; Lamar & Luke, 2016) also linked the lack of caring/cared-for roles with the ability to enjoy the activity on an equal basis, which was supported by a further three studies (Camic et al., 2014; Eekelaar et al., 2012; Mittelman & Epstein, 2009). The activity not being about dementia, and so not about individuals' caring/cared-for roles related to dementia, was linked to shared respite or enjoyment by four papers reporting on three studies (Baker, 2014; Burnside et al., 2017; Camic et al., 2016; Flatt et al., 2015). Shared respite helping to build relationships was suggested in three studies (Burnside et al., 2017; Camic et al., 2016; Lamar, 2015). The importance of the non-medical context was highlighted in three studies (Camic et al., 2014; Johnson et al., 2017; McGuigan et al., 2015).

*They did not feel they had to be in charge for that time of the day: "It just allowed me to be his wife. Go there and just be a wife. I wasn't his nurse... I was his wife. We were partners in that activity."*

*Lamar & Luke (2016) – p215 – results section*

*One carer...said that she enjoyed her relationship with her mother more, because she was relaxed when she was there. She didn't feel as though she was a carer. So it was respite time for her...she could chat with her mother as an equal about whatever it was they were doing...So they were sort of communing as mates (facilitator).*

*Baker (2014) – p25 – results section*

*Theory statement (g)*

**Shared respite (C) means the dyad can interact and communicate outside of dementia roles (M), which builds their relationship (O) and also feeds back into enjoying the activity together (O).**

Eekelaar et al. (2012) discussed the shared experience allowing meaningful communication to occur. The shared respite described in theory (f) also feeds back into enjoyment of the activity (Eekelaar et al., 2012; Lamar, 2015; Lamar & Luke, 2016). In this way, (f) and this theory are mutually reinforcing processes – enjoying

the activity on an equal basis leads to shared respite, and this shared respite further enables the dyad to enjoy the activity together.

*“It’s hard when you are responsible for someone with memory problems, you become, a carer, and your relationship changes in that way. With the group, we were doing it together. It was nice, like learning something from scratch together.” (family carer)*

*Eekelaar et al (2012) – p269 – discussion section*

*Theory statement (h)*

**The participatory activity with a ‘product’ e.g. artwork/verbal contribution (M/res), in the context of high carer expectations or a dyad struggling to accept dementia (C), means the carer compares the person with dementia’s current to their past abilities or negatively with other people with dementia in the group (M/rea), which leads to the group highlighting losses or reinforcing limitations (O).**

Five papers reporting on four studies discussed the group highlighting losses or negatives about dementia for the carer, particularly where current and past abilities were compared. Humphrey et al. (2017) discussed some carers feeling initially discouraged by the person with dementia’s artwork being less skilled than that they had produced in the past. Lamar (2015) and Lamar and Luke (2016) reported two carers who found the programme anxiety-inducing as a ‘confrontation with the reality’ of dementia, another who found it difficult that her mother seemed to have greater difficulties than others, and another who discussed feeling isolated because they could not talk about the shared experience of the programme afterwards as the person with dementia had forgotten it. Burnside et al. (2017) found the carer expressing frustration with the person with dementia’s limitations was a barrier to the dyad’s engagement. Baker’s (2014) theorising regarding carer-perceived competency, described in (a) and (i), also relates to this theory. As in theory (a), carer expectations are theorised as context, but here where the carer has higher expectations of the person with dementia than they are capable of achieving.

*“[It’s] nice to be around other people in similar situations. But it was actually kind of hard; it was kind of like, heartbreaking to watch. [Person with dementia] has a hard time with her vision due to her Alzheimer’s so she had a*

*very hard time seeing what it was we were even looking at and she really had a hard time with it and other people who appeared to be worse off than my mom as far as their Alzheimer's or dementia, were able to respond better, were able to see the picture and see whatever it was we were looking at and like, respond better to it. So it was actually pretty heartbreaking...the experience." (family carer)*

*Lamar (2015) – p23 – results section*

*Theory statement (i)*

**Where the carer has high expectations of the person with dementia (C), or the group highlights losses (C), the carer does not perceive the person with dementia to have achieved competency (M), so the carer does not feel respite (O) and the carer does not see the person with dementia in a new way (O).**

Related to theory (h), and in contrast to (a), Baker (2014) theorised the reason one carer did not experience a sense of respite was that they did not perceive the person with dementia to have achieved 'competency', so could not step out of their caring role. As theory (a) suggests, if the carer cannot step out of their caring role, they also cannot see the person with dementia in a new way.

*For at least one carer, a sense of respite was not experienced and this was best explained by the person she cared for having failed to achieve a sense of competency (or her carer not perceiving this), undermining the ability of the carer to step out of the caring role. Carers who benefited the most had an experience of seeing those with dementia in a new perspective. The new perspective appeared to be contingent on those with dementia having achieved a sense of "competency", even if that competency was only in the moment.*

*Baker (2014) – p19 – results section*

*Theory statement (j)*

**When the carer has caring responsibilities in the group (C), the dyad cannot enjoy on a completely equal basis (M) so the carer does not get respite (O) and feels increased stress (O).**



Lamar (2015) reported some carers felt the programme had stressors related to caring responsibilities, such as the logistics of getting around the museum or the person with dementia's behaviour. This implies carers feeling a caring responsibility inhibits stress relief, which is suggested in the same study to be related to a lack of responsibility and the safe environment. In theory (f), five papers reporting on three studies (Baker, 2014; Camic et al., 2016; Lamar, 2015; Lamar & Luke, 2016; McGuigan et al., 2015) suggested the carer not having caring responsibilities in the group is a context for enjoying the activity together equally. This implies *having* caring responsibilities inhibits enjoying equally.

In four studies which explicitly described carers having responsibilities for the person with dementia within the programme, one did not report carer outcomes (MacPherson et al., 2009), while the remaining three suggested some positive outcomes for the carer or relationship building (Gould, 2013; Livingston et al., 2016; Roe et al., 2016) due to the social context. However, as none of the three focussed on carer outcomes, and other studies which highlighted responsibilities as an issue did not report how much responsibility the carer had, it is not clear if there is a 'threshold of responsibility' that impacts on carer outcomes, or if it is about the carer's perceptions of responsibility, rather than the actual. This CMO configuration may be more usefully conceptualised as a 'dimmer switch', with activation of the mechanism operating on a continuum rather than an on/off switch (Dalkin et al., 2015).

*For those that felt the program did have stressors (n=14), the stressors were mostly due to the [person with dementia] being reluctant or not participating (n=5), related to the person with dementia's behaviors (n=5) or the logistics of getting to/from and around the museum (n=3). One [care partner] said, "It was just stressful anyway. You know, getting her there, making sure that she participated, that she came..." Referring to a [person with dementia]'s reluctance, "It was a little stressful at first because she kept saying 'I'm not an artist, I'm not talented...' It was stressful for her, you think you are going to be judged I guess."*

*Lamar (2015) – p28 – results section*

### 3.6.3 Theme 3: Excess disability

#### *Theory statement (k)*

**Anxious carers (C) intervene on the person with dementia's behalf (M), so the person with dementia cannot engage fully (O) and the carer has no respite (O).**

MacPherson et al. (2009) specifically focused on the idea of excess disability. They found, for people with dementia from residential care, anxious professional carers intervened and the person with dementia seemed to lose confidence. When the carers were not involved, the person with dementia showed greater capacity and positive affect. On this basis, Windle et al. (2017) did not recruit dyads, though some carers attended, and suggested facilitators needed to intervene at times to stop carers inadvertently taking over and preventing the person with dementia from doing tasks at their own pace (Windle, personal communication, 1<sup>st</sup> May, 2018).

*"It was a strain when we had some carers there at the last programme, each of the participants tended to refer back to their carers a bit and they weren't as spontaneous. [When carers were absent] their confidence changed, people became more vocal ... otherwise they depend on the carer" (museum educator)*

*MacPherson et al (2009) – p749 – results section*

#### Theory statement (l)

**Professional carer-person with dementia dyads have only had a caring/work relationship *find it harder to step outside of dementia roles (C)*, so the carer intervenes on the person with dementia's behalf (M), and the person with dementia can't engage fully (O).**

The finding by MacPherson et al. (2009) described in theory (k) could be due to the professional carers being at work during the group, so finding it difficult to switch to a more social way of being within what it is, for them, a work context. However, Roe et al. (2016) also evaluated a programme with professional carers, and did not mention excess disability as an issue, and did highlight how carers were able to see the person with dementia in a social context, as described in theory (b). The factors which affect whether dyads including a professional carer can switch to a more social way of being is unclear from the current literature.

*Theory statement (m)*

**People with dementia may find it more difficult to speak up in a group setting (C), so where there is poor facilitation (M/res) carers dominate the conversations (M/rea), so the person with dementia cannot engage and does not have a sense of belonging in the group and cannot gain potential positive outcomes (O).**

'Poor facilitation' in this context means that not all participants are enabled to participate or contribute in the discussions. A carer in Lamar's (2015) study suggested carers spoke up most in the group, and Mittelman and Epstein's (2006) evaluation stated carers could be enthusiastic which may have discouraged people with dementia from taking part. Mittelman and Epstein (2006) also measured the number of spontaneous comments made by people with dementia and found no difference between comments to the group and those to carers, so it may be that people with dementia spoke less in general rather than simply due to carers' presence in the group setting. However, it also suggests the importance of facilitation that encourages people with dementia to participate, rather than relying on spontaneous involvement. In the 'hints and tips' section of their report, Gould (2013) specifically stated a general question to the group is usually answered only by carers. Relatedly, as discussed in theory (k), MacPherson et al. (2009) and Windle et al.'s (2017) studies suggest the importance of facilitation in ensuring carers do not dominate.

*A general question to the group tends to be answered only by carers.*

*Gould (2013) – p115 – recommendations section*

*During the course of the Meet Me at MoMA tour, participants with dementia rarely responded to the educator spontaneously, without prompting. This may be because they were waiting for the prompt from the educator before speaking. On the other hand, this may reflect reduced verbal ability or reduced initiative due to the illness. It may also be that the participation of some of the caregivers, which could be quite enthusiastic, discouraged some of the people with dementia from responding.*

*Mittelman & Epstein (2006) – p96 – results section*

### 3.6.4 Theme 4: Social isolation

#### *Theory statement (n)*

***Where carers are not in contact, or have limited contact, with other carers (C), the activity happening in a group means carers meet others in similar situations (M/res) and feel connected to others in a similar situation and the wider community (M/rea), so feel less socially isolated (O), and leads some to continue friendships outside the group (O) or join other dementia-friendly groups (O).***

Although mainly carers, not people with dementia, were asked about this, the social aspect of the group and peer support were highlighted as important to participants. Ten documents reporting on eight studies reported participants saying social interaction and connections with others in similar situations was important and helpful (Baker, 2014; Burnside et al., 2017; Camic et al., 2016; Eekelaar et al., 2012; Flatt et al., 2015; Gaugler et al., 2010; Lamar, 2015; Lamar & Luke, 2016; McGuigan et al., 2015; Mittelman & Epstein, 2009). Eekelaar et al. (2012) specifically found the programme reduced feelings of social isolation, while four studies reported participants informally socialising after the programme or at other events (Baker, 2014; Burnside et al., 2017; Lamar, 2015; Roe et al., 2016). Lamar (2015) reported participants joining other dementia-friendly activities after the programme. The importance of the group as a social space was highlighted by Flatt et al. (2015), who found overall satisfaction with the programme was related to a greater sense of belonging to the group. However, the programmes cannot be wholly reduced to being a social group, as in another study wellbeing significantly increased to a greater degree during the active programme time than in a purely social break (Johnson et al., 2017).

*A number of caregivers also talked about the importance of interacting with others during the art engagement activity and the opportunity to bond and connect with others who are facing similar challenges. For instance, one caregiver said, "Other caregivers and the patients, it's just developing that bond, you know, art's a good medium to do that for us...I think that's an important part of the journey that we're on." Another family caregiver also expressed how the art engagement activity allowed them to connect with*

*others. “We weren’t just talking about art, we were talking about life. So many things that...connecting the artists to it, connecting other people to it, and talking about the motives of the persons who were being painted.”*

*Flatt et al (2015) – p387 – results section*

*Theory statement (o)*

**A positive experience in the museum (M/res), in the context of a ‘shrinking world’ for the dyad (C), makes the dyad feel the museum is a ‘safe’ place they can return to (M/rea), so they intend to return outside of the group (O) and feel less socially isolated (O).**

Three studies (Camic et al., 2016; Camic et al., 2014; Mittelman & Epstein, 2006) report participants discussed an intention to return to the museum following their programmes, though none had long-term follow-up to determine whether they actually did. Gaugler, Mojsilov, and Gerber (2010) measured additional participation in museums during the programme and found dyads attended an average of 1.2 additional museums. However, as they did not measure whether people attended museums prior to the programme, it is not clear if this is more or less than usual.

*“We came to all but one session and now we both can come back to the gallery and continue this.” (carer)*

*Camic et al (2014) – p165 – results section*

*Theory statement (p)*

**A positive experience in the museum (M/res), in the context of a ‘shrinking world’ but where the carer does not have capacity to include leisure in day-to-day life (C), means the carer does not see the museum as a place they can return to (M/rea), so they do not intend to return and do not feel less isolated (O).**

One study (Camic et al., 2016) included quotes from two carers specifically discussing the demands of caring and lack of practical value of the programme, one calling it an ‘indulgence’, as a reason they would not return.

*“I seem to just be able to get through every day doing all the stuff I need to do. I am not able to do stuff that is fun” (carer). Another expressed, “I have no use for it, it’s not going to pay the rent, it’s like an indulgence... I would never set*

*time to do it that's the thing" (carer). So whilst the experience was valued, and future visits planned, for some the burden of day-to-day care demands overshadowed perceived benefits of the gallery experience.*

*Camic et al (2016) – 1038 – results section*

### 3.6.5 Outcomes when carers are not included

The second search was conducted to compare outcomes for people with dementia when their carers were or were not included. One study (Camic et al., 2017) was specifically designed to see if the programme was still effective without carers present. They found an increase in wellbeing for all participants, but that people with mild dementia had greater increases than those with moderate. Windle et al.'s (2017) study did not specifically recruit dyads, and does not state how many carers participated. They also found people with dementia had increased wellbeing following the programme. These two studies suggest increased wellbeing is not dependent on the presence of carers, though caution must be taken given little research without carers.

### 3.6.6 Interaction of CMO configurations

Some of the theories interact with each other, and more than one mechanism can lead to the same outcome. The mapping of CMOs has been split into sections according to interaction for ease of comprehension, and are visually depicted in Figures 6, 7, and 8.

As shown in Figure 6, dyads may experience relationship building in one or more ways. The outcome of shared respite is also self-strengthening, as it feeds back into enjoying together on an equal basis which is a mechanism for shared respite.

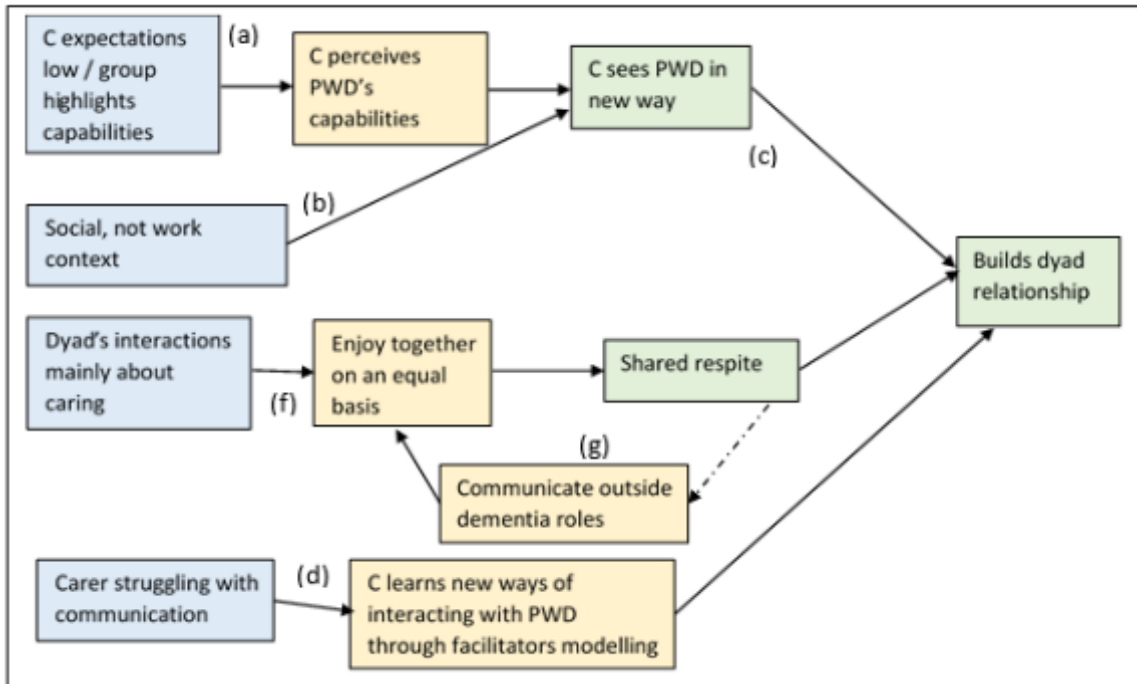


Figure 6. Interaction of CMOs related to positive outcomes, including references to theory statements

A reduction in feeling socially isolated is not only about feeling connected to others in group, but may also be due to the museum as a public space that can be re-visited outside of the group. However, where the dyad does not have capacity to return, this contribution to reducing social isolation is lost. As presented in Figure 7.

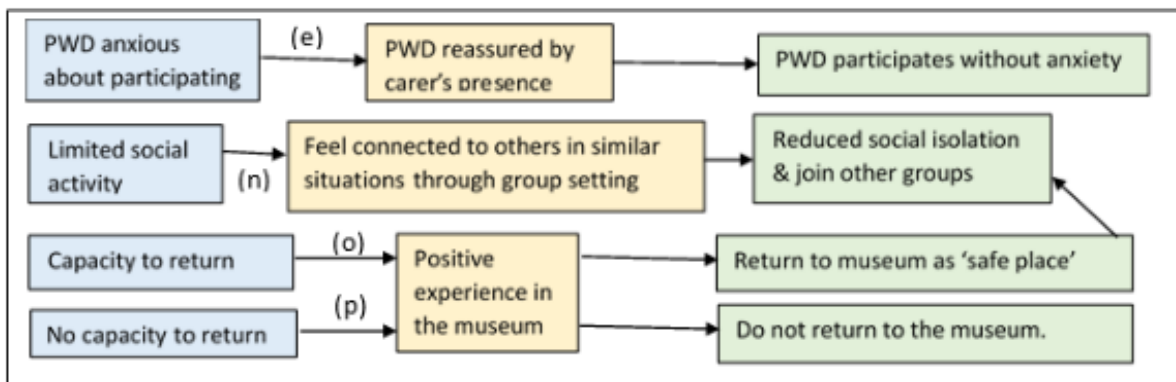


Figure 7. Interaction of CMOs related to social isolation, including references to theory statements

A lack of respite can be achieved via three mechanisms, including where the outcome of the group highlighting losses becomes a context for the carer not perceiving the Person with dementia's competency. Two mechanisms can also lead to the person with dementia being unable to engage fully. See Figure 8.

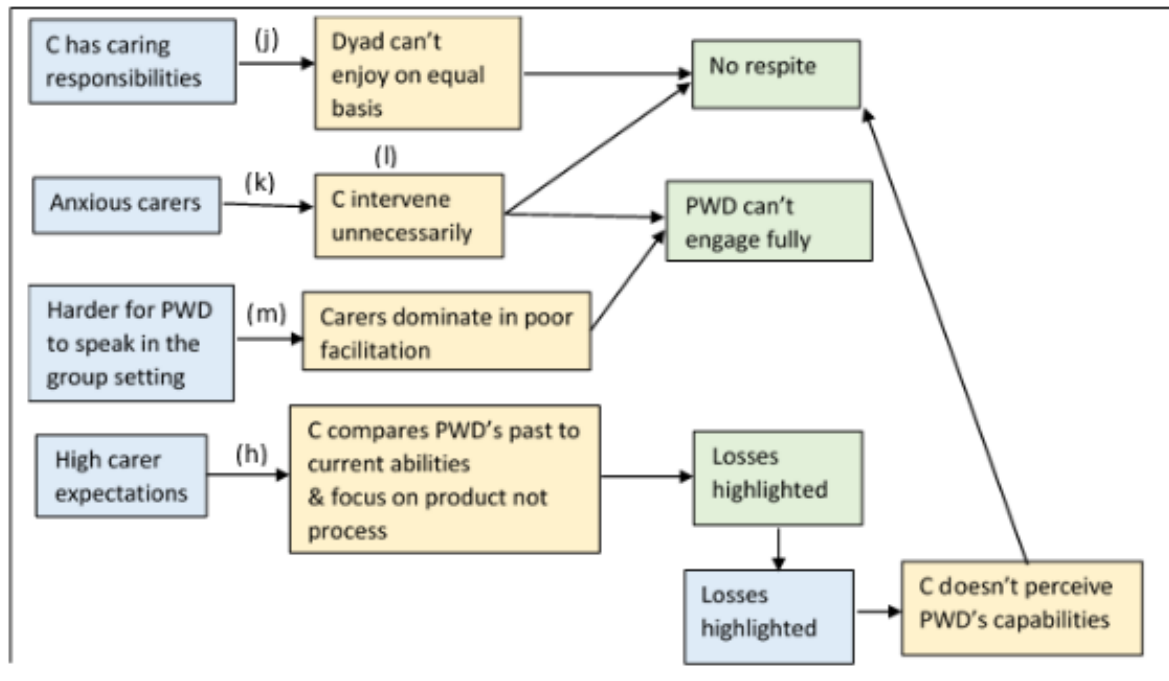


Figure 8. Interaction of CMOS related to negative outcomes, including references to theory statements

### 3.7 Discussion

This review aimed to examine how including carers in museum programmes for people with dementia has an impact on the person with dementia, the carer, and the relationship between them. Four themes of outcomes were identified: seeing the person with dementia in a new way and building relationships, shared respite, excess disability, and reduced social isolation. Sixteen evidence-informed programme theory statements were developed within these themes, some of which interacted with each other. Including carers had both positive and negative aspects, and the same outcome could occur through a number of different mechanisms.

The results may indicate an overarching impact that including carers in programmes contributes to outcomes which extend beyond the moment of the group, such as relationship building, whereas, without the carers' presence, the person with dementia can experience wellbeing outcomes but these are 'in the moment' rather than long-term. However, there is little research on long-term outcomes and on programmes which do not include carers, so this can only be tentative. There is also not enough evidence to propose theory for the secondary aims of the review, such as whether the impact is different for different dyad types. Issues related to these gaps will be considered throughout the discussion.



In this review, shared respite does not refer to a physical break away from one another, but to respite from caring/cared-for roles, with a focus on the relationship not defined by dementia (Burnside et al., 2017). This was well supported as an outcome. However, it may also be that some carers do not want *shared* respite, and would like more traditional breaks from caring responsibilities. The studies included in this review had participants who either specifically volunteered or were already attending programmes, so would likely be more interested in shared activity. Additionally, most studies interviewed dyads together which could make it difficult for participants to discuss negative aspects related to their relationship (Pesonen, 2011). Furthermore, as both relationship dynamics and symptoms of dementia can fluctuate, what each individual in the dyad wants in terms of respite may also fluctuate over time. Most included studies used a cross-sectional design, which may not capture a fluctuation of outcomes and dyad preferences. Further research should consider following dyads through a number of sessions, and consider that outcomes may not be static so individuals may need different kinds of support at different times.

Studies interviewing dyads together may also have had an impact on the focus of the developed theories. As carers' voices were dominant, it is unsurprising that most of the theories centre the carer, rather than the person with dementia. For example, there may be similar processes of losses being highlighted for the person with dementia, as well as the carer (theory (h)), but this is not apparent in the current literature.

'Enjoying together on an equal basis' acting as both a mechanism for, and an outcome of, shared respite may be due to the two elements working at differing levels of stratified reality. Levels of a system do not have effects in only one direction and can have effects at higher and lower levels, which means that mechanisms can be conceptualised at different levels (Westhorp, 2018). 'Enjoying together on an equal basis' can be seen as an individual process within a dyadic context, whereas 'shared respite' is a dyadic process because it is the removal of roles which only exist in relation to the other (i.e. you are only a 'carer' due to another you are caring for). The theory thus becomes self-strengthening because at the level of shared respite, a mechanism is generated which leads downwards to enjoying together, and enjoying together upwardly generates shared respite.

The theories could be further strengthened, resulting in more nuanced practice implications, if the mechanisms within the context are also investigated to understand why particular mechanisms fire in particular contexts (Westthorp, 2018). This issue of what it is about the context that generates or activates the mechanism is a gap in a number of areas. For example, although reduced feelings of social isolation were discussed in a number of studies, it is unclear how socially active participants were prior to the programme. This outcome, as well as shared respite, may be influenced by the amount and quality of other social activities the dyad participated in, both together and as individuals. Though it may be related to logistical issues such as access to transport or financial means, the current evidence base does not allow for theorising on what it is about a dyad that means the programme reduces feelings of social isolation compared to those for whom it does not.

There is also a lack of evidence about the context of the dyad in terms of their relationship dynamics and type. In this review, relationship dynamics have been conceptualised as 'high/low carer expectations' of how the person with dementia would contribute, as it made most sense in terms of the framing given in included studies. However, this is inadequate to explain why it is some dyads experience positive outcomes and others negative, which means recommendations cannot be given about which dyads may benefit and how. Realist review methodology includes scope to search widely to fill theoretical gaps, however there is a lack of research generally in how the dyadic relationship in dementia has an impact (e.g. Edwards et al., 2018), rather than the impact of dementia on the relationship. Some evidence suggests it does have an impact, such as current and past relationship quality having positive and negative effects on emotional wellbeing and coping (Ablitt et al., 2009), but not on how this may affect programme outcomes (Rausch et al., 2017). Further research examining the dyadic context within programme evaluation could provide better understanding of for whom these programmes work, and provide potential practice implications for those who do not benefit, such as a differing kind of support during the programme. For example, the group highlighting losses for the carer due to comparison with others in the group (theory h) is contrasted with those for whom others in the group highlight the person with dementia's capabilities (theory a). It could be that this relates to social comparison theory in which people positively or

negatively interpret downward or upward comparisons with others (Dibb & Yardley, 2006). However, there is no indication of what it is about a carer or dyad that means one carer may have a positive interpretation and another negative. Further research examining the dyadic context could provide more nuanced understanding of for whom these programmes work, and provide potential practice implications for those who do not benefit, such as a differing kind of support during the programme.

There is also a lack of consideration given to the type of caregiving dyad, such as spousal, parent/child, or paid professional, and if there are differences in outcomes in differing relationship contexts. This may be important given the socio-relational challenges faced by different dyad types are likely to be different (Rausch et al., 2017). The evidence gap is particularly apparent for professional carers. One review found some residential care staff were hesitant to engage with interventions promoting closeness because they feared getting emotionally attached to the person with dementia (Rapaport et al., 2017). This suggests, in museum programmes, some professional carers may not engage fully and this may impact outcomes. Further research should consider the socio-relational contexts of the dyad to better understand outcomes.

Relatedly, most participants in studies were white, had previous arts experience, and, in the case of couples, in a heterosexual relationship. There may be differing contexts, mechanisms, and outcomes in different demographics. For example, whether the museum becomes a 'safe place' to return to (theories (o) and (p)) may not simply rely on the context of having capacity return, but also on previous experience with museums. Although museums can be non-stigmatising, non-medical settings (Camic & Chatterjee, 2013), they are also more likely to be attended by people from higher socio-economic groups without a disability or long-term illness (Matthews, Xu, Matusiak, & Prior, 2016). A dyad that has capacity to return but do not feel they 'belong' may not return, or, conversely, the programme may help them to feel they belong, having a greater effect than if they already felt comfortable in the setting.

As well as dyadic context, facilitation was a key factor as both a resource (e.g. theory a) and a context (e.g. theory m). The importance of facilitation as a contextual factor has also been found in a review of visual arts programmes (Windle, Gregory, et al.,

2018) and singing groups (Unadkat, Camic, & Vella-Burrows, 2017) for people with dementia and their carers. Windle et al. (2017) suggest good facilitation requires an understanding of dementia alongside general facilitation skill. Further research could examine the elements of facilitation which contribute to outcomes to enable better training of facilitators.

As most theories developed in this review do not refer to the museum or the type of activities specifically, but rather to the facilitation style, they may have applicability to other activities where the person with dementia and carer take part together on an equal basis, without a focus on reminiscence, and to museum activities in other settings. However, there may be different dynamics involved in taking museum activities into, for example, a care home. When people go to the museum, they are in a space separate from their home/work environment, whereas in a care home they are in their usual care environment. This could have implications for how easily dyads are able to step outside of their carer/cared-for roles, and for facilitation (for example whether the museum or care staff feel they have a lead role). Windle, Joling, et al. (2017)'s visual arts intervention was equally beneficial across different settings, but found some differences in communication and social behaviour, which may have particular significance when considering the impact of including carers.

A synthesis is inevitably limited by the scope of the current literature and this review is limited by a lack of research on the dyadic context and long-term follow-up. As a result, some of the theories are better supported than others. For example, due to few studies focussing on professional carers, nor differentiating between carer types in outcomes when they included both family and professional carers, the theories specifically about them do not have as much evidence as those about family carers or carers in general.

There may also have been useful pieces of grey literature which were missed due to difficulties of locating documents which are not located in formal databases. There is no central source of internal museum reports, so I had to rely mainly on search engines such as Google. However, search engines can give differing results depending on the searcher's location and the current popularity of pages (Mahood, Van Eerd, & Irvin, 2014), which means some reports which could have been discoverable did not appear in my searches. I also searched some individual

museum's webpages, but it was not possible to check the website of every museum, and some internal reports may not be published online. Posting on relevant email lists may have mitigated this to some extent, however potential informants may have moved to new posts or simply forgotten about undocumented reports (Adams et al., 2016).

However, this review acted as a starting point. This is the first review to examine the impact of carers on outcomes in museum programmes for people with dementia. As both positive and negative impacts were found, it is important to consider programmes may not be beneficial for all dyads. The review suggests that to enable positive outcomes for dyads, programmes need: (1) good facilitation which enables all to participate as equally as possible, (2) few caring responsibilities for the carer, and (3) management of carers' expectations of people with dementia's spoken comments or artwork. These recommendations may be applicable to other arts programmes for people with dementia and their carers. Further research examining the dyadic context within museum programmes in more detail may enable more detailed recommendations about who would most benefit and how to facilitate positive outcomes.

The theories developed in this review provided the basis for empirical evaluation of museum programmes.

### 3.8 Conclusion

This chapter detailed a realist review of the literature, examining how including carers in museum programmes may have an impact. Sixteen evidence-informed programme theory statements were developed within four outcome themes, some of which interacted with each other. These theories were used as the basis for an evaluation of museum programmes. The next chapter discusses the methods used for the evaluation.

## Chapter 4 - Evaluation Methods

### 4.1 Introduction

This chapter describes the methods used for the evaluation at museum programmes. It first details the conceptualisation of the study, including how time spent volunteering on a museum programme informed how to fit the methods to the setting. I then go on to describe the data collection methods, research ethics, sampling of sites and individuals, and data analysis methods.

### 4.2 Conceptualisation of the study

#### 4.2.1 Aims and research questions

This part of the PhD aimed to investigate the impact of including carers in museum programmes for people with dementia, test the theories developed through the review of the literature, and create refined theory in relation to the research questions.

Given the gaps in the literature identified in the previous chapter, there were a number of secondary research questions in addition to the main overarching question:

Overarching research question:

How does including carers in museum programmes for people with dementia have an impact on people with dementia, their carers, and the relationship between them?

Secondary questions:

- Dyadic context:

- What is it about the context of the dyad that leads to positive / negative outcomes?
- How socially active are participants outside of the museum activities? (and does this change following attending the museum?)
- How does the dyad type have an impact? (spousal, parent/child, consistent paid carer, changing paid carer)
- How does amount of past experience with museum settings have an impact?

- Does 'shared respite' fluctuate over time?

- Does the amount of caring responsibility the carer has in the group have an impact?

- Is the impact different for different types of activities?

#### 4.2.2 Conceptualisation of the study

Research methods need to be appropriate to the research questions, the setting, the participants, and ethically sound. As discussed in Chapter 2, realist methodology does not prescribe a particular set of methods in evaluation, but does seek to open the 'black box' of the intervention in order to understand causal processes leading to outcomes (Pawson & Tilley, 1997). The methods should therefore aim to investigate participants' reasoning and responses, as well as contexts and outcomes.

Prior to developing the methodology for this study and applying for ethical approval, I spent approximately 10 months volunteering on the dementia-friendly programme at one of my research sites. This enabled me to gain a good understanding of how the sessions worked practically, and what research methods may or may not work in that context. For example, in order to investigate participants' reasoning during sessions, it may have been beneficial to ask them to talk through what they were doing during the session itself, particularly as some may not have had memory for it afterwards. Asking people why they were doing something in a particular way, while they were doing it, has been used successfully in realist research in the past (e.g. Handley, Bunn, Lynch, & Goodman, 2019). The museum sessions were social, but structured and facilitator-led, such as a group discussion on a tour, or a guided art activity. This meant, in the museum session setting, asking a person to describe their thought process would have interrupted the activities for the person or dyad, and would have also likely interrupted the whole group, particularly if that person was the facilitator. My research, if it were obtrusive in this way, may therefore also have disrupted and changed the processes I was investigating. Additionally, it would be difficult to investigate potential negative impacts in a sensitive manner using this method. For example, it may cause embarrassment or additional distress if I asked a carer in front of the group what was about the activity that was causing them upset, or what made them decide to answer a question posed directly to the person with dementia. The ways in which the context of the session impacted the development of the methods is considered throughout the rest of this chapter.

#### 4.3 Data collection methods

##### 4.3.1 More than one approach

Pawson and Tilley (1997; p85) state that, although they are pluralists in choice of methods, realist evaluators should not be "pluralists for pluralisms sake, but that the

choice of method has to be carefully tailored to the exact form of hypotheses developed". I would argue that the context of the setting, as well as the theories to be tested, needs to be considered. Given my experience of volunteering at a number of sessions, I decided that interviews and participant-observation would be the most appropriate methods for the setting, and to test the programme theories from the review. These methods and the reasons for choosing them will be elaborated in the two following sections.

Using more than one data collection method aligns with the realist evaluation approach, beyond Pawson and Tilley's stated preference for pluralism. Although Greene, Caracelli, and Graham's (1989) work on mixed methods concerns combining qualitative and quantitative methods, it also provides a useful framework for combining two different qualitative approaches. They suggest that mixed methods designs have five purposes: triangulation (corroboration of results), complementarity (elaboration of results), initiation (seeking contradiction or new perspective on the results), expansion (using different methods to assess different phenomena of a programme), and development (using the results from one method to inform the other method) (Greene et al., 1989). All of these five purposes could be argued to be a key part of realist evaluation. Realist theory-testing involves juxtaposing, reconciling, and consolidating different pieces of evidence to develop, refine, and better understand programme theories (Pawson, 2006b), which involves the first four of Greene et al's (1989) purposes. Realist evaluation is also an iterative process, in which developing theories are tested in later interviews or observations (Pawson & Tilley, 1997), which also fits with Greene et al's (1989) idea of mixed methods being used for 'development'. Combining direct observation of sessions and interviews (with carers, people with dementia, and museum staff) thus allowed for richer understanding and the inclusion of a wider variety of perspectives to test the review theories.

#### 4.3.2 Interviews

As stated in section 4.2.2, asking questions of participants during the sessions would likely have been too disruptive to the museum sessions. I therefore decided to use interviews, at a time separate to the session, to explore and test the review theories. Interviews are widely used in qualitative research to generate data about participants' motivations, experiences, and perspectives (Gill, Stewart, Treasure, &



Chadwick, 2008). In the case of my research, it would be important to understand people with dementia and carers' experiences within sessions, how these relate to the review theories, and their explanations of ideas and actions which could provide insight into their reasoning (and so theory mechanisms) (Manzano, 2016). Different "actors" have knowledge about different aspects of a system. For example, programme facilitators may have a broad knowledge of (intended) underlying programme theory, successes, and unintended consequences, whereas programme participants may be more attuned to outcomes and how mechanisms may relate to their own specific outcomes (Manzano, 2016; Pawson & Tilley, 1997). This meant it was also important to include the perspective of museum staff and volunteers as well as people with dementia and carers, to understand, for example, why programmes are facilitated in a particular way, and for examples of experiences from sessions in the past or that I could not attend.

Interviewing within a realist framework is theory driven, and the developing theories are used explicitly. Pawson and Tilley (1997) describe realist interviews as having a 'teacher-learner' cycle in which the interviewer teaches the interviewee about their theories, and the interviewee teaches the interviewer about how that does or does not apply in their experience and their own theories. The role of 'teacher' and 'learner' are therefore iterative and the process of the interview refines, refutes, and creates new theory.

Manzano (2016) suggests there are three types of realist interview depending on the phase of the project – theory gleaning (generating theory), theory refining (testing theory), and theory consolidation (further refinement of theories supported in theory testing). Theory can be put to interviewees on a continuum of explicit to implicit theory-testing (Jagosh, 2018b). Explicit theory testing states the theory directly. For example, a question to a staff member explicitly testing theory may be:

*There's an idea that carers can sometimes do too much for the person with dementia on the programme, which means the person can't get as much out of the sessions as they could. Do you think there's any truth to that?*

*Has this been an issue in sessions you've facilitated?*

*What happened? Can you talk me through an example?*

Implicit theory testing questions are more open-ended but with a focus on theory. For example:

*You said sometimes carers speak more in the group than people with dementia, can you tell me a bit more about that?*

*Are there times it happens more and times it happens less?*

*What is it about the times it happens more/less than you think makes a difference?*

*Can you talk me through an example of when it happened more/less?*

Other realist studies have found people can tend towards agreeing with theory put to them (e.g. Mukumbang, Marchal, Van Belle, & van Wyk, 2019). To mitigate this, I specifically asked for examples where it applied to their experiences and for examples where it did not (Mukumbang et al., 2019). I also tried to flatten potential power dynamics (and so help people feel more able to disagree if they wish) by ensuring I introduced each interview by explicitly stating that I was interested in the *interviewee's* experience and insights, due to their expertise from their job role or attendance on the programme. I also said that I may share ideas from some previous research, but that what I was interested in was *their* opinion on the idea, and that they could agree, disagree, or say they were not sure. This included considering my word choices when explicitly sharing theory to give an objective tone (such as using "There's an idea that..." rather than "Research says...").

As it was possible some of my interviewees may have no memory for specific aspects of the programme at the time of being interviewed, I also planned to ask questions which were indirectly related to the theories being tested. For example, in a conversation about talking in groups more generally, asking "what is something other people could do to help you talk as much as you wanted in the group?" or "what makes it more difficult for you to talk in a group?"

My interviews included both theory gleaning and theory refining and took a semi-structured approach. Interviews started with a broad opening question, such as "what is your role on the programme" (for museum staff) or "how long have you been going to the sessions at the museum". I started with more open questions to understand general experiences, and used those experiences to ask more specific questions related to theories under test (theory refining) or to generate new theory

(theory gleaning). The follow-up questions in the examples of explicit and implicit theory-testing were ways of doing this, such as asking for examples (and counter-examples) and what it was about a particular element that they thought made the difference. After going down a particular path of follow-up questions, I asked an open question again to gain different answers and a potential new line of questioning. I regularly summarised what I thought the interviewee had said and asked them if my understanding was correct, and asked them to explain and clarify further (termed 'conceptual refinement process' in Pawson & Tilley, 1997).

As there were a large number of theories from the review, as well as developing ideas during the evaluation, it was not possible to present every theory to every participant. Manzano (2016) suggests that different people may be able to offer insights on different aspects of a programme, particularly dependant on the difference in their role (such as programme participant or policy maker). As all the theories being tested included some element of how the programme was facilitated and the interaction between the dyad, the group, and/or the facilitator, I did not prioritise theories by participant type as I felt all interviewees would be able to comment on some aspect of each, if it had been part of their experience. I was led by the experiences the interviewee discussed in answer to open questions and also specifically asked about theories where there was conflicting or little evidence.

All interviews with museum staff were conducted one-to-one, but people with dementia and carers could choose whether they wanted to be interviewed together or alone. As some of the theories from the review concerned the relationship between the dyad, individual interviews would allow them to feel more able to talk freely about their caring relationship. However, interviewees were not required to be interviewed alone if they preferred not. Ideally, I would have interviewed people multiple times and used a combination of joint and individual interviews as this may give a more holistic view of relationship factors (Wadham et al., 2016), but unfortunately this was not possible due to recruitment difficulties.

If participants preferred a joint interview, I needed to consider that this may prevent them from discussing difficulties in their relationship or that one person may dominate the conversation (Pesonen, 2011). Alternatively, it was possible one of the dyad may have described their difficulties in the relationship in front of the other

person and cause them upset or created difficulties once the interview was over. In joint interviews, I tried to demonstrate that I valued both of their perspectives equally by making eye contact with both and asking questions of both. If only one person answered a question I asked it again to the other person directly, and if one person was regularly not answering questions I asked more direct questions of them rather than to the dyad as a whole. The information sheet included sources of support and I directed interviewees to it, regardless of whether there was any distress (there was none apparent in any of my interviews), as well as my contact details should they have any questions after the interview. I also considered in my analysis that the context of the data was different in shared interviews compared to individual interviews. Unfortunately, I conducted very few interviews with people with dementia and carers so it is not possible to ascertain if there was a difference between evidence from shared and individual interviews.

All interviews were recorded and transcribed verbatim. Example interview schedules are given in Appendices 3 (museum staff member), 4 (dyad interviewed together), 5 (carer interviewed alone), and 6 (person with dementia interviewed alone).

#### 4.3.3 Participant-observation

What people may say may differ from how they act, or how their policies are enacted (Maxwell, 2012; Mays & Pope, 1995). For example, a programme facilitator may state that they ensure the sessions give carers respite from their caring roles, but then within the session the carers are actually heavily relied upon to provide support (and care) for the person with dementia they attend with. Observation allows for direct learning about how dyads interact in the session, how facilitators manage sessions, and the way sessions are run. It also allows inferences to be made about participants' reasoning, tacit understanding, and "theory-in-use" (Maxwell, 2012).

There are differing levels of participation in observation, from 'complete participation' in which the researcher participates but their role as 'researcher' is covert, to 'complete observer' in which the researcher does not participate or interact with participants but simply observes (Gold, 1958). Most observational research falls somewhere between these extremes (Hammersley & Atkinson, 2007). I attended programme sessions at each museum site, with the balance between my position as an observer and as a participant determined in advance through discussion with the programme's facilitator or manager about what would be most appropriate for their

sessions. Every programme manager stated that a non-participatory, direct observation approach may have made participants feel uncomfortable as the sessions are social sessions where interaction and discussion was encouraged. My participation never involved leading or having responsibility for sessions, but was usually a minor volunteer role such as helping staff set up the room, make refreshments for participants, and carrying stools during tours. I also participated in the activities, but tried to balance this with my role of observing the session and existing dynamics. For example, when a question was asked to the group as a whole about a particular artwork, I did not give my opinion without being asked directly, but I often chatted to participants as we walked between pieces (led by whatever they wanted to talk about, and not me asking questions relevant to my research) and observed others' interactions when I was not talking to another participant. My role as researcher was always overt, which will be discussed later in the chapter when considering research ethics.

Depending on the nature of the session and my level of participation, I wrote fieldnotes during the session or immediately afterwards, with clear distinctions between what was observed and my reflections and analytic notes (Hammersley & Atkinson, 2007). In most cases, fieldnotes were written following the session as it was often not possible during the session either due to the activity (such as art-making) or due to being unable to write notes discreetly because of the way the session was set up. Inevitably, there were differences in the level of detail in fieldnotes depending on whether they were written during the session or immediately afterwards, and the size of the group. For example, in one session, there were only two dyads present which resulted in very detailed notes about each dyad's interactions. However, during another session with sixteen participants I was unable to capture the same level of detail about individual dyad interactions, and instead wrote more broadly about each dyad's behaviour during the group.

Writing fieldnotes is not an objective act – fieldnotes are constructed by my decisions on what to include or not include, my theoretical priorities, and my experiences (Emerson, Fretz, & Shaw, 2011). It was therefore important to take a reflexive approach in both the writing of fieldnotes and in their analysis. This will be discussed further in Chapter 8.

As well as differing levels of participation, observation research may be overt (the researcher is open with participants that they are conducting research) or covert (the researcher conceals from participants that they are conducting research), though some argue this is not a binary but that all research falls on a continuum (e.g. Hammersley & Atkinson, 2007). Although covert observation may mitigate the impact of participants altering their behaviour due to knowing they are being observed, it also has a number of ethical implications, particularly in terms of informed consent (Sandiford, 2015). Given the ethical implications, many ethics committees state that covert research should only be conducted in situations where the data cannot be gathered overtly, and often only when that research is also addressing an important issue or matters of social significance (e.g. British Sociological Association, 2017; ESRC, 2020). There was no reason why my research should be covert, given other methods were available to me to collect the data. Additionally, as discussed in Chapter 2, a realist approach views context as a fundamental part of the causal process, so does not attempt to ‘control out’ context, but account for it as part of analysis (Sayer, 2010). The researcher, and their impact on the research, is also viewed as ‘real’ and as having real affects (Maxwell, 2012), so is a part of the overarching context for the research. Therefore, my presence cannot be ‘controlled out’ by making the research covert – it simply has a different impact. My impact as a researcher on the findings is discussed further in Chapter 8.

My participant-observation was overt, in that I fully informed all participants of my role in sessions and the nature of my research (explored further in the following section on research ethics); although it could be argued to be on a continuum of covert to overt (Hammersley & Atkinson, 2007), given I did not write fieldnotes if this could not be done discreetly. However, this was done mainly to ensure session participants could not see what was written, particularly about other participants, rather than to conceal my role as researcher.

#### 4.4 Research ethics

Research ethics includes two main dimensions – procedural ethics (approval of procedures and materials by an ethics committee) and practical ethics (situations that arise in the doing of the research which may or may not have been addressed in procedural ethics) (Guillemin & Gillam, 2004). The issue for ethics-in-practice is that it is not possible to predict or cover all possible human behaviour that may arise

during the course of research work, and there are a number of subtleties in, for example, the boundary between participant and observer which can be difficult to fully address during a procedural ethics application.

As mentioned in the Preface to this thesis, and discussed further in Chapter 8, a researcher's own positioning in relation to the research is important in understanding the perspective the research takes and the results themselves (Malterud, 2001). This reflexivity is also key in research ethics – both in developing ethical procedures and responding to 'ethically important moments' (Guillemin & Gillam, 2004) arising which may not have been considered during an ethics committee application (and so there is not a standard procedure for responding to them). Through considering the context and purpose of the research, my potential participants (and non-participants), and my position in relation to the context and participants, I was able to consider broadly what ethical issues may arise for my committee application (such as the potential to cause distress during interviews), as well as a need to be aware of and respond to issues which may arise in the moment (such as the nature of and reason for that distress). My research was relatively low risk as, aside from interviews, I was not asking participants to do anything they were not already intending to do. However, it is important to acknowledge that even 'low risk' research can have a high impact on an individual for a number of reasons, from the interactions between researcher and participant, to consent procedures, to how the research is reported (Orb, Eisenhauer, & Wynaden, 2000).

This section therefore details my ethical considerations for how and why I designed the research in the way I did, as well as procedures, such as gaining consent, and procedural ethics approval from an ethics committee.

#### 4.4.1 Ethical considerations

My experience as a volunteer for ten months prior to the start of the evaluation gave me insight into the ethos and facilitation style of these programmes, as well as the way programmes are run and how my research may have an adverse impact on the sessions themselves or session participants. There were a number of issues that I needed to take account of when developing my research procedures.

a) The way sessions were set up and run, and burden on participants

As discussed in the section on participant-observation previously, the programmes were social sessions where interaction was encouraged, so a person in the group actively not participating and simply observing would likely be disruptive. I actively took part in sessions, most often as a volunteer, to minimise this potential disruption. However, during the consent process at the start of each session, it was always made clear that I was also a researcher so that the research was an overt, rather than covert, process.

Relatedly, making fieldnotes would have been disruptive while actively participating, such as during art-making activities or when making participants their refreshments, for example. As stated in section 4.3.3, fieldnotes were mainly written after the session, rather than during, for this reason, or because the way the session was set up meant it was not possible to write notes without being overlooked.

It may have been useful to collect demographic information about participants of sessions or ask them to fill in short 'in-the-moment' scales, particularly for those who have little memory for the session after the fact. The stated aims of programmes included to not differentiate between carers and people with dementia, and they did not specifically ask or talk about dementia. My doing so could have potentially changed the dynamic and ethos of sessions, particularly when considering ideas such as shared respite. Additionally, although research participants may have perceived benefits in taking part in research and actively wanted to share their stories, it could also have been a burdensome process due to the time it would have taken or the re-telling painful stories, for example (Ulrich et al., 2012). Including written questionnaires would have been adding additional elements to the sessions, and I wanted to keep the burden of form-filling to a minimum, particularly as many programmes included forms of their own (registration form at the start and evaluation form at the end). The only element I added was the consent process for my research at the beginning of the session, as it was necessary (though of course this could have had the effect of disrupting the session dynamic in itself).

During my period of volunteering, I noticed that often session participants could be quite fatigued at the end of the session, some even needing to leave early. It may have been useful to schedule interviews immediately after sessions, both so the



memory of the session was fresh and for practical reasons. However, I told participants that interviews could occur at any mutually convenient time, and did not have to happen at the same time as the museum session, to account for this fatigue. This also placed greater importance on planning interview questions for when the person may have limited or no memory for the programme (as described previously in section 4.3.2 on interviews).

#### b) Capacity to consent

Dementia may impact a person's capacity to consent, but does not in itself mean a person has no capacity to consent at all (McKeown, Clarke, Ingleton, & Repper, 2010). I considered capacity according to the Mental Capacity Act (The Department of Health, 2005) and as such was viewed as situational and fluctuating as symptoms fluctuate. Introducing myself to dyads individually, rather than to the group as a whole, meant I could have individual discussions with people and informally assess their capacity to consent. This was a judgement made using my previous clinical psychology training and consideration of the terms of the Capacity Act in that the person must be able to:

- Understand the information relevant to the decision;
- Retain the information for long enough to use it;
- Use or weigh the information;
- Communicate their decision.

When a person appeared unable to do one or more of the above, or it was not clear, they were excluded from the research. However, as capacity is situational, people may be able to consent to some aspects of research but not others, for example they may have capacity to consent to the participant-observation but not to interviews. Capacity was thus considered separately for each research activity. Additionally, informed consent was not considered a 'one-off' but as an ongoing process (Dewing, 2007). As such, all participants (including those without dementia) were re-consented at every contact to account for potential fluctuation in symptoms or opinions (written at first contact, and verbal at subsequent contacts for the same research activity).

In order to maximise the capacity of people with dementia to consent, the information sheets were written in clear, accessible language. They were not just handed out, but were discussed with the potential participant in case of reading or processing difficulties, and to ensure the information was understood. As will be discussed later in this chapter and in Chapter 8, there were some elements of the information sheets which had to be written in, what I argue, was inaccessible language due to the requirement of the Ethics Committee. Relatedly, the information sheets and consent forms were quite long given the amount of information that needed to be included and the format required. Both of these issues may have unfortunately limited the capacity for some potential participants to consent.

As both the symptoms of dementia and a person's capacity to consent can fluctuate, it was possible that a person could lose (and re-gain) capacity over the course of the research. As part of the consent process, people were asked if they gave approval for me to use their data following loss of capacity. If they did not give me prior approval and on a subsequent contact they had appeared to have lost capacity, their data was destroyed. If the person did give approval for their data to be retained, lost capacity, and then regained it, they were re-consented. If they decided at that point not to continue in the study, they could choose to have their data destroyed, regardless of whether they had previously given consent.

A challenge in considering ethical procedures was what to do if a person did not have capacity to consent to the research – did this mean they did not have capacity to consent to my presence in the sessions and so I could not be present in any session with a person lacking capacity? I spent some time discussing this issue with my supervisors and the chair of the University of Exeter Medical School Research Ethics Committee (UEMS REC). They advised that I could treat those who cannot give consent in the same way as those who do not – to approach them as a dyad (rather than individuals) and take my cues from them if they are happy for me to stay in the session and assure them that they will not be included in any data. Essentially, this was separating the consent to take part in the research from consent for me to be in session, so the person did not need to have capacity to understand and weigh up the information about the implications of taking part in the research, only that I am doing some research but they are not included in it.

### c) Building relationships

I did not know who was attending the session in advance, and some people come for just one session rather than regularly. This meant I could not build a relationship with people prior to starting the research and could not always send research information in advance. I asked the museum to give a short summary of my role to people when they rang to book so they would know I would be there (though this was not possible with people who booked online tickets). I also ensured I spoke to each dyad individually about the research and my role in the session. I did this individually rather than to the group as a whole so that I could ensure each person understood, assess capacity to consent, and allow them to ask any questions (as some people find it more difficult to ask questions in a group setting). It also helped me to briefly build a relationship with each participant in a session.

I also ensured I dressed informally (to match the staff and the participants) and did not introduce myself as an 'expert' but instead as someone who was genuinely interested in how the session worked. As discussed above, the sessions were social and the research was overt, but an issue for ethics-in-practice was how much personal information to share, much like finding the balance between being an observer and a participant. In sessions, participants often talked to me about a variety of topics, as they did with everyone in the group, from the general (the weather) to the personal (do you have/want children). I took the approach of treating these conversations as the human interactions they were – being overt about my role as a researcher in the situation but disclosing personal information at a level I was comfortable with and felt appropriate for the situation and the person to whom I was talking.

Although no participant asked me for advice about dementia (perhaps because dementia was not explicitly discussed in the sessions or they did not see me in that role), I had planned to signpost (using the information sheet as a useful resource they could take away) as a way of addressing their question without stepping beyond the boundaries of my role or dismissing them. Equally, although I have training as a clinical psychologist, I planned to use my experience in dealing with acute distress should it arise in interviews, but not move beyond this to a therapy/advice role and signpost to where they may find further support.

#### 4.4.2 Formal ethical approvals

I received ethical approval for the study from the UEMS REC (application number: 25/09/186). The approval certificate can be found in Appendix 7.

I decided to go through the UEMS REC rather than the NHS REC (HRA) partly for pragmatic reasons – it would take less time to go through the UEMS REC, my research was a better fit there, and they were able to give me all of the approvals I required as I was not working with NHS staff or sites. I did make a mistake in not realising that the inclusion of social-care-funded residential homes can only be approved by the HRA, so social-care-funded care staff and people with dementia had to be excluded from the research. Many residential homes are private, but residents can be wholly or partly funded through social care. It was unrealistic to expect people with dementia or their professional carers to know exactly how their care was funded, nor that they would be willing to disclose this to a stranger in the public setting of the museum sessions. This therefore meant the majority of professional care dyads had to be excluded as I could not be certain if the person with dementia's care was funded through social care.

Between submitting my required amendments to the UEMS REC and their approval by the chair, some rules around what university RECs could and could not approve changed. My original proposal was to include people who lacked capacity to consent if their carer had capacity to consent on their behalf (and the person with dementia assented). The new rules meant that this would require HRA approval, rather than university REC, so potential participants who lacked capacity to consent were excluded.

Some of the REC's requirements did affect my ability to conduct the research in some settings. The new rules around GDPR and the REC's interpretation meant I had to include a paragraph stating the university's position and contacts regarding GDPR, and in the consent forms include a separate line to initial for each separate use of data, for example one for published reports and another for public engagement activities. This meant that both consent and information sheets were longer than preferable. I was also not allowed to re-write the GDPR, or other required paragraphs, into more accessible language, which at times reduced the capacity for a person to consent who may have had capacity otherwise. I verbally explained the information in the sheets to ensure potential participants understood,

as many did not read the sheets or were confused by the GDPR section. Additionally, as some people struggled with reading large volumes of text or had a reduced processing speed, the long information sheets and consent form felt like adding a burden to participants within a method that was designed to be as unobtrusive as possible. In fact, site 2 did not give permission for me to conduct the observation part of my research during the sessions as they felt this additional burden would be too much.

#### 4.4.3 Procedures

The following sections detail the recruitment procedures of different participant types for the session observations and interviews. All information sheets included a section on sources of further support, such as general and dementia-specific helplines and advice to contact their GP.

##### 4.4.3.1 Observations

Any staff member or session participant who did not consent to, or could not be included in, the research was not included in any fieldnotes. As discussed in section 4.4.1, consent to participate in the research was separate from consent for me to be present in the session. If a participant was excluded, or did not want to take part, I still explained my role in the sessions as I would for a potential research participant and ensured they were happy for me to be present in the session, reiterated that I would not be including them in any notes, and gave them the opportunity to ask any questions. This was a verbal consent procedure, rather than the written consent required to participate in the research. If any person did not want me to be present, the session was not observed (though this did not occur).

##### a) Museum staff

Information sheets were sent to all staff and volunteers on the programme in advance of any sessions being observed, including an offer to answer any questions or concerns, via my contact at the museum (usually the programme lead). When attending sessions, I reiterated why I was there and that staff could request that I did not attend at any time without any penalty to them, and I sought written or verbal consent (written for the first session mutually attended; verbal for subsequent sessions). Information sheets and consent forms for staff included both the session observation and interviews. These can be found in Appendix 8 (information sheet) and Appendix 9 (consent form).

#### b) People with dementia and carers

Site 2 was the only programme which did not advertise publically, ran on the museum's closure day, and tried to create a regular group that attended all sessions, so did not allow participants to attend without pre-booking. At site 2, I gave the participants research information in advance (via the programme lead), which included my contact details and an invitation to contact me with any questions beforehand. All other programmes did not recruit all participants in advance and allowed people to attend without booking, so it was not always possible to send information in advance. In this case, participants were given brief information by museum staff when they booked for the session, and given my contact information and an invitation to contact me to explain the research in more detail or ask any questions.

At all sites, at the beginning of every session as participants arrived, I introduced myself as a researcher to each dyad individually (rather than to the group as a whole) and reiterated why I was there, and that they did not have to take part and could also object to my presence. Written and verbal consent for the observation was then sought. People who were assessed as not having capacity to consent (or where I was uncertain) were not included in the research. No fieldnotes were made on any dyad who did not or could not consent. Dyads who gave written consent were verbally re-consented at the beginning of every subsequent session observed. The information sheet about the session observation for people with dementia and carers are given in Appendix 10; the consent form is given in Appendix 11.

#### 4.4.3.2 Interviews

Interviews were audio-recorded using a portable dictaphone and uploaded to a password-protected folder on the university's secure server immediately after the interview. The recording was deleted following transcription. Any identifying information (of the interviewee, others, or the museum site) was removed during transcription. The same or similar staff roles at different sites often had different names, and so unique role names may reveal individuals or sites. Within transcripts and this thesis, I have therefore standardised the names of roles across sites for anonymity. Standardised role names have been used as follows:

- Manager – leads the programme

- Facilitator – leads a session. Some staff members may both lead sessions and facilitate sessions, and are referred to as ‘manager-facilitator’
- Support staff – provide support in the session and are employed by the museum
- Volunteers – provide support in the session but are volunteers rather than museum employees

Procedures for recruiting participants to interview:

a) Museum staff

Museum staff and volunteers involved in the programme were recruited through information sheets circulated through the named contact at the museum and at the end of sessions I attended. If staff agreed to take part, written consent was sought at the beginning of the interview, including whether they would be happy to be contacted for a follow-up interview or for other parts of the research.

b) People with dementia and carers

If they gave permission to receive information, people with dementia and their carers attending sessions that I also attended were given information sheets to take away at their first session, and followed-up on their next. If a research site was still in contact with previous participants of their programme, the museum staff asked previous participants if they were happy for me to send them information about interviews, including my contact details and an opportunity to ask any questions about the research. If a dyad agreed to an interview, written consent was sought at the beginning of the interview, including whether they would be happy to be contacted for a follow-up interview if required. If a person did not have capacity to consent to being interviewed, they were not interviewed. The information sheet about the interview for people with dementia and carers is given in Appendix 12; the consent form is given in Appendix 13.

#### 4.5 Sampling museum sites

##### 4.5.1 Sampling strategy

Within a realist framework, the sampling of sites and individuals is ‘real’ and has real effects on the findings of the research. A description of the sample is not enough; the mechanisms that generated that sample must be made as transparent as possible – in other words, the choices I made and external powers such as gatekeepers and

funding (mechanisms) that led to the sample (outcome) should be made clear (Emmel, 2013). This means the assumptions underlying, and context around, the sample can be better understood, and therefore the impact of the sample on the findings and conclusions of the research can be better understood (Emmel, 2013).

The type of museum programme I was interested in was often dependent on external funding, which inevitably meant where programmes were running at any particular time varied. I aimed to sample museums purposively and include a range of contexts (such as how the programme is run or type of museum), but adopted a pragmatic approach considering the programmes that were running during the fieldwork year. I initially started with two museum sites, and then expanded to six following difficulties in interview recruitment. However, this expansion allowed me to include a wider variety of museums and types of sessions, which ultimately strengthens the work.

#### 4.5.2 Anonymous descriptions of sites with levels of access

Anonymised information about the sites, their sessions, and the level of access I was granted is given below.

##### *Site 1*

Site 1 is a local authority museum in a city in the southwest with 250,000 visits a year.

Site 1 offered monthly sessions for people with dementia and carers, which cost between £5 and £15 per person. The sessions were loosely based around the seasons, and each month focused on either a tour, object-handling, or art-making. Each session started with refreshments and lasted two hours. At the end of the session all participants were given a short evaluation form. They have been offering the sessions since 2013.

I had permission to conduct participant-observation within sessions and to recruit participants and staff for interviews.

##### *Site 2*

Site 2 is a local authority museum in a city in the southwest with 500,000 visits a year.



Site 2 offered four sessions over seven weeks (sessions in weeks 1, 4, 5, and 7). There was no cost for attendance and participants' travel was paid for by the museum. Participants were recruited via local dementia charities and not advertised publically. Each session started with refreshments and lasted two hours. Each session had a different focus – 1: textiles related to one painting then a self-guided tour; 2: short talk about one painting then a self-guided tour with some mini-talks; 3: (recorded) classical music and linked responses to paintings; 4: found poetry activities and then poetry in response to one painting. At the end of the session, all participants and staff were given a short evaluation form. After each session, the staff had a half-hour reflective meeting to discuss the session. They have offered one other short series of sessions in 2018.

I had permission to conduct participant-observation in the staff meetings following the sessions but not the sessions themselves. I was initially given permission to recruit session participants for interviews but this was withdrawn when the museum decided to conduct their own evaluation of the programme (which included interviewing participants). I did have permission to recruit staff for interviews.

### *Site 3*

Site 3 is a local authority museum in a city in the Midlands with around 830,000 visits a year.

Site 3 offered free monthly sessions. Each session included a short tour followed by object-handling related to the theme of the tour, and lasted one and a half hours. Tour themes related to section of the main gallery used, such as local history and childhood toys. At the end of the session, only participants with dementia were given evaluation forms, and volunteers were given different evaluation forms after the session. The sessions started in mid-2019.

I had permission to conduct participant-observation in sessions and to recruit participants and staff for interviews.

### *Site 4*

Site 4 comprises two unoccupied royal palaces (sites 4a and 4b) run and funded by an independent charity in a large city in the southeast. Site 4a has approximately 1 million visitors a year, and site 4b has 230,000 visitors a year.

Each session started with refreshments, and then included a tour followed by an activity related to theme of the tour. Themes related to stories about particular residents of the palaces, and activities included music-making and object-handling. Each session lasted two hours. Site 4 has offered sessions since 2013, with this regular programme running since 2016.

I had permission to conduct participant-observation in sessions and to recruit participants and staff for interviews.

#### *Site 5*

Site 5 is a local authority museum in a large city in the southeast with around 310,000 visits a year.

The sessions lasted one and a half hours, and included a tour followed by refreshments and object-handling related to the theme of the tour. Themes related to local history collections being toured. At the end of the session all participants (including volunteers, though not museum staff) were given an evaluation form. The sessions started in mid-2019.

I had permission to conduct participant-observation in sessions and to recruit participants and staff for interviews.

#### *Site 6*

Site 6 is a national art museum in a large city in the southeast with around 4 million visits per year.

The sessions lasted two hours. They started with refreshments which were then followed by a tour. Tours were conducted by regular museum guides with extra training on dementia, and included four to six objects from various parts of the museum, which may or may not be linked by a theme. These sessions started in mid-2019, but the site had previously hosted a Cognitive Stimulation Group (Spector et al., 2003) for people with dementia in early 2019.

I had permission to conduct participant-observation in sessions and to recruit participants and staff for interviews.

### 4.6 Sampling Individuals

#### 4.6.1 Overall inclusion/exclusion criteria

People with dementia and carers were eligible for inclusion if:

- one of the dyad self-described as having a diagnosis of dementia;
- they both attended the programme at the time of the fieldwork, or had previously attended the programme.

The dyad were excluded if:

- one or both people in the dyad lacked capacity to consent;
- one of the dyad did not attend the programme (i.e. if a person with dementia attended with a paid carer and not their spouse, the person with dementia and their paid carer are the dyad eligible for inclusion, not the person with dementia and their spouse);
- the professional care was paid for by the NHS or social care providers, rather than privately.

There were no exclusion criteria related to the type of carer (i.e. whether they were paid or informal/family carers).

Staff and volunteers were eligible for inclusion if:

- they took part in the programme within the sessions or as part of programme development.

Staff and volunteers were excluded if:

- they had no input or experience with the programme under evaluation.

#### 4.6.2 Observations

As all attendees were part of the session being observed, and numbers were relatively low (maximum of 15), all attendees of museum sessions were approached about the research if they were eligible to be included. There were a number of occasions where I attended a session and it was not possible to conduct the observation part of the research – usually because all attendees arrived as a large group and it was not possible to consent everyone prior to the session, or because no one in the group was eligible to participate.

#### 4.6.3 Interviews

I had intended to recruit purposively, including a range of different dyad types and levels of experience with the programme, however there were a number of difficulties in recruiting people with dementia and carers in particular. After having volunteered on the programme at one of my sites for approximately 10 months prior to beginning the evaluation, I felt I had a good idea of the demographic composition of the sessions. For this reason, I did not think needing to exclude professional care dyads

who were funded by social care would adversely impact the research as the majority of people attending were family dyads living at home. However, by the time I started my evaluation, many of the regular attendees had stopped attending (reported to the museum to be due to a progression in their dementia), and the demographics of the group changed. Care homes booked as a group at many of the sessions at my sites, which meant they were the largest type of attendee but could not be included. Additionally, as many people did not attend regularly, it meant I could not follow up with them to see if they were willing to be interviewed. This was a particular problem at sites which had monthly sessions, because if they missed one session or more it would be months before I saw them again and I would need to start the process of informing them of the research again. Sampling for interviewing, therefore, aimed to be purposive, but became more pragmatic and all eligible dyads were invited for interview.

#### 4.6.4 Numbers at each site

Table 2 gives detail on the number of sessions attended, sessions included in the research, and number of interviews conducted.

*Table 2. Number of sessions attended and participants included at each site*

	Session observations		Interviews		
	Number of sessions attended	Number of sessions in which fieldnotes were possible	People with dementia	Carers	Staff / volunteers
<b>Site 1</b>	6	5	0	0	2
<b>Site 2</b>	4	4 (staff meetings only)	0	0	2
<b>Site 3</b>	4	2	0	0	1
<b>Site 4</b>	6	3	2	2	2
<b>Site 5</b>	5	3	0	0	1
<b>Site 6</b>	3	2	0	0	4
<b>TOTAL</b>	<b>28</b>	<b>19</b>	<b>2</b>	<b>2</b>	<b>12</b>

## 4.7 Data analysis

### 4.7.1 Analysis methods

As described in chapter 2, realist evaluation seeks to understand how and why outcomes occur, rather than simply whether they occur. The 'output' of realist work is evidence informed theory in relation to the research questions, understanding

causation in terms of context-mechanism-outcome (CMO) configurations (Pawson & Tilley, 1997). It then follows that analysis needs to understand and evaluate the data in terms of these ideas.

The methods used to analyse the evaluation data took the same overarching approach as the methods used to analyse data in the literature review. Very broadly, this meant the analysis was inductive (creating theory from the data), deductive (testing theory with the data), and retroductive. As discussed in Chapter 3, retroduction, in realist terms, is the process of inferring or identifying underlying causal mechanisms, which includes inductive, deductive, and abductive thinking (Sayer, 2000). I also used a combination of connecting and categorising strategies so that the connecting analysis considers the context and connections which may not have been included in the categorising analyses (Maxwell, 2012), as described further in Chapter 3.

The realist framework was used to refine, refute, and create new theory in relation to the research questions and was an iterative process throughout the study, rather than in a clearly defined period after all data was collected. I applied this framework to my data analysis through the process below. Though this is described in a linear manner, it was an iterative process moving back and forward between the levels of the data, the coding, and the theory.

- a) I coded data (such as an interview transcript) for theory in relation to the impact of carers, (which may be in support of theories generated in the review, against those theories, or new theory), for individual potential contexts, mechanisms or outcomes, or for partial CMOs (such as context-outcome, or mechanism-outcome).
- b) I created documents for each code which included the coded extracts and their origin (research site, participant type, and data type). Within each code document, I annotated extracts for explanatory content, and how different extracts may connect with each other. An example of a code document is given in Appendix 14.
- c) From these annotations I created 'mapping' documents. These included one document for each theory with any data relevant to that theory, and documents for explanatory content, outcomes, and ideas not included in the

review theories. These were also annotated with theorising and how they may have linked with other mapping documents or theory. An example of a mapping document is given in Appendix 15.

- d) I made cross-data comparisons of coding, both within the same data type (such as comparing interviews) and between different data types (such as between interviews and fieldnotes). For example, comparing how museum staff explained a particular dyadic interaction with what was observed in sessions, or how different museum staff explained the same kind of interaction.
- e) I also made cross-data comparisons of coding between research sites. This was not a formal case study approach as data was limited at each site, but was to ensure that how the data was examined considered the overarching context of the programme it was taken from (which may not have been apparent in the data itself, such as museum size or how participants were recruited).
- f) Additionally, as one of my research questions was interested in whether shared respite fluctuates over time, I also conducted 'dyad analysis' wherever possible. Where a dyad had appeared in more than one transcript (such as in two or more session fieldnotes and/or were also mentioned in an interview), I took the extracts from those transcripts and brought them together in one document (separate documents for each dyad). I then coded the document in relation to how they were using the programme, for example whether they were doing activities together or separately, or whether and how much museum staff took on a caring role. I then created narrative summaries for each dyad on how they used the programme, including contextual factors related to caring such as whether one of the dyad needed support to use the bathroom or used a wheelchair.

Comparisons at both the level of the data and level of the themes/codes were completed by adapting Pawson's (2006) guide for realist reviews, meaning evidence was juxtaposed, adjudicated, consolidated, and situated to refine and develop theory. Extracts of data were also always considered within the context of the transcript they were taken from to ensure contexts, mechanisms, and outcomes were assessed in configuration (Pawson & Manzano-Santaella, 2012). As illustrated

in the review, the function in explanation of elements or ideas may be different for different theories, such as shared respite being an outcome in one CMO but a context in another.

#### 4.7.2 Rigour & reflexivity in analysis

As I was using the analysis to test the theories generated in the review, as well as generate new theory where appropriate, it was important that reflexivity and rigour underpinned my analysis, to ensure that I was not discounting evidence that did not support the theories or using an approach that ensured my prior conceptions were supported (Hammersley & Atkinson, 2007).

Although I was testing theory, I took the approach of not creating codes in advance to try to mitigate the risk of constraining myself to my preconceptions. Instead, I first coded line-by-line with the question of “what is the impact of including carers”, using my previous work as a useful language (such as the concept of ‘shared respite’) but being open to new or contradictory ideas in the data. Only then did I compare the data to the review theories, and consider how it may or may not have supported them or where new theory was apparent. As above, I then moved between the data and the theory iteratively.

All interview transcripts and session fieldnotes were read multiple times to ensure familiarity with the data, and when new codes were created I went back through older data to check for the new code. As the data was collected and analysed over a year, and my thinking and developing ideas may have changed between the beginning and end of the fieldwork period, I also re-coded unannotated transcripts towards the end of the fieldwork that I had previously coded at the beginning. This allowed me to check for internal validity and to mitigate any recency effects (where ideas developing from sites visited in the later stages are given greater importance simply because they were most recent). Nothing significantly different was found when I compared my re-coded data to my original codes, other than a refinement of language and more detail in describing ideas. I had been revisiting older data regularly to check for codes developed in later data, which likely also helped to reduce recency effects.

Multiple coders are often used in qualitative research to show inter-rater reliability (and so evidence of rigour of the analysis) (Yardley, 2007). The nature of PhD

research means that it is conducted as an individual, rather than within a team, which makes using multiple coders practically difficult. However, having high concordance between coders may actually measure how well all coders are trained to code in the same way rather than 'objectivity' (Braun & Clarke, 2019b). This fits with the ideas within a realist framework, as described in Chapter 2, that the researcher's perspective is partial and constructed and this cannot be 'controlled out' (Maxwell, 2012). The value of multiple coders may instead lie in the discussion of disagreements and alternative explanations for the data (Barbour, 2001). This consideration of the possible alternatives was key for my data, as I did not want my pre-existing theory to inadvertently bias my interpretations. Rather than multiple coders, I sought opportunities to have these discussions and disagreements.

- a) Raw (anonymised) data was taken to a qualitative analysis group for interpretations to be shared and discussed. The group were not given my coding, ideas, or theory before they examined the data themselves, and were just given my overarching research question about the impact of including carers. Once they individually examined, for example, an interview transcript, and completed their own rough coding, we had a whole group discussion about our ideas linked to the data. This provided outside insights on the data and a process of sense-checking on my own interpretations.
- b) I worked on my PhD from museum offices at site 1 one day per week. Though I did not share data with staff in the office, I did speak to them regularly to check my assumptions about the broader museum context. I asked these same questions of staff when I visited other museums to check whether particular issues were the same or different at different sites. This helped me to place my thinking and developing theories within the broader of museums, which was not an environment or industry I was familiar with prior to this research.
- c) The iterative nature of realist work meant that my developing theories were regularly tested in session observations and interviews. This was particularly important in interviews, as I could explicitly put my interpretations to those in the field as they were developed, and continue to refine them.

Detailed considerations about reflexivity, my positionality, and my reflections on how my positionality may have impacted this research, including data analysis, is given in



Chapter 8. This includes discussion of my strategies for reflexive practice during the research, such as how I used my research diary as a mediator.

#### 4.8 Conclusion

This chapter detailed the methods used for the evaluation, including the conceptualisation of the study, data collection methods, and research ethics. The results of the evaluation will be described in the following three chapters. Chapter 5 will consider findings in the evaluation which were not apparent in the literature review; Chapter 6 examines how the evaluation findings do, or do not, support the theories developed in the review; Chapter 7 uses the refined theories from chapters 5 and 6 to develop a reusable conceptual platform on the impact of including carers in museum programmes for people with dementia.

## Chapter 5 - Evaluation results 1: New findings

### 5.1 Introduction

The results from the evaluation will be discussed across two chapters, with a third chapter which develops those results into a reusable conceptual platform. The results have been split into two chapters for readability and clarity of results. As some of the new findings need to be integrated into considering the theories developed in the review (Chapter 3), Chapter 5 will consider findings not apparent in the review, and Chapter 6 will examine how evaluation evidence supports, or does not support, the theories developed in the literature review. Chapter 7 will use the use the programme theories developed in Chapters 5 and 6 to create a reusable conceptual platform (explained further in Chapter 7).

Any new theories developed in this chapter will use the same structure as those in the review – unless the mechanism could not be separated into resource and reasoning, the theory statements use Dalkin et al's (2015) method of structuring CMO configurations whereby the mechanism's resource (M/res) is introduced into a context (C), which together change the participants' reasoning (M/rea), leading to the outcome (O). Any elements of the CMO configuration which have been theorised rather than in evidence will be stated in italics for transparency.

Any names given in quotations or explanations are pseudonyms, and museum staff's roles have been standardised across sites for anonymity as discussed in Chapter 4 on evaluation methods.

This chapter will discuss eight areas of new findings in separate sections – session function, caring responsibilities, who the programme is for, the carer controlling dyad attendance, carer enjoyment and balancing this with caring responsibilities, the carer forcing a particular kind of engagement, the long-term impact of including carers, and serving tea.

### 5.2 Session function

As described in the introduction, one of the common aims of these museum programmes is an 'enjoying together' for the dyad, and one of the key positive outcomes outlined in the review was the idea of shared respite – a break, together, away from dementia and their roles as carer and cared-for. However, from both

observations and interviews, it is apparent that a person with dementia and their carer can use the session in different ways. Whilst some enjoy the session together, for others the aim is not this 'enjoying together' but enjoying *separately*, much like a more traditional model of respite.

During my analysis, I coded how dyads were participating in sessions, whether together or separately. I coded 'enjoying together' as distinct from the dyad having to be together due to the person with dementia's needs and/or due to caring responsibility.

There was evidence of dyads enjoying the session together in fieldnotes from all six museum sites and from descriptions in six interviews (one with a professional carer-person with dementia dyad at site 4, and five with staff at sites 1, 2, 4, and 6). For example:

*Another woman who used to come with her mother, and they used to pretty much stay together and say that they really enjoyed being able to do something creative that was in a supportive group but that they could do together.*

*- Manager-facilitator interview, site 2*

*...Fiona [facilitator] talked a bit about that, and the Australian links between the painting and the BBQ. Pearl [person with dementia] said "Australian" in an Australian accent to Naomi [carer] and they both laughed. Fiona talked to Naomi and Pearl about the accent, while Stella [person with dementia] and Robert [carer] talk to each other about the BBQ, also making jokes and laughing.*

*- Fieldnotes, site 1*

There was also evidence of dyads enjoying the session separately in fieldnotes from all sites except site 5, and in descriptions in five staff interviews at sites 1, 2, 4, and 6.

*When we walked over to [building], a member of museum staff pushed Beryl's [person with dementia] wheelchair. Throughout the session Beryl and Louisa [carer] were separate, with the member of staff talking to Beryl and involving her in the session...*

*- Fieldnotes, site 4b*

*During tea, [the dyad] sat at the same part of the table, but each on one side of the table's corner and mostly talked to other people in the group or staff. During the session they very rarely walked together between objects and never sat together at objects. They talked to other people in the group but rarely to each other.*

– *Fieldnotes, site 6*

Having high staffing levels, relative to other kinds of museum programmes, appeared to support dyads to enjoy the session separately. In fieldnotes at all sites except site 5, and in interviews with seven members of staff from sites 1, 2, 4, and 6, having high staffing levels appeared to be a resource which allowed staff to support individual people with dementia (and carers) when needed, taking some of the responsibility of support from the carer and enabling them to be separate in the session.

*...because we've developed quite high staffing levels because we realised that that was important and also necessary, it has often been the case, I think, that particularly family member carers have been able to actually have a bit of space in the group. And that the person that they've come with has been, you know, we've been able to support them and chat to them and, you know, give them quite a bit more time. And so if it's a partner, for example, they've been able to be a bit more independent and have a chat to the curator or wander around a different part of the gallery and know we are there to support their partner.*

– *Manager-facilitator interview, site 2*

*Volunteers helped [person with dementia] to stand as she was struggling with the slippery floor. [Volunteer] moved her chair and helped her to sit back down again. [Carer, her husband] was talking to [other carer] on the other side of the room.*

– *Fieldnotes, site 1*

However, staff also discussed limits on what responsibility they could take, for example they could not support the person with dementia to go to the bathroom. This meant staff could support the person with dementia, enabling the carer to enjoy the session separately if they wished, until the person with dementia's needs reached a certain level or type, or the person with dementia wanted the carer specifically to support them.

*I think for a start we realised involving carers is important because it removes the barrier of like...the safeguarding barrier from us. Because otherwise our [facilitators] would have to...they would have to have a lot of...a lot more training, and we don't want to put that much pressure on any of our staff, that they are carers.*

*– Manager interview, site 5*

*I don't think I'm meant to be able to push wheelchairs for health and safety reasons.*

*– Facilitator interview, site 4*

At times there was a mismatch in the way the person with dementia and carer wanted to use the session. For example, at site 1, there were two clear instances where there seemed to be this mismatch in the desired session function. In the first, the carer could not be separate as the person with dementia wanted their support. In the session, Robert [carer, husband] did not stay with or assist Stella [person with dementia, wife] unless she specifically asked for his help, and he always left her again as soon as he had helped her, whereas she would walk to stay close to him. For example:

*Stella was struggling to get out of the chair. I held the back of it but that didn't help enough. She looked over at Robert and said 'I can't get out of here'. Robert came over and helped her stand up. As soon she was standing, he told her he was going to look at the photographs and walked to the other side of the gallery. Stella stood with us while we folded chairs, and then walked over to Robert.*

*– Fieldnotes, site 1*

In the second, the carer was separate in the session with the person with dementia supported by staff, but the person with dementia was stressed and unhappy that they were not with the carer. This was also observed at site 2:

*[Facilitator] said that during the drawing activity James [person with dementia] seemed to struggle and after starting to make some marks he sat and didn't participate. [Facilitator 2] said she had noticed Jo [carer, wife] and James didn't walk around the gallery together, and didn't sit together during the art activity. She said she thought James wanted to sit with Jo but Jo didn't want to.*

*– Fieldnotes, site 2*

As stated in the analysis section in Chapter 4, I tracked dyads who appeared in more than one piece of data (such as more than one set of fieldnotes or fieldnotes and interview transcripts) to see if the function of sessions fluctuated for individual dyads over time. Nine dyads across five sites could be included in this analysis, including two professional carer-person with dementia dyads as described by staff in meetings and interviews rather than through observations (due to research ethics restrictions of professional dyads' inclusion, as described in section 4.4.2 of Chapter 4). They are summarised in Table 3 below.

*Table 3. Summary of dyad tracking*

<b>Site</b>	<b>Dyad type</b>	<b>Appearances in the data</b>	<b>Brief notes on session function</b>
1	Family (mother & daughter – daughter as carer)	Attended 1 of 5 sessions and mentioned in 1 staff interview	<ul style="list-style-type: none"> <li>- Always together as person with dementia needs physical support and reassurance.</li> <li>- Enjoy together and a number of shared moments.</li> <li>- Person with dementia does not seem consistently engaged in the session. Carer often talks to facilitator and others in group when person with dementia is not engaged.</li> </ul>
	Family (spouses – wife as carer)	Attended 2 of 5 sessions	<ul style="list-style-type: none"> <li>- Always together as person with dementia has high physical needs and person with dementia only responds to his wife.</li> <li>- Person with dementia does not seem very engaged, but carer enjoys talking to others in the group and staff.</li> <li>- Despite high levels of caring responsibility, sessions seem to be more for the carer to enjoy.</li> </ul>
	Family (spouses – husband as carer)	Attended 4 of 5 sessions and mentioned in 2 staff interviews	<ul style="list-style-type: none"> <li>- Always enter separately. Carer takes every opportunity possible to be separate from her (and at times the whole group), only supporting the person with dementia when staff are struggling or she specifically asks for his help. After helping her he leaves to go elsewhere in the gallery or expresses frustration.</li> <li>- Do enjoy together at times through joking and teasing (initiated by both)</li> <li>- Person with dementia is engaged in the sessions but less so than the carer.</li> <li>- He wants to keep attending after she dies, so it is not just a place he can have respite, but something he genuinely enjoys for himself.</li> </ul>

			- Described as being one of increasingly fewer places he can persuade his wife to go.
2	Family (spouses – wife as carer)	Attended 3 of 4 sessions. Mentioned in 3 meeting notes and 1 staff interview.	- Always separate in sessions, though at least once the person with dementia wanted closeness where the carer did not. - Staff give person with dementia support to do the activities, so carer can do it separately.
	Professional (care home)	Attended 2 of 4 sessions (different professional carer each session). Mentioned in 1 meeting note and 1 staff interview.	- Person with dementia is a wheelchair user so have to be together as museum staff not allowed to push wheelchairs. - Enjoying together in sessions – talking about their reactions to the activities.
	Professional (care home) and family (siblings – sister as carer)	Attended 3 of 4 sessions (professional carer for first two and sister in the third). Mentioned in 2 meeting notes.	- Person with dementia initially spent time alone in sessions (including away from museum staff), but in the final session stayed more with the group and spoke more to others. - Professional carers report he likes to be independent at home as well. - Person with dementia does not need much support in sessions so able to choose to be separate or close.
3	Family (mother & 2 daughters – daughters as carers)	Attended 1 session and mentioned in 1 staff interview.	- Always together as person with dementia needs physical support. - At a previous museum they were more separate as person with dementia did not need as much support.
4	Family (spouses – wife as carer)	Attended 2 sessions (1 set of fieldnotes) and each did an individual interview.	- Always together in sessions (not due to person with dementia's support needs) - Carer much more interested in the sessions, but person with dementia 'happy to go along' - Less of a 'shared experience' as he is not as interested, but was a way of getting out together when both hesitant to do so after initial diagnosis.
6	Family (spouses – wife as carer)	Attended 3 sessions (2 sets of fieldnotes)	- Always enjoy the session separately. Both enjoy it and talk to others but rarely with or to each other. Carer often irritated when they do speak. - Staff stay with the person with dementia when he wants to take a different or slower route through the museum than the rest of

			the group. He has no physical or mental support needs in the session beyond this.
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All dyads were generally consistent in the way they used sessions and session function did not appear to fluctuate. Two staff members (at sites 2 and 4) also described session function as being consistent. However, this may be due to the relatively short period of time spent at each programme, as there were indications that session function could change as the person with dementia's dementia progresses or they need greater support from their carer. For example, at site 1, one dyad (Robert, carer, and Stella, person with dementia, spouses) appeared to enjoy the session separately, with Robert in particular using it to have time to himself to enjoy the museum. This couple had also attended every session when I was volunteering at site 1 for ten months prior to beginning my research there. During my time at site 1, Stella's support needs, both in terms of physical support, such as sitting and standing, and mental support, such as reassurance, gradually increased. During the research phase, Robert increasingly needed to support Stella, particularly as she wanted the support from him rather than from staff. He often expressed frustration and would immediately move away to be on his own after supporting Stella.

This transition period, when a carer who uses the session for more traditional respite but then must increasingly be with the person with dementia to support them, may be challenging for some carers. The function of the sessions for the carer has been forced to change due to caring responsibilities at a time when their caring responsibilities outside of sessions may also have increased (and so at a time when they may feel even greater need for the more traditional respite for which they usually come to the sessions ).

This interaction of caring responsibilities with the function of sessions for the dyad as a whole, or for them as individuals, is complex. For example, some carers enjoyed the session in a 'shared respite' way while needing to be with the person with dementia due to their support needs (i.e. there is no choice for the carer in being together). In the following example, Louisa (professional carer) had to stay with Jane (person with dementia) to push her wheelchair and support her to do the activities, but they enjoyed the session together:



*[Facilitator 3] said Louisa and Jane seemed to be really enjoying it together, like they were a team. Jane had a magnifying glass and they were chatting the whole time about different things sparked off from the illustrations. And during the drawing Louisa helped Jane by repeating the instructions for her, and they both talked about their drawings and laughed together afterwards. [Support staff member] said Jane was very enthusiastic when they left, and Louisa said she was 'glad it was something they did together'*

*– Fieldnotes, site 2*

Whereas, for others, the carer only seemed to enjoy the session if they were able to have no responsibilities. In this session, the museum staff supported the person with dementia to do the activity while his wife, his carer, sat on the other side of the table and completed her own artwork:

*[Facilitator 2] said that [person with dementia, husband] and [carer, wife] do a lot of activities together, but she always has to be looking out for him, so she can't always enjoy it for herself. At the museum she knows we will look out for him so she can relax herself too.*

*– Fieldnotes, site 2*

At other times, the carer enjoys the session as a more traditional respite, with it seemingly more for the carer than for the person with dementia, despite the fact they must be with the person with dementia at all times to support them. For example, one of the spousal dyads included in the site 1 dyad tracking was George (person with dementia) and Lucy (his wife). Despite Lucy having to be with George at all times due to his support needs, the sessions appeared to be more for her to enjoy as George was usually not engaged with them. They seemed to be a form of respite through the activities themselves and through having conversations with others that she could not have with George. This fits with the idea of 'internal respite' in Chappell, Reid, and Dow's (2001) research examining carers' (including, but not exclusively, those caring for people with dementia) conceptualisations of respite. 'Internal respite', according to this study, is where the carer feels they are taking a break whilst remaining in the caregiving situation, and can include 'stolen moments' (something that is not an absolute break from caring but is a routine task such as taking a shower, or caregiving in a new enjoyable setting) and connections with

others. In the case of Lucy and George, for example, Lucy may have experienced an internal respite through connection and stolen moments (specifically being a new setting and activity). However, evidence for this was limited to session observations and connections to the literature, as I was unable to interview any carers who seemed to be experiencing the session in this way.

What the interaction between levels of caregiving, session function, and outcomes means for developed theories will be discussed further in examination of the results as related to review theories (f) and (j) in Chapter 6.

This section discussed findings on the function of sessions for dyads, particularly that some want to use the session as a more traditional form of respite (enjoying separately) rather than as a shared respite, and that there can be mismatch in how the two people in the dyad want to use the session. From these findings, three new theories were developed related to session function:

1. When the carer wants to enjoy the session separately (C), high staffing levels (M/res) mean the staff are able to support the person with dementia when needed (M/rea), so the carer has fewer responsibilities (O) and is able to enjoy the session alone (O).
2. When the carer wants to enjoy the session separately but the person with dementia wants to be close to them (C), then either:
  - a. High staffing levels (M/res) mean the staff support the person with dementia (M/rea), so the carer can enjoy the session alone (O) but the person with dementia is unhappy or stressed (O).
  - b. The carer supports the person with dementia (M) so the dyad stays together (O), but the carer is unhappy or stressed (O).
3. When the carer has always enjoyed the session through being separate (C), but the person with dementia's support needs have increased as their dementia progresses (C), the carer provides more support in the session (M), and is unhappy or stressed as they can no longer use the session for traditional respite (O).

### 5.3 Caring responsibilities

Two of the review theories (theories f and j) include the carer as either having or not having caring responsibilities as contexts or mechanisms for outcomes. How results

from the evaluation apply to these theories will be discussed in Chapter 6. This section will discuss the ways in which carers had responsibility or supported the person with dementia in the session. 'Caring responsibility' can include supporting the person with dementia physically or emotionally, as well as being responsible for the safety or wellbeing of the person with dementia.

From the perspective of interviewed staff, carers had to be included in these sessions due to the responsibility they could take for the person with dementia. This view was apparent in staff interviews at all six sites:

*And also because they're public tours, and they are...well they are well-supported but it's a slightly different set-up, it is a little more open and public, so we didn't want to sort of I guess claim complete responsibility of everyone in the group.....it also takes a little pressure off the [facilitators] as well I think.*

– Manager interview, site 6

*...those people [museum volunteers] don't necessarily have DBS. So they can't...so these are things we have to be aware of and why I have carers, is because I can't...a vulnerable person can't be alone with someone who's not got that. I've got a limited number of people who have that*

– Manager-facilitator interview, site 2

Staff also described the limits of the caring responsibility they were able to take and what their role as museum staff could be. At all sites, safeguarding was described as the main reason for including carers, whether the programme initially planned to include them or not. Staff also described being limited by health and safety guidelines (such as not pushing wheelchairs, though this varied between sites). They also discussed how museum staff did not have the training to be carers and that caring tasks were not part of their job role.

*...you really do need the carers for wheeling the wheelchairs and dealing with toilets and...because you get into all sorts of legal things like taking people to the loo and all that sort of thing, that would all be very tricky.*

– Support staff interview, site 2

There were some differences in how different staff saw the balance between the carer attending purely to support the person with dementia and the carer enjoying it

for themselves. This will be discussed further in sections 5.4 and 5.6 on who the programme is for and carer enjoyment.

There were a number of ways carers took responsibility or supported the person with dementia in museum sessions:

a. Bringing knowledge of the person with dementia

The carer brought different kinds of knowledge about the person with dementia that staff did not have, and this was seen as an important reason for their inclusion by staff.

*...it also means that often they know the person with dementia best and they know how they're feeling if they can't express it to us as people who've just met them that day or once before. They know what they might like to do or not do.*

*– Manager interview, site 4*

Carers brought knowledge so staff knew how best to support the person with dementia, and on their interests and preferences, their health issues or needs, how the person with dementia engages, their methods of communication, and on knowing when the person with dementia needed something or was fatigued or needed to leave. In this example, the carer knew the person with dementia (her mother) well, so was able to notice the signs her mother was fatigued, where the facilitator could not:

*The first time we stopped for a longer discussion, after a few minutes [carer] asked [person with dementia] if she needed to sit down. [Person with dementia] said 'oh yes please I'm a bit tired' and then her daughter helped her to sit.*

*– Fieldnotes, site 3*

b. Enabling the person with dementia to leave early

As well as bringing knowledge of when the person with dementia was fatigued or needed to leave, the carer being present also enabled them to leave early.

*When the gallery part was over, [carer] told the facilitator it was really good but that 30 minutes was about enough for her husband as he has a short attention span so they wouldn't come for the tea and discussion. They left at that point.*

*– Fieldnotes, site 5*

c. Translating for the person with dementia

The carer could act as a kind of translator for the person with dementia, particularly when they were hard of hearing or needed things explained in a particular way.

*Throughout the session, [carer] held a speaker for her husband's hearing aid and spoke into it – either repeating what the facilitator said or giving him the general idea.*

– *Fieldnotes, site 5*

d. Providing physical support

Carers supported people with dementia to walk, guided them where to sit, to sit/stand, to put on or adjust clothing, to do physical aspects of activities such as reaching objects for object handling, to use the bathroom, and by pushing the person with dementia's wheelchair. Some staff also stated that carers were responsible for the physical safety of the person with dementia.

*[Carer] helped [person with dementia, sister] to stand and turn while I moved the chair around, and then she helped her to sit back down.*

– *Fieldnotes, site 1*

*I think the main thing is where it's something that's to do with safety. We haven't got one-on-one support so...but otherwise it may not be necessary to really pull on the person, on the carer, much really.*

– *Manager-facilitator interview, site 2*

e. Supporting the person with dementia to take part in the activity or discussion

Carers supported people with dementia in activities in various ways such as repeating instructions, reminding them when it was their turn, and repeating questions or making suggestions when they were struggling to find the word they wanted.

*...the [facilitator] passed around a teapot for people to handle and a bag of spices for them to smell. The wife [carer] of dyad 3 handed her husband the bag and he paused, just holding it. She told him he could smell it, which he then did, before passing it on to the next person.*

– *Fieldnotes, site 6*

f. Encouraging the person with dementia to take part

Carers encouraged the person with dementia they were supporting to both come to the session in the first place, and to take part in the session's activities through verbal encouragement, asking them specific questions, and modelling how to use technology.

*Because in the beginning he was really reluctant, he just wanted to stay home all the time and watch tv, so I kind of had to force him in the beginning. Now he's quite happy, quite happy to do it. And we do a lot more other things as well, so he's much more active.*

– Carer interview, site 4b

g. Providing reassurance to the person with dementia

Carers provided reassurance to people with dementia through physical reassurances such as placing a hand on their back, their physical presence or proximity, and answering anxious questions. This will be discussed in more depth in Chapter 6 when considering review theory (e) which focuses on reassurance-giving.

*In the next part of the gallery, [person with dementia] asks 'where are we going?' and [carer, her daughter] said 'we're just gently walking around'. [person with dementia] said, 'ok okay'. Throughout the session there seems to be lots of small reassurances like this from [carer] to [person with dementia].*

– Fieldnotes, site 1

h. Completing forms

Registration forms (which included information such as contact details) were always completed by the carers for both themselves and the person with dementia, sometimes completing more than one form if they each required their own, without input from the person with dementia. Carers also sometimes completed end-of-session evaluation forms for the person with dementia, but always asking them the questions and what they would like to be written. A few activities included writing and, again, carers wrote for the person with dementia while asking them what to write.

*[Carer] filled in the registration forms for her mother during the tea break and said her mother was unable to.*

*– Fieldnotes, site 1*

*[Facilitator] gave [carer] an evaluation form and told her and [person with dementia] that this was a form to try and measure what the sessions were like. There was one form for [person with dementia] only. [Carer] read out the questions and [person with dementia] answered or asked [carer] questions about what it meant. [Carer] circled the answers [person with dementia] chose.*

*– Fieldnotes, site 3*

However, it should also be noted here that not all people with dementia wanted or needed support for some or any of the above. Some people with dementia completed their own evaluation forms, for example, or needed no physical support to stand or take part in an activity, or actually physically support the carer.

*When we got up to go to the next object, the husband [person with dementia] from dyad 2 picked up two chairs and said he would like to carry them. When we got to the second object he unfolded the chair for his wife [carer] and encouraged her to sit. He did this for the remainder of the tour.*

*– Fieldnotes, site 6*

*[Volunteer] also talked about how [person with dementia] walked around the exhibit mostly by himself, but that he likes to spend some time by himself and for staff just to pop in and pop out of what he's doing. She said the care home staff mentioned today that they like to give [person with dementia] as much independence as possible, so let him be.*

*– Fieldnotes, site 2*

Although not all people with dementia needed this kind of support from a carer in the session, all programmes in this research required people with dementia to attend with someone else. This requirement prevented those who would have liked, and were able, to attend alone to do so. One programme manager noted that as long the person's needs did not exceed the limit of the responsibility the museum could take for participants (as discussed above), people with dementia could attend alone or groups from care homes could attend without one-to-one carer/person with dementia ratios. This may have allowed more people with dementia to participate. However, as

the manager suggested, this would require more planning or for staff to find out the information about the person with dementia's needs that they usually relied on the carer bringing. It also means considerations would then need to be given to how to manage new situations that may then arise, such as if the person's dementia progresses and their needs become more than a museum staff member could support.

*...really you should just say on the website the only thing you can't support is toileting, because everything else, you know, really, with enough planning and notice as far as our end of the session, we can manage those situations. We can plan and we can cope with people who are getting dropped off by their carer if that's...if that has to be it, or the carer's bringing more than one person with dementia, or they're bringing their group from their care home or their café or their faith group or their church or whatever. Yeah and just to realise that not everyone has someone...*

– Manager interview, site 4

#### 5.4 Who is the programme for?

As discussed in section 5.3 above, carers were included because of the responsibility they could take for the person with dementia, and they enacted this in supporting the person with dementia in a number of ways during the session. But as most programmes had 'enjoying together' as a key aim, who is the programme perceived to be for?

Some staff members described or implied the session was primarily for the person with dementia, with the carer included in mainly or only a support role, or it was implied in the programme structure by having feedback forms for people with dementia but none for carers. For example, one facilitator at site 6 always gave answers related to the person with dementia, not carers, when asked about why she thought people attend the sessions or the benefits they receive from attending, and referred to carers in their supportive role only. At site 3, only people with dementia and not carers were given evaluation forms, though carers often sought out a separate form themselves as they wanted to give their own feedback.

There were also occasions when carers, particularly professional carers, were not actively involved in a session, but it was seen as successful because the person with



dementia they attended with were engaged and enjoying themselves, implying the session was more focused on the person with dementia's experience. For example, the manager at site 3 described a session she saw as being very successful and where the participants had an enjoyable time. The session had a small group from a care home and the professional carers did not get involved in the activity, but the people with dementia did:

*...apparently they really loved it and the carers were really happy that [the people with dementia] were so involved in it, like grinding up the cocoa and the sugar nippers.*

– Manager interview, site 3

Some managers stated that the session was for both the carer and the person with dementia equally, with the aim of a shared experience:

*I was really influenced by the New York MoMA...Meet Me at MoMa programme. And I really like the idea of trying to provide a shared experience for people as well. So I think I was trying...I was trying from the start to find a balance between those...those different needs.*

– Manager interview, site 1

or that, as carers had to be included due to the responsibility they can take for the person with dementia, the programme was then designed in a way to be equally for them.

*...[carers being included] was really necessary from a practical point of view. And then since that had to be there, I felt then well actually these people are as much participants. The carers are as much participants as the people living with dementia, and we're not just designing it for the people with a dementia diagnosis but for the carers as well.*

– Manager-facilitator interview, site 2

However, some staff viewed professional and family carers differently in this respect, or staff within the same site viewed them differently. For example, at site 4 a member of support staff frequently suggested professional carers were there to support the person with dementia and the session was not about their enjoyment:

*Well, if they're paid, it's very different to if they're not paid, I think. There's been times when a paid person, who might not have ever been to [site] before, might be more interested in looking at the [site] than actually doing what they're paid to do, you know, supporting the person with dementia. That's happened a few times.*

*– Support staff interview, site 4*

But the manager at site 4 felt that the sessions were for the professional carer to also enjoy, in their dual role of carer and participant:

*...paid carers generally it's the same. And again they're having a nice day out as well, and for most of them quite a change from their regular routine. And they themselves might not have ever come to the [site] or learnt about that thing or enjoyed a session that's more interactive or led by someone in that way.*

*– Manager interview, site 4*

From the carer's perspective, there were also times when the session appeared to be more for the carer than the person with dementia. This is linked with the discussions of session function in section 5.2, in which the carer may use the session as a more traditional form of respite and be separate from the person with dementia. When this occurs and the person with dementia is not particularly interested in either the type of activities or setting, then the session is likely to be more for the carer.

*And I'm really interested in art so I really like that. And he's not so keen on that but he comes along and he's happy to have the coffee and biscuits. [laughs]*

*– Carer interview, site 4*

*...we've definitely had a husband and wife team who, there's no doubt about it, the wife [carer] needed a day out more than her husband [person with dementia], and she got a great deal out of it.*

*– Support staff interview, site 2*

There were also three occasions at two different sites where carers attended alone, two of whom directly suggested they came without the person with dementia because they wanted more traditional respite and to enjoy themselves. Not only does this suggest that, for these carers, the level of responsibility they had when the person with dementia also attended impeded their enjoyment of sessions (which will

be discussed further in section 5.6 on carer enjoyment), but that these sessions were seen by them as being something that was for them as individuals, not just as a dyad. One carer at site 1 also told staff he wanted to keep going to the sessions alone after his partner died, again suggesting the session was something that he enjoyed for himself rather than just as a shared experience.

*She said she was originally going to bring her husband [person with dementia] but rang before booking and asked if she was allowed to come by herself, as the day of the tour was her respite day and she would like to do the tour for herself.*

*– Fieldnotes, site 5*

*[Carer] said he was preparing himself for [person with dementia, his wife] to die very soon. He also told [museum support staff member] he would like to keep coming to the museum sessions after [person with dementia] had died.*

*– Fieldnotes, site 1*

Despite this, there were also carers who expected the session to be solely for the person with dementia, and not for them. For example, some staff members described occasions when carers had been surprised when included in the activities, or where they had to explicitly tell carers the session was also for them to enjoy.

*...to say to people, you know, 'don't forget this session is for you as well and, you know, it's just as much your right to participate in it and enjoy it and learn from it and whatever you want to take from it really'. But we have quite often had to remind people or even inform them because they didn't really know. They kind of presumed that the session was for the people with dementia and not them.*

*– Manager-facilitator interview, site 2*

*[The carers] immediately take on the role that they are there as kind of that facilitator and to...and there for the safety and to look after that person, but they don't naturally take on the role of 'this is for me as well'. I think it's important to...set a kind of level playing field right from the beginning, and say, actually state, 'this is for everyone'.*

*– Manager interview, site 5*

Indeed, there were also occasions in sessions where carers suggested it was primarily for the person with dementia, even when they were also enjoying the

session. For example, in an activity at site 4, carers only wrote the person with dementia's name on their shared booklets, implying they felt it was more for the person with dementia.

All but site 3 included tea and coffee during the session (which will be discussed in more depth in section 5.9). One of the functions of the tea, which was made and served by staff, appeared to be a way of modelling to the carer that the session was also for them, that they could relax and enjoy it, and that they did not hold all of the responsibility. A number of carers were surprised when they did not have to make the tea themselves.

*When we first got to the room, [carer] stood up and told [person with dementia] she would get their coffees while [person with dementia] got settled in. I said I would get them for them. [Carer] said 'oh really? Only if you're sure!'*

*– Fieldnotes, site 1*

*And people would even very much appreciate the fact that we would serve them tea and things, you know, that they didn't have to do that on the person with dementia's behalf and that they weren't responsible for that, that we were taking on some of that responsibility and kind of saying 'oh yeah sit down, we'll bring you a cup of tea, you don't...you know you don't need to'*

*– Manager-facilitator interview, site 2*

In contrast to those dyads who attended due to the carer's interest in the activity or setting, there were also dyads where the carer was not interested but only attended due to supporting the person with dementia. This will be discussed further in Chapter 6 on review theory (o) about opening up the museum.

*[Support staff member] said that whenever they do these sessions, every week there's a reluctant professional carer who arrives not really wanting to be there and saying the museum isn't really for them.*

*– Fieldnotes, site 2*

Staff and carers described how the way the sessions and activities were facilitated (being adapted for dementia but not overly simplified or patronising) also made the programme for both carers and people with dementia. This was also supported by members of the public joining in with tours for short periods of time to listen and ask

questions at sites 5 and 6, suggesting the tours are interesting to, and at the level of, a general museum audience.

*Interviewer: So do you find, for you coming, you get things out of it as well?*

*Carer: Oh yeah, it's great fun. I think what's good is that the sessions are given completely in an adult way. Like it's not...it's not...I can't think of the word, do you know what I mean? It's not made easier like we're sat round with people who might not understand everything.*

*– Professional carer & person with dementia joint interview, site 4*

*But the people who do it are just really aware of what might be wrong but they aren't intrusive or they don't talk down to you, it's...the information is there and if you ask a question they'll tell you and if someone's having trouble talking they'll accommodate that. It's nice!*

*– Carer interview, site 4*

Programmes were generally seen by staff as being primarily for the person with dementia but also for the carer to enjoy, with efforts made to ensure the carer knew they were included, such as through serving tea. However, some staff viewed professional and family carers differently, suggesting the sessions were more for family carers to enjoy than professional carers. Linked to the discussions of session function in section 5.2, some carers viewed and used the sessions as more for them than the person with dementia, however others thought the sessions were just for the person with dementia and were surprised to be included.

#### 5.5 Carer controls the dyad's attendance

Related to the ways carers supported the person with dementia in the session if they needed it, carers also enabled the person with dementia to attend the session through:

- a. finding out about the session and booking

Both people with dementia who were interviewed stated it was the carer who found out about the sessions, including one person with dementia who lived across the road from the site but it was her daughter who lived much further away who found them.

b. dealing with the logistics of getting to the session

This included managing travel, parking, and navigation. One programme manager discussed how it could be harder for family carers to attend for this reason, as care homes often have a member of staff whose role is to manage these logistics while family carers do not have this support.

*Person with dementia: Because a lot of us, obviously we have people, like I've got [carer], I've got my family, and some people haven't got anything, so they'll never get to [museum] because it's not advertised or anything. There's not enough space.*

*Carer: Yeah you wouldn't have found out about it without [daughter] finding out about it, would you? You wouldn't have known where to look.*

*Person with dementia: No. Absolutely not.*

*– Professional carer & person with dementia joint interview, site 4*

As the carer is the one who found out about the session and booked, they effectively controlled whether the dyad (and so the person with dementia) attended. As discussed in the introduction, one of the reasons there can be a 'shrinking social world' in dementia is due to difficulty with unfamiliar places or people, and, from the carer's perspective, not knowing how the person with dementia will respond and all the caring tasks that go with that.

*But [facilitator] said it's a real shame, having now delivered something and knowing that there are things out there for people to experience in safe environments, in welcoming environments, that her friend's [carer for husband with dementia] reaction was that the only way she could cope with it was just to keep him at home all the time.*

*– Manager interview, site 3*

The manager at site 5 talked at length in her interview about how much research and planning went into making the sessions dementia-friendly, including talking to a number of carers about how to adapt activities for people with dementia's needs. During the period of my research, these sessions were very poorly attended, with usually only a few participants or cancelled due to lack of bookings. At my final session at site 5, the manager said she had recently delivered an outreach session

to carers (mainly professional but with some family carers) in which she discussed the tours, what happened on them, and demonstrated example activities. She said the carers told her they would not have brought people to the tours prior to the outreach session as they had never been to site 5 and were not sure how suitable the tours or setting would be. The bookings for tours following the outreach session did then increase. This suggests programmes also need to focus on what makes it accessible or comfortable for carers, not just people with dementia, even where the person with dementia is the main focus of the session and the session is primarily for the person with dementia (as discussed in section 5.4 above).

Two programmes (at site 4 and 5) sent out information to carers following booking on what to expect in the session and the logistics of getting to the museum. Site 4 also included a pre-session telephone call with the manager to give further information, answer any questions, and for the manager to find out if the carer or person with dementia had any particular support needs. The managers at site 4 and 5 both felt this was an important way of supporting carers and helping them to feel comfortable attending. However, no museum site provided this level of information in advance of booking, so it would not help with those carers who felt too unfamiliar or unsure of what would happen to book in the first place. This is exemplified by the carers in the outreach session at site 5 saying they would not book without that information, only offered by site 5 after booking. It may suggest that publicity or marketing materials need to be tailored to what the carer needs to know to feel comfortable attending, particularly if they have not visited the site previously.

This evidence around carers controlling attendance led to the development of a new theory:

In the context of the carer being the one who finds out about the programme and decides whether to attend (C), the person with dementia (dyad) does not attend (O) when the programme does not provide the resources needed to support the carer to feel comfortable or able to attend (M).

#### 5.6 Carer enjoyment and the balance with caring responsibilities

There was evidence in fieldnotes and interviews at all sites of carers enjoying the sessions. There appeared to be two main ways carers enjoyed the session – for themselves and through the person with dementia’s enjoyment.

Carers enjoyed the session for themselves through a number of mechanisms:

a. The fun/relaxing activity

*His wife [carer] took the iPad and started pressing the strings. She turned to me while she was playing and said it was great, she really liked the app, and wondered if she could find something like it at home...She continued playing until it was time to go on the tour.*

– Fieldnotes, site 4a

b. Learning new things

*I've had a few carers kind of ask me questions after I've mentioned a particular thing because they're like 'oh that's really interesting, tell me more about that'. So they are having a good experience as well and they're getting something out of it.*

– Manager interview, site 3

c. It being a setting or activity the carer is interested in

*I just...I love [site 4] so that's why we went along." And later: "...because I grew up in the States, so British history is sort of new to me and it's fascinating. So that's why I enjoy it.*

– Carer interview, site 4

d. Being outside of their normal routine

*...and [for carers] we do really quite cool things in terms of looking at a painting in a lot of detail, and with really professional people as well. And when would they get a chance to do that?*

– Support staff interview, site 2

Some carers also appeared to get enjoyment from seeing the person with dementia's enjoyment, whether they were personally involved or interested in the activity themselves or not.

*They both put headphones on and [person with dementia, mostly non-verbal] started dancing and singing. [Carer, daughter] bobbed to the music with her, watching her and smiling. She turned and gave a thumbs up to me and [facilitator].*

– Fieldnotes, site 1



Two staff members at two different sites suggested that if the carers enjoyed themselves, they felt better or happier, and were then able to have more patience in their caring role, which has a positive impact on the person with dementia. This may be linked with some research that suggests that the wellbeing of the carer impacts the wellbeing of the person with dementia (Ablitt et al., 2009). However, as no carers spoke about this, it can only be suggested as an aim or suggested outcome by staff, rather than there being evidence from this evaluation.

*But then anything that's good for carers, that keeps them happy, also means they're going to have more patience to be good carers too so that is good for both people as well.*

– *Manager interview, site 1*

*[Support staff member] said 'carers feel they're getting something for them, and their positivity lifts the person with dementia'.*

– *Fieldnotes, site 2*

However, as described in section 5.3, carers were primarily included because of the responsibility they could take for the person with dementia, although many programmes also aimed for them to enjoy it as well. The interaction between the carer having responsibilities and the carer enjoying the session themselves is complex, and different for different dyads. For example, in the session function section (5.2) some carers only seemed to be able to enjoy the session if they had very few caring responsibilities, much like the carers who came alone and implied having responsibility for the person with dementia would have impeded their enjoyment (in section 5.4 on who the programme is for). However, others used the session as more traditional respite and their own enjoyment despite having high levels of caring responsibility in the group.

Five staff members at sites 3, 4, 5, and 6 were directly asked how they balanced carers enjoying it for themselves with carers also having caring responsibilities in the session. Two staff members at site 2 discussed it unprompted. One felt it was the carer's decision on how to manage this, not the staff's to facilitate:

*I think that's quite hard, for some people, who need to be supportive as well. So I think it is quite difficult having a dual role. But on the whole I think carers really*

*enjoy the session. I think [balancing role is] up to the carer when they come to be honest.*

– Support staff interview, site 4

Two felt most carers thought they were only included for their caring role, so staff need to explicitly tell them it is also for them to enjoy and include them through asking them direct questions in group discussions as well. They suggested this helps to balance carers' dual role through giving them permission to enjoy it:

*I think it's difficult to get a good balance because from the carers that I've met, both professional and family carers, they immediately take on the role that they are there as kind of that facilitator...but they don't naturally take on the role on 'this is for me as well'. And I think it's important to, in all of our tours and all of the outreach sessions that we do, to kind of set a level playing field right from the beginning as well and say, actually state, 'this is for everyone'.*

– Manager interview, site 5

One staff member said the balance came through carers having minimal responsibilities in the group, so anything more than 'necessary' is the carer's choice:

*I think the main thing is where it's something that's to do with safety. We haven't got one-on-one support so...but otherwise it may not be necessary to really pull on the person, on the carer, much really, if they don't chose.*

– Manager-facilitator interview, site 2

A staff member at site 6 said that through repeated visits, staff could get to know the carer and person with dementia and be responsive to their needs, giving them more support when needed in order to balance that dual role. Staff members at other sites also suggested providing the person with dementia and carer with more support when needed helped with this balance. This was also seen in practice at site 2 in which staff discussed the carer's needs in one session (second quote below) and, in the following sessions the dyad attended, gave the person with dementia more support during the activities while the carer sat separately.

*...although that isn't necessarily the case if you have people that are attending for the first time, you do sort of get to know people in the group and you might pick up on that they're having a bad day and then you hopefully try and be a bit more*

*supportive or maybe just pay a little bit more attention to that person, and try and kind of alleviate that pressure somewhat.*

– *Manager interview, site 6*

*Helen [Support staff member] discussed how Jo [carer] spoke to her about how she had suddenly realised a few days ago that she no longer does anything creative for her – everything is taken up with care of her husband. Helen said Jo told her had been a very emotional realisation and that she seemed to be feeling a little sad about it when she was talking to her.....[Manager] said they needed to take note of this, and make sure during art-making sessions in the future they make sure she has space to make things for her, not just supporting her husband to do his art-making.*

– *Fieldnotes, site 2*

However, as discussed in section 5.4, some staff members did not view the programme as being for the carer, but primarily for the person with dementia. This may suggest finding this balance in carers' dual role of being a participant and a carer was not a priority for those staff. But these ideas are not always mutually exclusive: in the same way a carer can feel they have high levels of responsibility and feel enjoyment, staff can see the session as being mainly for the person with dementia and support the carer to enjoy it. For example, the manager at site 4 described the main focus of the session as *"the person living with dementia and making sure it's accessible to them"*. But she also described the importance of high staffing levels to support people with dementia if a carer *"wants to take a bit of a backseat"*, making it explicit to carers that the support (balance) was available in their pre-session conversation, and trying to make them feel special and welcome as well – *"...once everyone's in the room, everyone's sort of treated the same and given the same love and care and tea and biscuits so hopefully they feel just as special"*. The person with dementia can come first in the design and facilitation of the session, but that does not mean the carer is not given any focus at all.

An area of conflict between how carers view that balance and how staff view that balance may not only be in terms of session function (section 5.2 – for example where a carer wants to use the session as traditional respite but staff want them to support the person with dementia), but also what constitutes 'necessary'

responsibilities. Some staff, such as the facilitator-manager at site 2 quoted earlier, felt they only relied on the carer to support the person with dementia when 'necessary', so any further responsibility the carer took was their choice. However, the carer may view 'only necessary' differently, so what appears to be a choice to a member of staff may not be felt as such by the carer.

The balance between levels of caring responsibilities and outcomes, such as carer and dyadic enjoyment, will be further discussed in relation to review theories (f) and (j) in Chapter 6.

### 5.7 Carer forcing a particular kind of engagement

One part of the ethos of these programmes, as described in the introduction chapter, is the idea of the participant's identity and meeting them 'in the moment' – not who they were in the past or what they were interested in then, but with interaction based on who they are and what they are interested in on the day of the museum visit. This is enacted in the sessions through the way activities are structured and facilitated, such as not focussing on reminiscence or memories but on the person's response to a particular piece of artwork, for example.

However, there was evidence of some carers struggling with this. There were occasions, both observed in sessions and from descriptions in staff interviews, where carers tried to prompt a particular memory or shared memory linked to the activity or discussion from the person with dementia. There was never a negative response from the person with dementia when this happened during sessions I attended. When it seemed like the person with dementia could not remember what the carer was trying to prompt, they usually just answered with a simple yes or no, changed the subject, or walked away.

*[Carer] turned to [person with dementia] and said 'look! [Place name]! You used to live there.' [Person with dementia] looked unsure and said 'oh yes' and continued walking...[Carer] turned back to me and started talking about [place name].*

*– Fieldnotes, site 3*

*...sometimes carers have expectations, they'll say, 'oh my husband used to be a painter, he really wants to see paintings' or 'my husband used to be a carpenter, we have to find him some wood'. And that actually what you find is that often when every time we've tried to do that with people, so...we did have those specific*

*examples one time....And the man who was a carpenter, one of the curators let him touch some Victorian wood carving. He didn't actually recognise that it was wood. But there were some modern ceramics that he really loved looking at and touching. So I feel like the process of seeing something that you like that day may or may not be anything to do with your previous identity.*

*– Manager interview, site 1*

At times the carer tried to make the person with dementia engage in a particular way with the activity or discussion, based on things they used to enjoy or an aspect of their identity. For example, in one session at site 4, a person with dementia who used to be a musician did not want to get actively involved in a music-making activity and said he just wanted to listen. His wife (his carer) had mentioned earlier that they had sold his instruments as he was no longer able to play them – so the person with dementia may not have wanted to get involved due to a grief for that skill or because he was no longer interested. However, the carer persisted in trying to get him to make music, and later to answer music-related questions. The person with dementia became increasingly annoyed with his wife during the session.

*In dyad 1, the husband [person with dementia] said something quietly to himself, and his wife [carer] nudged him and loudly told him to speak up to the group. He shook his head and said no, that he didn't want to. His wife kept telling him to speak up. The husband seemed irritated and said he didn't want to and that he wanted to be left alone. During this time the group conversation had identified the composer and piece of music. The wife said to the group 'we've got [incorrect composer name] over here', and the facilitator said 'that's very close, it's [name]'. The wife turned to her husband and said 'oh it was [name]' and at the same time the husband said in the same irritated tone as before 'I didn't want to'.*

*– Fieldnotes, site 4a*

It may be that, in some cases, the way the mechanism of 'in the moment' ethos on identity, and the way the staff enact that, does not have enough leverage to overcome the context of the carer (Jagosh, 2017). The carer may have had a long, close relationship with the person and so has a very strong idea of who they are compared to much more rapid changes related to dementia. This may be combined with a grief for the way their lives were, or who the person was, before dementia

(Blandin & Pepin, 2017) which is not easily overcome in a two-hour museum session.

A new theory was developed on this potential negative impact of including carers:

Where the carer is trying to hold on to the person with dementia's previous identity/interests (C), they try to make the person with dementia engage in a particular way tied to this (M). The person with dementia does not want to (M) and feels annoyed and cannot engage in the way they want to (O).

#### 5.8 Long-term impact of including carers

This evaluation did not include a long-term follow-up of dyads outside of the sessions to assess any long-term impacts. However, there were two potential long-term impacts of including carers suggested by the data.

##### 1. Seeking out or replicating the activity

Staff from care home groups at site 2 were described as intending to replicate the art-making activity in the care home with other residents:

*There's quite a lot of examples of [professional] carers going 'oh we never thought of approaching something like that, that's really interesting to do that kind of drawing activity' or 'we didn't know people would receive it like that and you know we could go back and do some of these kinds of things'*

– *Manager-facilitator interview, site 2*

And family carers were described by a manager at site 4 as seeking out other similar activities as the person with dementia had enjoyed their experience in the museum:

*And sometimes we'll do an activity and perhaps a carer will say something like 'oh my partner really enjoyed doing X, that's great for me to know because I'll try and find more things that we can either do at home that's doing that, or going elsewhere to do that'. It might be like painting, or listening to a certain type of music, or they might have used a musical app on the iPad and think 'oh well I'll try and download that because my partner really enjoyed making music that way'. So that's always nice to see.*

– *Manager interview, site 4*

By including carers, who, as previously discussed in section 5.5, were the ones who found out and booked activities for the dyad, the person with dementia (and the carer) could then get involved in similar activities elsewhere, or care home residents who did not attend the session could enjoy a similar activity in the home. However, it can only be suggested as an intention of carers, as there was no long-term follow-up to determine if they actually did re-create the activities afterwards.

## 2. New conversations outside the session

Review theory (c) (to be discussed in Chapter 6), suggests coming to the session means the dyad has new conversations, which helps them to learn new things about each other and build their relationship. All but one study included in the development of theory (c) focused on new conversations within the session. One study (Lamar, 2015) asked carers if they had talked with the person with dementia about their museum visit afterwards, finding that some did but others could not due to the person with dementia's lack of memory for the session. As this potential long-term impact was not discussed in any depth in the review, it will be discussed here.

Staff interviews and a professional carer-person with dementia dyad in this evaluation suggested attending the session together also gave them new things to discuss outside of the session and new things to share with others.

*...so to have something that you've had time out as well, that you bring into the relationship, the conversation over support, has to be beneficial I think.*

*– Facilitator 3 interview, site 6*

*...instead of having to talk about when people's next hospital appointments are, this issue, that issue, they're able to say 'oh we had a lovely time at the museum and we went to do this shared experience'.*

*– Manager interview, site 3*

If the person with dementia attended the session alone, they may have had new things to discuss with the carer when they returned home. However, the professional carer-person with dementia dyad at site 4 suggested it helped that it was a shared experience, as they could prompt each other about different aspects of the experience. It may also link with the idea of shared respite from caring roles, as it is

a source of conversation unrelated to caring tasks (with the caveat of the varied level of caring responsibilities different carers feel or wish to take within the session).

*Person with dementia: ... I actually very much enjoy listening to it, but if you ask me questions afterwards then I wouldn't be able to deal with that. You can understand that.*

*Carer: But then you always remember if I remind you of things, you do normally remember us doing it in a session.*

And later in the interview:

*Carer: Yeah we do [chat about it afterwards]. And we often come away with something, and you've got them all laid out in your house, haven't you?*

*– Professional carer & person with dementia interview, site 4*

This therefore led to the development of two new theories about the longer-term impact of including carers:

1. *Where the dyad is unsure of new activities to try or often does the same type of activities (C), coming to a new/different kind of activity that the person with dementia enjoys/engages in (M), means the carer seeks out similar activities or replicates them at home (O). In care home groups, the activity is replicated with other residents who did not attend the session (O), extending the impact to those people with dementia outside of the session itself.*
2. *Where the dyad's home interactions are mainly about caring tasks or with limited leisure activities (C), doing a shared activity outside of caring routines (M) means they have new things to talk about and share with others after the session (as well as during) (O).*

The second of these theories may be linked with review theory (c). Review theory (c) includes the dyad doing an activity outside of their usual routine which means they have new kinds of interactions within the session. Whether, and how, these theories could be combined will be discussed in section 6.4 of Chapter 6 which examines this review theory.

#### 5.9 Time for tea

All sites except site 3 included a tea and coffee break in their sessions. All but site 5 had their tea at the very beginning of the session, whereas site 5 had theirs following



the tour during the object-handling. Although site 3 did not include a tea break, the manager said (unprompted) that it was something she wanted to include, and had done so at a different museum, but could not due to restrictions on food and drinks in the space she was using.

Having tea, particularly tea at the start of the session, appeared to serve a number of functions related to the inclusion of carers. As discussed in section 5.4 on who the programme is for, the tea being made and served by staff was one way staff modelled that the sessions were also for the carer and that they did not hold all of the responsibility within the session. It also seemed to set the tone in other ways, by indicating the session was relaxed and informal. It was also used to welcome the participants to the museum and allow unstructured time for staff and participants to socialise and get to know one another.

*[Tea and biscuits] sets the tone, you know, that this is going to be fun or it's relaxed and you're welcome here.*

– Carer interview, site 4

*At [previous museum] the really good thing was there was a hot drink to start with, there was a hot drink at the end, and it really set the tone of this nice friendly place, we're just going to take our time, we're just going to enjoy ourselves.*

*Whereas here, it's a different set-up....I think for the carers that would help as well because they would immediately feel more at ease, whereas at the moment it's kind like 'we're going to begin in the [gallery name] and then we're going to walk down together' instead of getting to know each other a bit I guess.*

– Manager interview, site 3

It was also a way of supporting carers. As described in section 5.5, carers usually had responsibility for getting the dyad to the session, and that these logistical issues could be quite stressful. Having tea at the start allowed space to de-stress after the journey and allowed some gathering time for people who may be late.

*I think [having tea at the beginning] does a lot of things. It kind of gives, I mean, you never know what journey people have had to get here, that could be really stressful, so just giving them a space where they can just sit down, have a breather, have a cup of tea, go to the loo if they need to, and just kind of collect themselves before going off on a tour I think is quite important. Also being kind of*

*welcomed into the space, familiarising themselves with the [facilitators]. The [facilitators] tend to go round and introduce themselves individually before they gather everyone together....And I think it somehow brings them together as a group before they go off. And hopefully it makes people feel a bit calmer. Because also just finding your way around the building itself is really confusing, so it just builds in that buffer so if people are late we're still here and it's fine and they haven't come all the way to the museum and then are stuck or lost or anything like that.*

*– Manager interview, site 6*

A theory on serving tea has been developed below:

Where carers are unsure if the session is for them or are feeling stressed at the beginning of the session (C), museum staff serving them tea (M/res) helps carers to feel they can also participate, they do not hold all of the responsibility in the session, and gives them space to relax (M/rea). The carer then feels less stressed and welcomed (O).

#### 5.10 Conclusion

This chapter discussed findings from the evaluation which were not found in the review (Chapter 3), including the ways the function of the sessions can be different for different individuals, the carer's caring responsibilities, who the programme is for (from the perspective of both staff and carers), how the carer controls the dyad's attendance, carer enjoyment and the balance with caring responsibilities, how some carers try to get the person with dementia to engage in a particular way, the potential long-term impact of including carers, and the function of tea during the sessions. These ideas will be included in considering how evidence from the evaluation is mapped to theories from the review in Chapter 6.

## Chapter 6 - Evaluation results 2: Review theory mapping

### 6.1 Introduction

Chapter 5 considered findings in the evaluation which were not apparent in the review (Chapter 3). This chapter will examine how the evaluation results support, or do not support, the theories developed in the review. Chapter 7 will use the programme theories developed in Chapters 5 and 6 to create a reusable conceptual platform (explained further in Chapter 7).

Sixteen theories were developed in the review, and these will each be examined in turn. For each review theory, the original theory will be given, evaluation results as relates to part, or the whole, of the theory will be described, and then a refined theory will be developed as appropriate.

Any new theories developed in this chapter will use the same structure as those in the review – unless the mechanism could not be separated into resource and reasoning, the theory statements use Dalkin et al's (2015) method of structuring CMO configurations whereby the mechanism's resource (M/res) is introduced into a context (C), which together change the participants' reasoning (M/rea), leading to the outcome (O). Any elements of the CMO configuration which have been theorised rather than in evidence will be stated in italics for transparency.

Any names given in quotations or explanations are pseudonyms, and museum staff's roles have been standardised across sites for anonymity.

### 6.2 Theory (a)

From the review:

“When the facilitation enables the person with dementia to ‘maximise capacity’ to participate (M/res) and *the carer’s expectations of the person with dementia are low* (C) and/or others in the group highlight the person with dementia’s capabilities (C), the carer perceives the person with dementia to have achieved competency (M/rea), so the carer sees the person with dementia in a new way (O), which also helps build their relationship (O).”

There was some evidence of a shift in carers’ expectations of what the person with dementia would be able to do or how they would engage with the activities during the

session. For example, in interviews from sites 2 and 3, staff members described occasions of professional carers expecting less engagement from the person with dementia and being surprised by how much they then did engage. This surprise may suggest the carer's expectations were initially low, supporting the hypothesised context for this theory.

*...and her carers from the retirement village said "oh you won't get a lot out of her". And at the end she was looking through this magazine and she suddenly said something like "I used to be a..." something like a conglomerate girl or something, I don't know what the word was...it was to do with copying magazines and typefaces, and she said "this would have been very expensive" to [museum support staff]. .... But the fact that they said she won't engage and she did.*  
- Manager-facilitator interview, site 3

A manager at site 1 described an occasion where others in the group highlighted the person with dementia's capabilities and that this led to the carer seeing the person with dementia in a new way.

*So we did have...it was a husband and wife where the husband had been an artist as well. And she didn't let him paint at home anymore because she found the mess too stressful. ... And sometimes she would snap at him. And he had dietary requirements and he would try and eat biscuits and she would snatch them away from him. ...we did collage which was not at all the kind of artwork that he used to do. ... And we had paper and scissors and he was really confident, he was making these big bright pictures that were...it was like watching Matisse. ...you could see his wife, watching him being praised by other people – genuinely, sincerely – both people with dementia and museum staff, that I think it made her feel differently about him. And also in herself in seeing...like it's great to feel proud of somebody you're connected to.*  
- Manager interview, site 1

However, no carers were asked about these aspects of context, so evidence for the context of this theory is still limited.

There was a perception from two members of staff that an enabling facilitation leads the person with dementia to respond in a new or different way, and then the carer increases their expectations of them or sees them in a new way.

*I think also there are quite long silences often which [carers] feel awkward about, and sometimes it's best just to wait and then the client will come out with something extraordinary. Well, not necessarily, but something you weren't expecting, and that's just a really good way to go. But yeah we have had occasions when you do have to just step in and just "oh just hold on a sec, let's just see what she's going to say".*

*- Support staff interview, site 2*

The 'maximising capacity to participate' of the original theory may be more specifically this 'responding in a new or different way'. This is also linked with this being a new or different activity to their usual routine, which may also lead to new or unexpected responses from the person with dementia.

*I can imagine that would be very true that you'd see your partner do things or...and you hadn't known because you'd never been in that situation before and didn't know they enjoyed it or that they could do it or that they wanted to do it.*

*- Manager interview, site 4*

In both observations (fieldnotes) and interviews, 'enabling facilitation' appeared to be a supportive kind of facilitation – from being responsive and patient with the ways different people tried to communicate, to not making negative comments about participants' contributions, to finding ways to help keep the session focused while giving people the space they need:

*There's quite a few people there who have a few little quirks about what they say or how they say it, and the people who lead the discussions are just really good at keeping it in focus and not making negative comments, but at the same time moving things on.*

*- Carer interview, site 4*

*Pearl [person with dementia] described the shape of the wings using her hands and fingers and said "wings". It was too quiet for [others in the group] to hear, but Naomi [carer] and [facilitator] responded that they liked the wings, and that they seemed difficult to make. Pearl smiled and nodded and repeated the gesture and said "wings" again.*

*- Fieldnotes, site 1*

One staff interview at site 2 suggested a new outcome related to this theory, and to the idea of replicating activities in the care home with other residents after the session (discussed in Chapter 5, section 5.8). She suggested that it is not about professional carers shifting their thinking in terms of what the *individual* person with dementia is capable of, but it is more that their thinking shifts about what is possible in terms of activities with people with dementia more generally, for example the type and complexity of activities people can engage in and enjoy.

*...also [learning happens] around approaches to activities, you know, there's quite a lot of examples of carers going "oh we never thought of approaching something like that, that's really interesting to do that kind of drawing activity" or "we didn't know people would receive it like that and you know we could go back and do some of these kinds of things". I don't know whether I could confidently say that it alters people's way of communicating...I'd be quite confident to say that there was a shift in terms of people thinking what's possible in terms of the types of activities and kind of creative responses we work with.*

*- Manager-facilitator interview, site 2*

The mechanism of this review theory includes the carer perceiving the person with dementia to have "achieved competency" as this was the language used in the paper the evidence was drawn from. However, "competency" is a loaded, judgemental term, and falls into negative stereotypes of 'incompetency' which have a negative impact on the lived experience of people with dementia (Scholl & Sabat, 2008). The mechanism might be more usefully described as the person with dementia responding in a new or unexpected way (as discussed above), leading the carer to see them in a new way (the outcome). It can be difficult in realist theorising to categorise each element of the theory in the 'correct' position. It is possible that another researcher would suggest that the process of the carer seeing the person with dementia in a new way is the mechanism, with something else as the outcome of that process. However, I think the process of having a new or adjusted set of expectations about a person is an outcome, which could then go on to impact other interactions and activities in different ways (in realist terms – this outcome could become the context in new CMO configurations). In the original review theory, the mechanism is the perception that has changed in the carer, with the outcome being that perception as changed, which is only negligibly different. Having the person with

dementia's response as the mechanism is clearer about what is actually happening, and so is more useful in considering how the outcome is generated and what implications this may have.

Following the evaluation, this theory has been refined as follows:

When the facilitation enables the person with dementia to 'maximise capacity' to participate in an activity outside of their usual routine (M/res), the person with dementia responds in a new or unexpected way (M/rea). Where the carer's expectations of the person with dementia are low (C), and/or others in the group highlight the person with dementia's capabilities (C), the carer sees the individual person with dementia in a new way (O) or reconsiders the activities in which people with dementia in general are capable of engaging (O).

### 6.3 Theory (b)

From the review:

"Professional carers only have a relationship with the person with dementia in a work context (C) but take part in a shared activity outside of the work context (M/res) and are able to get to know the person with dementia beyond dementia (M/rea), which builds their relationship"

As stated in the evaluation methods chapter (Chapter 4), I could not include most professional care dyads in observations or interviews as I could not be sure if they were funded by social care. This means that the evidence for theories about them is limited to an interview with one professional carer dyad who could be included, and descriptions of other professional carer dyads in staff interviews.

Two members of staff at site 1 described situations where a professional carer dyad did not know each other well, but came to the sessions which treated them both as equal participants. Through their participation they learnt new things about each other and shared an enjoyable experience, which built their relationship with one another. This appears to support the full CMO of theory (b).

*...her daughter paid for a carer to spend time with her once a week I think. And this paid carer was a really not very confident young woman and at first she didn't enjoy being in the sessions being, I think she felt a little put on the spot when she was asked to give opinions or say anything. And then she kind of started coming*

*out of her shell a little bit ... And then it...over time it started becoming something that they were doing together. So she actually started requesting that her day's work, that she could work with this older woman on the days she was coming to the museum. And they started looking forward to doing it together. They both got little butterfly magnets from the museum shop that they had at home. And you could really see the bond between them building...that might just have happened over time anyway. But it felt like, it felt like it helped to provide something for them to bond around and to see each other as, I think to see each other as people in a humanising way.*

*- Manager interview, site 1*

There was also evidence from staff interviews supporting the mechanism's resource (M/res) of the shared activity outside of a work context leading to the mechanism's reasoning (M/rea) of the dyad learning new things about each other. For example:

*And [at] our last [site] tour, the paid carer said "oh it was really nice to see, to actually sing with him and to get to know him more as well".*

*- Manager interview, site 5*

However, in the one interview with a professional carer and person with dementia dyad, they both stated they had not learnt new things about each other through coming to the sessions as they already knew each other well and had done a number of activities together. This person with dementia lived in the community rather than a residential home, so the dyad had more of a one-to-one relationship. This may be different in a care home setting with a number of different staff members and residents where they do not have as much opportunity to develop a one-to-one relationship.

The evidence from the evaluation therefore refines the context – it is not solely that professional carers only have a relationship with the person with dementia in a work context, but also how well they already know each other or how much they have already engaged in social activities.

Given the evidence for this theory is limited both in this evaluation and in the review due to the lack of inclusion of professional carers, conclusions drawn can only be tentative.



The theory has therefore been refined as follows:

Professional carers who only have a relationship with the person with dementia in a work context with limited opportunities for shared or social activities (C), take part in a shared activity outside of the work context (M/res) and are able to get to know the person with dementia beyond dementia (M/rea), which builds their relationship.

#### 6.4 Theory (c)

From the review:

*“Where dyads have little opportunity for meaningful/leisurely activity (C), sharing a meaningful experience on an equal basis (M/res) means they have meaningful communications and interactions (M/rea) which helps the carer to see the person with dementia in a new way (O) and build their relationship (O).”*

There was some evidence from staff interviews of dyads having new conversations and this leading to the carer seeing the person with dementia in a new way or building their relationship. However, the mechanism’s resource appeared to be experiences outside of their usual routine, rather than a *meaningful* experience.

*And I think sometimes we’ve seen, certainly with one daughter and mother relationship, you could see her re-visiting her mother, just sort of seeing her mother slightly differently to when she arrived. Which is quite interesting. In a good way, you know, her mum was coming out with things that she just probably would never have come out with because they just go through the normal routine every day of just doing whatever you do, you know. And by being challenged and asked different things she just sort of saw a different side of her mum. And that was quite nice.*

*- Support staff interview, site 2*

However, the family carer interviewed said she had not learnt new things about her partner due to their longstanding relationship (which was also the reason given by the professional carer interviewed as discussed in theory (b) above).

*Sometimes he’ll say something about what he’s done in the far past and I think “was that true or not?” [laughs]. Something I didn’t know. But I don’t think [we’ve*

*learnt anything new about each other], no not really. We've been together for 35 years so I know him pretty well.*

*- Carer interview, site 4*

This was also something found in the review – that some family carers felt they did not learn anything new about their partner due to the length of their relationship (Lamar, 2015). It may be that carers are more likely to learn something new about the person with dementia when they do not already know them well, for example, professional carers who have only had a short or intermittent relationship with the person with dementia, particularly if they are living in a residential home. However, the evidence from the review for this theory also included family carers, so it is not limited to those professional dyads who may have had shorter relationships. It may also be related to how in tune the carer is with the person with dementia's current identity and interests (as described in Chapter 5, section 5.7, on carers forcing a particular kind of engagement) and how open or able they are to accept any changes in the person with dementia if they are present.

There was no evidence in the evaluation related to the hypothesised context, mainly because the two dyads who were interviewed said they did not learn anything new about each other so this could not be explored. Given the discussion above, the context may be more about how well the dyad knows each other. The hypothesised context of having little opportunity for leisurely activity may not lead to the carer to see the person with dementia in a new way if they already know them well. For example, the carer who was interviewed at site 4 discussed how she and her husband were struggling to go out and do activities after his diagnosis before coming to the museum, but she also said they did not learn new things about each other (despite all elements of the theory applying to their situation).

This theory is linked with theory (b), examined in the previous section (section 6.4). Theory (c)'s altered context (not knowing each other well) and mechanism (sharing an experience outside of their usual routine) is similar to theory (b)'s context (the professional carer only knowing the person with dementia in a work setting) and mechanism (getting to know them through sharing an activity outside of that context). Theory (c) could, therefore, supersede theory (b), particularly as there was less evidence for theory (b) given most professional carers could not be included in this

evaluation. However, the 'work context' includes more than just caring tasks, for example the culture of the care home, professional policies, and training. For this reason, theory (b) will not be incorporated into theory (c), in order to highlight particular issues around participating in the session while at work. The potential implications and meaning of the 'work context' will be further examined in Chapter 7.

This theory could also be linked with the theory and ideas in section 5.8 of Chapter 5, which discusses dyads having new conversations *after* the session, as well as within. The mechanism of section 5.8's theory is not split into resources and reasoning, and is simply sharing an activity outside of caring routines. This is the resource component of the mechanism for theory (c), with the reasoning component being having new communications and interactions within the session. It may be that having new interactions with each other within the session is the mechanism resource for having new things to talk about and share with others after the session. However, it may also be possible for a dyad to enjoy a session separately, so not have much interaction within a session, and still have new things to talk about afterwards, prompting each other as discussed in section 5.8, as they participated in the same session with the same people and activities. Additionally, the focus of the two theories is qualitatively different – theory (c) is essentially about getting to know one another (either for the first time or again), whereas 5.8's theory is about sharing together after the session (which may not include getting to know one another). For example, the professional carer dyad quoted in section 5.8 discussed sharing after the session being a benefit of attending together, but also stated they did not learn new things about each other because they already knew each other well. This suggests the differing contexts are key. For this reason, as well as dyads not necessarily needing to interact in the session to prompt each other in sharing afterwards, the theories will remain separate programme theories.

This theory has been developed as a result of the evaluation as follows:

Where dyads do not know each other well, or the person with dementia has changed some of their interests or aspects of their identity (C), sharing an experience outside of their usual routine on an equal basis (M/res) means they have meaningful or new communications and interactions (M/rea) which helps the

carer to see the person with dementia in a new way (O) and build their relationship (O).

#### 6.5 Theory (d)

From the review:

*“In dyads where the carer is unsure about how best to support the person with dementia or is struggling with communication (C), modelling by the facilitators (M/res) means carers learn new ways to interact with the person with dementia and new strategies (M/rea), which builds relationships through improved communication and a focus on process rather than product (O).”*

The context was only theorised, rather than evidenced, in the review. In this evaluation, the context appeared to be about having habitual patterns of interacting, or care homes having a particular culture so staff all work in a particular way with people.

*...and also I think it's quite good for [professional carers] to see other people talking to their clients, because in a care home environment it's just them all the time, whereas these are completely different people coming from a completely different viewpoint talking to their clients, and I think that's good. I did notice on one or two occasions that I would start talking to the client in a certain way, and the carer then changed their way of talking to them into, not mimicking, but taking a reference from the way I was talking to them. ...Not necessarily better, but just differently.*

*- Support staff interview, site 2*

*And then there is the issue of maybe being used to kind of helping the person quite quickly, or speaking for them a little fast, or, whereas for us as staff in the museum we might be a bit, wait a bit longer or try a few more different ways of accessing. If the person isn't very verbal there might be different ways in which we kind of enable that. Whereas there are kind of patterns already set up often within that kind of [caring relationship].*

*- Manager-facilitator interview, site 2*

Staff interviews supported the mechanism that staff interact differently with the person with dementia, and that this may lead to changes in the way carers interact

with them. For example, modelling in the session that people with dementia could speak for themselves and would be given the time needed, which could then reduce the amount carers intervened on the person with dementia's behalf within the session. They also discussed museum staff finding new ways of doing activities, and this helping the dyad to find new ways of interacting. Both of these are demonstrated in the two staff quotes above.

One manager at site 1 also suggested that the reason staff (and others in the group) are able to interact differently than family carers is because they have an emotional distance from the person with dementia that family carers often cannot have.

*...it's not just us that model behaviour, you see other people with dementia and other carers often really patient. Well that same thing where it's so much easier to be patient with somebody that you're not connected to.*

*- Manager interview, site 1*

However, there was also a suggestion that staff interactions do not have an impact on the way a carer interacts. Two staff members from sites 2 and 4 suggested that because there is a short period of time in the sessions (usually two hours), and many dyads have longstanding habitual patterns of interacting, staff behaviour does not change how that dyad interacts outside of the session. They also suggested that because museum staff are not trained in social work or care work, it is not the place, and not the aim, for sessions to change dyad interactions.

*Staff member: ...But I can see that particular carer does get quite frustrated with looking after [her husband]. And she does, you can see how frustrated she is and she tells him off for all sorts of things and you just feel like saying "no [carer], it's alright, perhaps go about this a different way". But I can't. I can't do that. I can't, yeah I don't feel that's my role really. I think that would change the role, my role.*

*Interviewer: So your role isn't to intervene when you feel like someone's, the dynamic of someone's relationship is...*

*Staff member: No, I couldn't do that. And I don't think, because I'm only with them once a month, you know, for a couple of hours. I mean, what on earth could I possibly do that would make any difference at all. But it would need to be somebody from within the community services really.*

*- Support staff interview, site 4*

“Habitual patterns of interacting” was suggested as the context for carers learning new ways to interact, but also as the context for why carers *do not* interact in new ways. It may be that, in some cases, the resources do not have enough leverage to overcome the context of habitual patterns. Alternatively, it may be that this suggested context is not specific enough to be useful. It may be, similarly to theories (b) and (c), the difference is between those dyads with longstanding relationships (such as spouses or professional carers who have a one-to-one relationship with the person with dementia) and those with more recent or intermittent relationships (such as professional carers in a residential home). The original theorised context may also apply within this. For example, if a person with dementia and a carer do not know each other well, the carer may not yet know the best way to support them, so the facilitators and activities give them new ideas of ways to interact and this helps to build their relationship.

There was no direct evidence regarding the outcome of theory (d) in the evaluation, so the evidence for this outcome is mainly drawn from the review. However, the examples staff members gave were around a shift in process, such as giving the person with dementia more time to speak. This may support the review findings in suggesting carers were less focused on, for example, giving the ‘correct answer’ (product), and more on the process of the person with dementia finding their own answer.

It should be noted, however, that the evidence from the evaluation is limited by only coming from staff interviews, and not from carers saying they are doing anything differently, nor from observations of carers seemingly trying out ways of interacting they witnessed in the session.

The review theory has therefore been revised as follows:

In dyads where the carer does not know the person with dementia well (C), is unsure how to support the person with dementia (C), or has fallen into habitual patterns of interacting (C), staff interacting with the person with dementia in a new way (M/res) means carers learn new ways to interact with them and new strategies (M/rea), which builds their relationship through improved communication and a focus on process rather than product (O).

## 6.6 Theory (e)

From the review:

*“Where the person with dementia is anxious about new activities (C), the carer reassuring or modelling taking part in a shared activity (M/res) helps the person with dementia to feel comfortable/able to take part (M/rea), so they are able to participate without anxiety (O).”*

There was evidence in session observations at sites 1, 4 and 6, interviews with staff at sites 1, 2, 3 and 4, and people with dementia at site 4, that carers provide reassurance to the person with dementia. And that this reassurance leads to the person with dementia participating in the session or feeling more comfortable in the session. There were three main ways carers provided reassurance in sessions:

- a. Through their physical presence or proximity to the person with dementia

This could be simply the carer’s presence in the session without them necessarily actively doing anything, being there so the person with dementia does not have to go to a new environment or group alone, or doing the activity alongside the person with dementia.

*During the tour they mostly walked/sat together. Occasionally [the person with dementia] would look unsure, then stretch out her hand and touch [carer] (his back or his hand) and visibly relax.*

*- Fieldnotes, site 6*

*Person with dementia: I couldn’t come by myself [the first time].*

*Carer: I don’t think you’d have ever come by yourself.*

*Person with dementia: No, absolutely not.*

*Carer: But I mean, I think you would now. ...[person with dementia] lives literally over the road so I think, in theory, you would come. If I said “oh I can’t come but it’s this morning”*

*Person with dementia: Oh no I would come now, definitely.*

*Carer: Exactly, now she knows people.*

*- Professional carer & person with dementia interview, site 4*

- b. Physical reassurance

Some carers demonstrated reassurance through physical gestures.

*Occasionally [carer] touched [person with dementia]'s back and stroked it.*

*- Fieldnotes, site 1*

c. Answering anxious questions and/or re-explaining what is happening

A few people with dementia repeated the same questions to their carer, such as repeatedly asking for the time or where they were going, and the carer responded by answering their question or explaining the session and the activity they were doing.

*Like for example there was one of the people who came to that session, he, I think he went to say "oh I'm going to go" or "it's time to go" or something. And she said, she was from the Alzheimer's Society I think, and she said "oh aren't we going to do this" or "we're not going to go yet because of this". And she distracted him kind of from what his thoughts were, so that he'd come back to the activity that was taking place.*

*- Manager-facilitator interview, site 3*

*In the next part of the gallery, [person with dementia] asks "where are we going?" And [carer, her daughter] said "we're just gently walking around". [Person with dementia] said "oh okay". Throughout the session there seems to be lots of small reassurances like this from [carer] to [person with dementia].*

*- Fieldnotes, site 1*

People with dementia appeared to be anxious in a range of ways within, or about, sessions (from anxiety about initially attending, to a more general anxiety), and the people with dementia who were anxious within sessions included those who had attended previously (so the activity or group was not new to them). This suggests the context may also include new groups of people as well as new activities, and generalised anxiety, as this can be a common experience of people with dementia (Seignourel, Kunik, Snow, Wilson, & Stanley, 2008).

As discussed in section 5.3 of Chapter 5, there were a number of ways carers had responsibility for the person with dementia they support, and reassurance was just one of them. It is therefore important to consider why this particular way of supporting people with dementia has its own theory separate from any overarching theories about caring responsibilities in sessions. Aside from this being a well-supported theory, reassurance-giving appears to be one of the 'responsibilities' that



museum staff can never fully take on behalf of the carer. In sessions, people with dementia always looked to the carer, not a member of staff, for reassurance, which is unsurprising given that they do not know the staff as well as their carer. If the person with dementia needs the carer to provide reassurance, particularly if they need physical reassurance or close physical proximity, this has implications for the function of the session for the carer (as described in section 5.2 of Chapter 5). If the carer wants more traditional respite, they are not able to have this and be separate in the session if the person with dementia needs them to be physically close, as staff cannot give the person with dementia the reassurance they need to be comfortable. It therefore seems important to highlight this type of caring responsibility separately, and link it to session function.

Though only one study in the review supported this theory, it was generally well supported in the evaluation, and has been revised as follows:

Where the person with dementia has anxiety, or is anxious about new activities or new people (C), the carer reassuring or modelling taking part in a shared activity (M/res) helps the person with dementia to feel comfortable/able to take part (M/rea), so the person with dementia is able to participate without anxiety (O), but the carer cannot be separate within the session (O).

#### 6.7 Theory (f)

From the review:

*“Where the dyad’s home interactions are mainly around caring (C), enabling facilitation in a non-medical setting in which the carer has no caring responsibilities (M/res) means the dyad can enjoy the activity together on an equal basis (M/rea), which leads to the dyad experiencing shared respite from dementia roles/life (O), which also helps to strengthen their relationship (O).”*

Five staff interviews at sites 1, 3, 4, and 5 suggested that, rather than it simply being a ‘non-medical setting’, it is the sessions not being about dementia, talking about difficulties, or reminiscence, which was the mechanism for respite. The evidence for this part of the theory from the review came from three papers, with only one directly noting the ‘non-medical’ setting (Johnson et al., 2017). The others stated that it was about it being a ‘normalised’ public space (McGuigan et al., 2015), or that it was doing an activity that was not about medical care (Camic et al., 2014). As discussed

in the section on theory (f) in Chapter 3 (section 3.6.2), four other papers (reporting on three studies) also supported the idea that the activity not being about dementia was linked to shared respite or enjoyment (Baker, 2014; Burnside et al., 2017; Camic et al., 2016; Flatt et al., 2015). It may therefore be more specific (and so more useful in terms of thinking through implications of theories) to re-write this part of the mechanism as being an activity not about dementia, in a community space. This also integrates Camic et al.'s (2016) grounded theory (included in the review) which suggests an important aspect of these museum programmes is the museum setting as a 'valued place'.

*...from the point of view of what's good for everybody is that sometimes what makes you feel good isn't talking about your problems. I felt like it was helping people to feel like themselves.*

*- Manager interview, site 1*

*...it doesn't matter that they've got dementia, they're both new to this, and it's a new experience. And it's not about reminiscence, it's not about looking at the past, their past, or trying to remember things, they don't have to, there's no work involved.*

*- Support staff interview, site 4*

There was also evidence for an enabling facilitation (mechanism resource) leading to equalising between the person with dementia and carer (mechanism reasoning) from staff interviews at sites 2 and 6. Some staff at sites 1, 2, 3, and 4 felt that the activity being new to both the person with dementia and the carer also helped to equalise.

*[Support staff] said she felt there was a high level of engagement from both the person with dementia and the carers, and it felt like a happy session. She said it felt like everyone was able to get involved at a level they felt able to*

*- Fieldnotes, site 2*

*It's a shared new experience for a lot of them. Because a lot of people say "oh we've been to the museum before" but they've probably never been on a tour before, and certainly not a tour that's specifically for them, it's for them. And I think there is an element of it being special for everyone, and it being an experience for everyone.*

*- Manager interview, site 5*

Staff members at site 2 thought staff also taking part in the activities helped to equalise between participants because it modelled that every attendee is an equal part of the session and that facilitators do not differentiate by role, which helps carers who are unsure if they can step out of their caring role to participate.

*It's the same with the volunteers and the [support] staff, everybody in the group. And that's how you create a kind of collective kind of community feel in a group, I guess. Where people all feel welcome and there's not hierarchy of "oh I'm this and you're that". So I think that's quite important.*

*- Manager-facilitator interview, site 2*

One staff member at site 1 and four at site 6 highlighted the fact they did not make a distinction between who was a carer and who was a person with dementia, and often did not know what role participants had as it was never discussed.

*And I can't really tell the difference between who is the carer and who is the dementia patient, because I don't make those connections, you know, they come in as a couple or they wander in, you know, or I wander in after they've arrived, and I have no idea who's the dementia patient and who's the carer.*

*- Facilitator interview, site 6*

However, although some staff members said they did not distinguish between carers and people with dementia, many of those same staff members did feel the carer had caring responsibilities in the group, so they did make a distinction, even if they felt it did not impact their facilitation style. For example, one of the facilitators at site 6 said not knowing who in the group has dementia helped to equalise, but also suggested in another part of their interview that carers were primarily included for the responsibility they could take.

*No, we're not told [who has dementia] and we just put on our name badges. So it's only in conversation that you might realise there is a bit of a problem perhaps. Which is good, because then when you're sort of, you're embracing everybody as a group.*

*...because [the professional carer] almost needed to be reminded that she was here to help the person rather than to sort of taking off herself.*

*- Facilitator interview, site 6*

This 'equalising' appears to be the key part of the mechanism, rather than enjoyment. The review studies which led to the development of theory (f) were mixed in terms of either suggesting it was enjoying the activity together which led to shared respite, or that it was participating as equals. As shared respite is about stepping outside of caring/cared-for roles, it would make sense that this is about an equalising or, in other words, not participating differently according to your caring role of being a carer or cared-for.

Three staff members at sites 2, 4, and 6 suggested it being a non-caring situation and activity was a mechanism for respite, implying the lack of caring responsibility is important.

*And that grandmother and granddaughter, it was nice to spend that time with her grandma but not in a situation where she was caring for her. So it was a very, it's a very different scenario that people are in and people, there were quite a few cases of people really saying that they really enjoyed that and they really valued that.*

*- Manager-facilitator interview, site 2*

However, as discussed in section 5.2 of Chapter 5 on session function, the interaction between caring responsibilities and respite is complex, and not the same for every dyad. Some carers appear to feel respite at the same time as having a number of caring responsibilities, whereas others need to have few, to no, responsibilities to feel respite in the session. Additionally, carers always have *some* responsibility for the people with dementia in the group. As discussed in section 5.3 of Chapter 5, there are limits to the support staff are able to offer the person with dementia, and carers are often included *because* they can be responsible. This suggests that the mechanism of 'the carer has no caring responsibilities' is not accurate. Additionally, even where the person with dementia needs a high level of support from the carer, the session always takes *some* responsibility from the carer simply through the structure of the session, which takes care of the content and provides some support for the process. As described in the new theories on session function (section 5.2 of Chapter 5), the higher staffing levels in these sessions also help to minimise what carers need to do, to an extent.

*Because it's a facilitator-led session with lots of support you can kind of, I mean I hope, they can kind of just let go because things are being done, they're just going along with the session and whatever's going to happen and it's led by someone and what we're going to do is all mapped out.*

*- Manager interview, site 4*

Given that different dyads use the session in different ways, it may be that the resource is not about a lack of caring responsibilities, but about the carer only having the level of responsibilities they want or are comfortable with, combined with some support from staff and the session structure.

This link to session function may also suggest the context is not only about a dyad's interactions being mainly about caring, but also that they want to do something together. Those who want to enjoy the session separately are unlikely to experience shared respite, whether they spend the session together or not (as detailed in the new theories in the session function section of Chapter 5).

Therefore the theory has been re-worded as follows:

Where the dyad's home interactions are mainly around caring and they want to spend time together (C), enabling facilitation of an activity not about dementia in a community setting, in which the carer only has to provide the level of care for the person with dementia that they want to (M/res), means the dyad can participate on an equal basis (M/rea), which leads to the dyad experiencing shared respite from dementia/caring roles (O), which also helps strengthen their relationship (O).

## 6.8 Theory (g)

From the review:

“Shared respite (C) means the dyad can interact and communicate outside of dementia roles (M), which builds their relationship (O) and also feeds back into enjoying the activity together (O).”

There was a view that shared respite could be relationship-building in staff interviews at sites 1 and 5.

*...to help try and reframe your relationship about something on an equal level that's not around caring or being cared for, that you can, I feel like sometimes little things can tilt the balance of a relationship and it doesn't necessarily have to be*

*over time that...any relationship can get out of balance in different ways and so I feel like it would be great if just...a morning at the museum could help to rebalance your relationship.*

*- Manager interview, site 1*

*It's also about [the professional carer], "did you have, were you a rebel when you were younger?" Because that, again, that kind of brings out similarities between them and they can realise that they do have these shared life experiences even if they weren't at the same time in their past.*

*- Manager interview, site 5*

And there was some evidence (from staff interviews at sites 1, 3, 4, and 6) for having conversations and doing activities that were not about dementia or their caring roles, leading to a shared enjoyable experience. Enjoying the activity together (as distinct from needing to be together due to the person with dementia's needs) was well-supported as an outcome. As described in section 5.2 of Chapter 5, evidence was found in fieldnotes at all six museum sites and from descriptions in six interviews (one with a professional carer-person with dementia dyad at site 4, and five with staff at sites 1, 2, 4, and 6).

*[Person with dementia] also told me she likes to have a joke after laughing with [her professional carer] about a painting in which the model would have been sitting with a bottle of water in her cleavage in order for the painter to get the flowers right.*

*- Fieldnotes, site 2*

*...whether it's making music or drama, then it's really nice for them to share a moment, for me to see them share a moment with their person they care for, perhaps doing something they would never normally do together.*

*- Manager interview, site 4*

Some evaluation forms from site 5 also focused on shared enjoyable experiences as a positive from the session, suggesting it was seen as a key outcome for those carers.

*So actually, to be honest, most of them do focus on what they liked, but usually it is those shared experiences, so like, in some of our evaluations we've had "we loved...", especially at [site], "we loved singing". And it's always WE loved singing.*  
- Manager interview, site 5

As discussed in the previous section on theory (f), the relationship between shared respite and caring responsibilities is complex. This means the relationship between shared respite and shared enjoyment is also complex because of the individual differences in how caring responsibilities impact on enjoyment. Shared respite and shared enjoyment are closely related concepts, but not the same – shared respite is about the focus of the relationship not being defined by dementia, whereas shared enjoyment is taking pleasure in the activity together. In the review it was suggested, through the link between theories 6 and 7, that they are mutually reinforcing processes – shared enjoyment contributing to shared respite, and shared respite further enabling them to enjoy the activity together. Although this makes conceptual sense, this link is now less clear at a theory level as 'enjoying together' was removed from theory (f) in favour of 'participating equally'. It may be that theory (g) is not separate from theory (f), but a CMO which details the process between the two outcomes of theory (f) (shared respite and relationship building).

No changes were made to theory (g) as a result of the evaluation.

Shared respite (C) means the dyad can interact and communicate outside of dementia roles (M), which builds their relationship (O) and also feeds back into enjoying the activity together (O).

#### 6.9 Theory (h)

From the review:

*"The participatory activity with a 'product' e.g. artwork/verbal contribution (M/res), in the context of high carer expectations or a dyad struggling to accept dementia (C), means the carer compares the person with dementia's current abilities to their former abilities or negatively with other people with dementia in the group (M/rea), which leads to the group highlighting losses or reinforcing limitations (O)."*

All of the evidence in the evaluation for this theory related to family carers, rather than professional carers. This evaluation could not directly include the majority of

professional carers due to ethics permissions, which may be why the evidence for them is missing here. However, as discussed in section 6.4 on theory (c), family carers may have had longer relationships, and more emotional history, with the person with dementia they support. This means theories related to that history or emotional connection may be more likely to apply to them. The five papers in the review which supported the development of theory (h) included a mix of family and professional carers, or did not specify the dyad type, which is why it was not specified in the review theory. However, as it concerns having a relationship history, it makes sense that this theory would apply more to family carers. The way those review papers report losses being highlighted implies, or directly states, a personal history between the person with dementia and the carer. For example, Humphrey et al. (2017) discussed some carers feeling discouraged that the person with dementia's artwork was less skilled than that they had produced in the past. This personal history suggests these results apply to family, rather than professional, carers. As this is also where the evidence lies in the evaluation, theory (h) will be made more specific to family carers.

There was evidence from six staff interviews at sites 1, 2 and, 4 that losses can be highlighted in the sessions.

*Sometimes the carers have found it hard during the sessions, and we've had quite a few instances where the carers will break down and cry because it's just so hard to watch their grandmother or wife in that situation. I guess, well who knows what they're thinking, but, you know, potential of what might have been or whatever. But I think that's quite hard.*

*- Support staff interview, site 2*

There was also some evidence of carers comparing the person with dementia's current abilities to their former abilities in interviews at sites 1, 2, and 4.

*And [the person with dementia] was finding [the art activity] really exciting and stimulating and [his wife] was going "oh that's not how he used to. Oh his stuff used to be really good and that's not what he used to do." It was really quite sad.*

*- Facilitator interview, site 1*

The review suggested that carers negatively comparing the person with dementia they support with others in the group was a mechanism (negatively meaning that the



person with dementia has more advanced dementia or greater difficulties than others in the group). Five interviews with staff, people with dementia, and carers at sites 3 and 4 suggested there is also a mechanism around comparing the person with dementia with others in the group *positively*. That is, the person with dementia is more mildly affected by their dementia than others in the group, and seeing people with dementia who have greater difficulties highlights a possible negative future.

*Well the only, yeah the bad thing [about the programme] would be seeing somebody gradually decline and seeing the difficulty they have.*

*- Carer interview, site 4*

*And she didn't volunteer again. And I spoke to her and I said "did you enjoy it?" And she said "yeah yeah I did enjoy it", but I could tell there was something going on there...And it was because she personally has been affected by dementia that she found it a bit much...she also said she was thinking of maybe her possible future [as a carer].*

*- Manager-facilitator interview, site 3*

However, one member of staff suggested this happens less in their museum sessions than in carers' groups they ran in the community because people stop attending the museum as their dementia progresses:

*I've run carers' groups and carers' groups are quite worrying like that, when someone's clearly looking after somebody who's really way down the road, and they think "oh god that's going to be me". But that hasn't really happened in this context because everybody's got quite early stages. And I think when they are deteriorating and that they're not really managing very well, they don't come back.*

*- Support staff interview, site 4*

Descriptions in interviews also suggested that the resource is not just about the activity having a 'product', but that it is an activity outside of their usual routine which means the person with dementia is asked to do things they may have stopped doing in their day-to-day life. For example:

*There was [wife] and [husband] who came today. The first session they came to, we asked them to write some, write their name on something, and [husband]*

*couldn't write his name and [wife] didn't know he couldn't write. And I think that really upset her. Because she didn't know, so that was quite sad for her.*

*- Support staff interview, site 4*

The carer feeling respite from their caring role could also be a context for the programme highlighting losses for them. A family carer being outside of their caring role, which they may not have felt for some time, makes them realise there are activities they miss which they used to enjoy, highlighting the carer's own losses. Carer respite is thus not always a positive experience if it also highlights these losses.

*[Support staff] discussed how [carer] spoke to her about how she had suddenly realised a few days ago that she no longer does anything creative for her – everything is taken up with the care of her husband. [Support staff] said [carer] told her it had been a very emotional realisation and that she seemed to be feeling a little sad about it when she was talking to her.*

*- Fieldnotes, site 2*

For one carer, however, this way of highlighting losses actually became a positive context. After these losses were highlighted and she was upset, she realised she needed to find other activities that were for her, and then sought out and joined another group (which did not include her spouse).

*The wife had been really creative and she actually got really emotional in the session because I think she just realised how she didn't have creativity in her life anymore and that, that reminded her of that. And that, she then got in touch with a craft group near [city]. She managed to get that as part of her regular week, to have something else going on.*

*- Manager interview, site 1*

However, much like theories (o) and (p) on opening up the museum, this likely depends on the carer's capacity to join other groups, whether through finances or the person with dementia having other sources of support while the carer attends, so this realisation could also be negative if they then do not have this capacity.

It was not clear from this evaluation what the difference is between carers for whom respite is positive, and those for whom it highlights losses. Chapter 7 will consider

the idea of losses being highlighted as related to models of grief in dementia, and how this may link with respite highlighting losses for some.

There were also no results in the evaluation which related to the hypothesised context of this theory, so this will remain italicised for transparency.

The review theory has been revised, and two new theories developed, as follows:

The participatory activity with a 'product' that is outside of their daily routine (M/res), *in the context of high carer expectations or a dyad struggling to accept dementia (C)*, means the family carer compares the person with dementia's current abilities to their former abilities or with other people with dementia in the group (M/rea), which leads to the group highlighting losses or reinforcing limitations (O).

Where the family carer feels respite in the session (C), they realise they are missing other activities they enjoy (M), and this highlights personal losses for the carer (O).

When personal losses are highlighted for the family carer (C), they realise they need to find activities just for them and seek them out (M), and then join other groups without the person with dementia (O) if they have the capacity to do so.

The outcome of the second of these theories becomes the context for third.

#### 6.10 Theory (i)

From review:

*"Where the carer has high expectations of the person with dementia (C), or the group highlights losses (C), the carer does not perceive the person with dementia to have achieved competency (M), so the carer does not feel respite (O) and does not see the person with dementia in a new way (O)."*

As discussed in section 6.2 on theory (a), the language of 'competency' is judgemental and will be changed to 'capabilities'. Like theory (h), the evidence for this theory from the evaluation only relates to family carers, and it was not always clear in the review to which dyad type the evidence was referring. However, as discussed in section 6.4 on theory (c), family carers may have had longer and more emotionally laden relationships with the person with dementia they support, so

theories related to that history or emotional connection are more likely to apply to them.

Two staff members describing the same dyad at site 1 suggested evidence for the full CMO. In this case, others in the group highlighting the person with dementia's capabilities (as per theory (a)), did not have enough leverage to overcome the carer comparing the person with dementia's current to past abilities, so she did not see him in a new way or from a new perspective.

*Facilitator: And [the person with dementia] was finding [the art activity] really exciting and stimulating and [his wife] was going "oh that's not how he used to. Oh his stuff used to be really good and that's not what he used to do." It was really quite sad.*

*Interview: What do you do in that situation?*

*Facilitator: Oh well I suppose for me I say "Oh I really like that. I really like the thing that he's done", but, you know, obviously I've not seen the things he used to do. But I just sort of said "I really like it", but it didn't change her opinion. To her it was just a mess.*

*- Facilitator interview, site 1*

As well as the mechanism being the carer not perceiving the person with dementia's capabilities, the evaluation also suggested that the carer feeling upset following losses being highlighted may be a mechanism. It may be that this upset feeling then contributes to the carer not feeling respite. In the examples given for highlighting losses in section 6.9 on theory (h), all involved the carer showing upset:

*...it had been a very emotional realisation*

*- Fieldnotes, site 2*

*...we've had quite a few instances where the carers will break down and cry*

*- Support staff interview, site 2*

*...I think that really upset her...that was quite sad for her*

*- Support staff interview, site 4*

*...she actually got really emotional in the session*

*- Manager interview, site 1*

Like theory (h), there was no evidence in the evaluation related to the hypothesised context of the carer having high expectations.

The theory was revised as follows:

*Where the family carer has high expectations of the person with dementia (C) or the group highlights losses (C), the carer does not perceive the person with dementia's capabilities or feels upset (M), so the carer does not feel respite (O) and does not see the person with dementia in a new way (O).*

#### 6.11 Theory (j)

From the review:

“When the carer has caring responsibilities in the group (C), the dyad cannot enjoy on a completely equal basis (M) so the carer does not get respite (O) and feels increased stress (O). (Not an on/off, but ‘dimmer switch’ programme theory as per Dalkin et al 2015. Also may be about ‘perception’ of responsibilities, as unlikely to have none at all).”

There was some evidence for stress related to caring responsibilities, especially the logistics of getting to a session. However, this is limited to staff perceptions, rather than carers describing sources of stress themselves.

*...because bringing someone to the museum, it's a new thing for [the carer] as well, coming, negotiating transport, finding the entrance to this place is impossible, and things like that can add so much stress to a person.*

*- Manager interview, site 5*

*I think sometimes people can be a bit stressed [at the start of the session] because it can be quite an early start to get here, or they might have had a difficult night, or be having a bad week, or the weather's been bad, or traffic's been bad.*

*- Manager interview, site 4*

There was also some evidence that having higher caring responsibilities in the session meant the carer could not engage with the activity, but they were able to engage when they had less caring responsibilities. As described in the section on carer enjoyment (Chapter 5, section 5.6), carers often enjoyed the session through the activity and setting itself, so if the carer cannot engage with those things due to the level of responsibilities they have, it may be less likely they would be able to

enjoy the session. The following quote from the manager at site 3 describes why she thinks carers engage less with the tour in the first half of the session, and more with the object-handling in the second. She suggests the carer was only able to engage with the session's activities when they had fewer responsibilities.

*...but sometimes with the tour, [the carers] can't really engage in what we're doing because they're trying to kind of make sure the people they're looking after are okay. So I think sitting down at the table really does help them also engage, because that's the moment where actually that person's not going to wander off, they know that person's probably mostly comfortable sitting down or whatever.*  
- Manager-facilitator interview, site 3

Relatedly, there was also some evidence linked to session function (as described in Chapter 5, section 5.2) that having more responsibilities in the group means less enjoyment for the carer. When the carer wants to use the session as more traditional respite, but cannot be separate in the session due to needing to support the person with dementia, they enjoy it less. This was most evident when the person with dementia's needs increased and the carer had to change from being separate in the session to assume more of a caring role. For example, as described in the session function section, at site 1, Robert (carer) liked to enjoy the session on his own, but increasingly needed to support his wife, Stella, and often expressed frustration and immediately moved to be by himself after supporting her.

As described in Chapter 5, section 5.3, on caring responsibilities, carers always have at least some responsibility for the person with dementia in the group, and are usually included because they can take that responsibility (section 5.4 on who the programme is for). It is therefore unlikely that the context is simply that 'the carer has responsibilities' because they always do. This was accounted for in the review to some extent by suggesting it was a 'dimmer switch' rather than an on/off process, but it was unclear what specifically it was about responsibilities that lead to the carer not being able to feel respite or enjoy the session.

As discussed in theory (f) (section 6.7), it is likely the context is linked to session function and the match (or mismatch) between how the carer *wants* to use the session and how they are *able* to use the session. This is dependent on the

expectations of the museum staff, the level of support the person with dementia needs, and whether this support is within the limits of responsibility staff can take.

The new theories in Chapter 5, section 5.2, on session function will also link with this theory, as it is not about having caring responsibilities per se, but the match in session function for that carer and the person with dementia's needs. However, there are occasions when the level of the person with dementia's needs, or the staff's expectations of the carer and their role in the session, means the level of responsibility prevents the carer from being able to engage fully, or almost entirely.

Theory (j) has been refined to reflect this:

When the carer has high levels of caring responsibilities in the session (C), they cannot engage with the activity (M), so they do not feel respite or enjoy the activities (O).

#### 6.12 Theory (k)

From the review:

"Anxious carers (C) intervene on the person with dementia's behalf (M), so the person with dementia cannot engage fully (O) and the carer has no respite (O)."

There was evidence in fieldnotes from sites 1 and 4, and staff interviews at sites 1, 2, and 3, of carers intervening on the person with dementia's behalf.

*As we were finishing off our drinks, the facilitator went around and asked everyone to say their names. Two carers said the name of the person with dementia they had come with, and when it was the person with dementia's turn they didn't say anything (both said "this is X, and I'm X").*

*- Fieldnotes, site 4a*

*Sometimes you feel like the carer speaks for them, that's quite sort of an obvious one. And when [the people with dementia] do start talking they jump in and predict what they're going to say. I think also there are quite long silences often which [carers] feel awkward about...*

*- Support staff interview, site 2*

However, there was no direct evidence related to the impact of that (the theory outcomes) as neither of the people with dementia interviewed had carers who had

intervened during the session. Evidence for the outcomes of this theory is therefore based on the review.

Additionally, in observations, it was difficult to determine if, when carers were intervening, it was unnecessary or actually a supportive practice. As discussed in section 5.3 in Chapter 5 on caring responsibilities, one thing some carers do is translate for the person with dementia, which means re-explaining what the facilitator has said in a way that makes sense to them or if they are hard of hearing. This translating can also work the other way around, from the person with dementia to the group, if the person with dementia has a particular way of communicating that others who do not know them well may find difficult to understand. For example:

*[Volunteer] said it was good having the carers there as sometimes [person with dementia] would say something that's difficult to understand, and [her carer] would know what she said and could share it with the group.*

*- Fieldnotes, site 2*

In this case, the carer speaking for the person with dementia is supportive, not an unnecessary intervention. Relatedly, there were times in observed sessions where the person with dementia struggled to answer, either because they seemed to find it difficult talking in groups or because they had word-finding difficulties that frustrated them. The carer, bringing that knowledge of the person's needs (as described in section 5.3 on caring responsibilities), answered for them as a supportive practice, not an unnecessary one.

*I asked [person with dementia] [if she would like tea or coffee] and she paused and said "tea or coffee". I asked again which she would like, and she replied "coffee" and turned away. [Her carer] said [person with dementia] would like it with just a little bit of milk and that she would have the same, then turned back to talk to [person with dementia].*

*- Fieldnotes, site 1*

*...the person who came alone answered [questions to the group] most often, but...[carer, son] also answered (rarely [his father] also answered, but this was usually directed to his son who then relayed it to the facilitator).*

*- Fieldnotes, site 5*



There were a number of possible reasons highlighted in the evaluation why carers may be anxious in a session, including:

a. The museum environment

Carers may be anxious as the museum is a new or unfamiliar environment to them, and/or can be perceived as a formal or intellectual place. This means carers are anxious themselves being in a new environment, but also about whether the person with dementia's behaviour will be 'inappropriate' in that setting.

*I think quite often [the carers] are not necessarily people that have been to the museum on a regular basis anyway, so there's that little bit of the museum being a slightly intellectually superior place, and they're coming in very much on the back foot with a relative with dementia, so you know, not only a lack of education but also in a slightly vulnerable position in that they've got somebody with them that perhaps, you know, might be inappropriate.*

*- Support staff interview, site 2*

b. The responsibility they hold for the person with dementia

As discussed in section 5.3 of Chapter 5, the carer ultimately has responsibility for the person with dementia in the session and this can be stressful. As well as being unsure how the person with dementia will respond or cope with a new physical environment, this also includes issues like a recent decline in the person with dementia's health.

*[Carer] asked [person with dementia] a few times throughout whether she was okay. I assume this is due to her heart attack on Monday, as I haven't noticed him doing this in previous sessions.*

*- Fieldnotes, site 1*

*I'm thinking of one particular couple where she definitely kind of manoeuvred him around the gallery I guess. And he was walking, but she was kind of like "oh step back from here" and that kind of thing.*

*- Manager-facilitator interview, site 3*

c. Stressors in their life outside of sessions

Carers also have stressors in their life outside of the session which may or may not be related to their caring role, which they then may bring into the session as a generally anxious feeling or mood.

*...carers perhaps bringing stresses of their life into the room, which is fine and understandable and everyone does that. And they might be tired or had a bad night or not particularly want to get involved, which is fine.*

*- Manager interview, site 4*

Theory (k) has not been altered as a result of the evaluation, but a new complementary theory has been added about intervention as a supportive practice:

Anxious carers (C) intervene on the person with dementia's behalf (M), so the person with dementia cannot engage fully (O) and the carer has no respite (O).

Where the person with dementia struggles with speaking or finds it stressful (C), the carer answers for them in the group or translates their answers for others (M), so the person with dementia is able to engage in a way which is comfortable for them (O).

### 6.13 Theory (l)

From the review:

“Professional carer-person with dementia dyads have only had a caring/work relationship and find it harder to step outside of caring roles (C), so the carer intervenes on the person with dementia's behalf (M), and the person with dementia cannot engage fully (O).”

As the majority of professional carers could not be included in observations or interviews due to ethical approval restrictions, evidence for theories about them is limited to descriptions in staff interviews or staff's perceptions about them.

Two staff members at site 2 suggested professional carers find it harder to step out of their caring roles, and that this leads them to intervene on behalf of, or speak for, the person with dementia more quickly.

*And then there is also the issue of [professional carers] maybe being used to helping the person quite quickly, or speaking for them a little fast*

*- Manager-facilitator interview, site 2*

However, as discussed in theory (k) (section 6.12), it is possible some of this early or 'unnecessary' intervention is actually a supportive practice related to the person with dementia's needs.

There was a new context suggested by three staff interviews at sites 4, 5, and 6 about how they perceive professional carers differently to family carers, as also discussed in section 5.4 of Chapter 5 on who the programme is for. These staff members saw professional carers as only being present for their caring responsibilities, and not as having a dual role of caring responsibilities and also enjoying it for themselves, which they did see family carers as having. This was not site-specific, as different staff members at the same site varied in their view of the role of professional carers in the session. For example, in contrast to a support staff member at site 4, the manager at site 4 said professional carers do have a dual role:

*...we did have one [professional] carer who seemed to enjoy far more than her patient, if you like, if that's a word, or client. And that was rather funny, because she almost needed to be reminded that she was here to help the person rather than to sort of taking off herself.*

*- Facilitator interview, site 6*

*Well, if they're paid, it's very different to if they're not paid, I think. There's been times when a paid person, who might not have ever been to [site] before, might be more interested in looking at the [site] than actually doing what they're paid to do, you know, supporting the person with dementia. That's happened a few times.*

*– Support staff interview, site 4*

*But, no, paid carers generally it's the same. And again they're having a nice day out as well, and for most of them quite a change from their regular routine. And they themselves might not have ever come to the [site] or learnt about that thing or enjoyed a session that's more interactive or led by someone in that way. So, no I can't say I ever notice any difference [between professional and family carers].*

*- Manager interview, site 4*

It is possible that the professional carers would step out of their caring role, but pick up on this staff perception because of how it may then cause staff to treat them differently than family carers. This then discourages them from actively participating as an equal member of the session.

Two staff members from sites 2 and 3 discussed how it can be more difficult to encourage professional carers to participate in the session as an active participant because they are attending as part of their work day. The professional carers then find it harder to step out of, or expand, that role to their own enjoyment. This means the outcome for this theory is not just about the person with dementia's engagement, but it is also preventing the carer's engagement (and consequent relationship-building within the dyad).

*Interviewer: Are there ever any times when it's more challenging to do that, to get everyone participating and on a kind of equal basis?*

*Facilitator: Yeah I think there are times when, and I think it's more apparent with carers who that's their job, that sometimes there's the kind of balance of the participation can get muddled somehow, or that there is an imbalance.*

*- Manager-facilitator interview, site 2*

The review theory has therefore been refined as follows:

Professional carer-person with dementia dyads have only had a caring/work relationship so find it harder to step out of caring roles (C), or museum staff perceive professional carers to only have a caring, and less participatory, role (C). This means the carer intervenes on the person with dementia's behalf or does not participate themselves (M), and the person with dementia and/or professional carer cannot engage fully (O) or gain potential relationship-building outcomes (O).

#### 6.14 Theory (m)

From the review:

*"People with dementia may find it more difficult to speak up in a group setting (C), so where there is poor facilitation (M/res) carers dominate conversations (M/rea), so the person with dementia cannot engage and do not have a sense of belonging in the group and cannot gain potential positive outcomes (O)."*

The new alternate theory developed in discussing theory (k) (section 6.12) on carers speaking for the person with dementia as a supportive practice, rather than an unnecessary intervention, also applies here as an alternate theory.

There was evidence of carers being more involved in group conversations than the people with dementia in observations of sessions at all sites except site 4. In most

sessions, general questions to the group were answered by carers, not people with dementia

*The tour was more passive than previous tours – it was more of a ‘lecture-style’ but with a few questions to the participants. Questions to the group were answered by carers and one person with dementia (Anna). When [facilitator] asked if anyone had any questions for him, the questions all came from carers, and included a group discussion about the cost of the art between some of the carers and [facilitator]. Anna was the only person with dementia who joined in any group discussions.*

*- Fieldnotes, site 1*

However, there were a few sessions where general questions were also answered by people with dementia. It may be that this depends on how the dementia impacts the person or the severity of their dementia. For example, word-finding difficulties are common across different types of dementia in its early stages (Klimova & Kuca, 2016), and this may impact how easily a person is able to contribute to a group discussion if they need more time to find the words they want to say. Dementia and its symptoms progress at different rates for different people, so even if two people with dementia in the group both have word-finding difficulties, one may need a great deal of space and time to contribute verbally to a discussion, or not be able to contribute in that way at all, but another may be able to find their words quickly enough to participate.

*During this talk, other people [with dementia] in the group made spontaneous comments about what [facilitator] was talking about it. No carers did.*

*- Fieldnotes, site 3*

Staff interviews suggested the importance of facilitation in whether, and how, carers or people with dementia were involved in group conversations. For example, a facilitator at site 1 suggested it was important to give people with dementia space in the conversation which then enables them to contribute. This was also seen at session observations with the same facilitator at site 1, where people with dementia responded when brought into the conversation individually, but only carers were involved in the conversation at other times when they were not.

*I think you do have to, yeah, maybe give people more time, be very conscious of giving people more time, and stop being that person who has to fill a gap, a silence, with chatter of any kind.*

*- Facilitator interview, site 1*

*[Facilitator] asks [person with dementia] directly what she thinks, and [person with dementia] says she wouldn't want the painting in her house because it reminds her of places she went when she used to be a nurse. [Carer] talks to [facilitator] about his preferred piece so far. Note – though she will sometimes, [person with dementia] makes far fewer spontaneous comments when not asked directly, but does always have something to say when she is asked.*

*- Fieldnotes, site 1*

However, one facilitator at site 6 suggested this was not a good method for involving people with dementia in conversations as direct questions can be more anxiety-provoking for some, which actually makes it harder for them to be involved. It is therefore important to note that not all facilitation techniques work for all people.

*And because I also do recall, with my mother, the last thing that was a red rag to a bull if you asked a direct question. Because there's that concern of "golly I'm being asked a question here, I know I don't know the answer" and then getting upset or getting angry or confused, and so one has to phrase things, the questions, sort of differently.*

*- Facilitator interview, site 6*

All staff who were interviewed were asked about how they manage group conversations in which more carers were participating than people with dementia. Some staff members discussed how it was difficult to plan how to balance these conversations because they do not know the participants' needs and wants as they often do not know them well or sometimes meet them for the first time at the session.

*Afterwards, [facilitator] talked about how it's difficult to prepare sometimes because you have to adapt what you're going to say depending on who's there and how many's there. Also said she wasn't sure when [person with dementia] was talking when to bring her comments into the group and when she wanted to*

*talk more to herself. Said one time she did [try to bring her in], [her carer] said “oh it’s okay, you carry on”.*

*- Fieldnotes, site 1*

*[Facilitator] said at times he wasn’t sure whether [person with dementia] was trying to say something or not, so wasn’t sure how much space to give her without it being a silence with everyone looking at her. He said a few times he gave more space and other times less, but sometimes felt uncomfortable when there was more silence and she didn’t seem to be wanting to talk after all.*

*- Fieldnotes, site 2*

But staff members described a number of different facilitation strategies to include people with dementia more in group discussions, such as putting more attention on the person with dementia, occupying the carer with something else, or asking the person with dementia more direct questions.

*I think I would actually put my attention a bit more on the person with dementia, spending a bit more time with them. I might say something, or I might kind of do...I think maybe it’s a bit of a kind of distraction thing, and kind of moving to a slightly different angle on the activity or whatever it is you’re talking about. And almost maybe kind of model something a bit, kind of suggest a way of “oh we could do it like this” or “we could answer it this way” or “what do you think if...”. Yeah, so I might suggest, I might suggest another option. Or I might be a bit more subtle in my kind of body language towards the person I thought wasn’t quite getting the space, I might be asking them quite specific questions directly.*

*- Manager-facilitator interview, site 2*

However, staff also said it was not just about balancing between those who have dementia and those who do not, but also balancing between those with more or less museum experience, or differing levels of interest in the museum:

*I’m sure that, for example, the guy that was quite excluded, the very middle-class guy who was quite well-educated, and the other lady that’s middle class and quite well-educated, they would have quite liked a dementia group but of their own intellectual level.*

*- Support staff interview, site 2*

They also said it was about balancing between people with dementia who have differing symptoms and a range of abilities, for example between those who are non-verbal and those who are verbally very articulate:

*The staff discussed the session having a mix of abilities – from James [person with dementia] who was quite articulate and very informed about the art/museum, to Bill [person with dementia] who was non-verbal. Staff said this was the widest range of abilities they'd had on the programme, but felt it still worked well for everyone. They noted the smaller group than expected, which meant that everyone got individualised attention as there was a high staff to participant ratio.*  
- Fieldnotes, site 2

Staff interviews at sites 1 and 2, and a session observation at site 4, suggested the mechanism was not just about poor facilitation, however. They suggested that the session being a new, enjoyable activity for the carer, which they do not have very often, meant that carers dominated conversations through their enthusiasm. This may also link with the questions around who the programme is for from the perspective of the dyad (Chapter 5, section 5.4). For example, for one dyad at site 1, the sessions seemed more for the carer's interest than the person with dementia's, and the carer was usually very often involved in group conversations in the session whereas the person with dementia was rarely involved unless asked a direct question.

*After the session, the facilitator said she notices the support workers can ask for lots of historical facts, which isn't what the session is about and can overload people.*  
- Fieldnotes, site 4

*I think one of the dangers sometimes then is [the carers] get really comfortable and also really enjoy it and sometimes they dominate just by the amount of time that they then want to speak, because it's also a space that they're not getting very much.*  
- Manager interview, site 1

There was no evidence directly related to the theory's outcome of whether the person with dementia then cannot engage in the session. The only two people with dementia who were interviewed did participate in group conversations. However,



there was evidence around considering what ‘engagement’ means. In fieldnotes at sites 1, 2, and 3, it was noted that some people with dementia seemed to be engaged non-verbally – through smiling, nodding, and pointing, for example. It is possible that, in group conversations, some people with dementia are engaged in the way they want to be, or that works for them, but this is non-verbal rather than verbal, whereas the carers are engaged in a verbal way. For example, the facilitator at site 2 quoted earlier, who was concerned whether he was giving a mostly non-verbal person with dementia the right amount of space to speak, also said:

*[Facilitator] said that [person with dementia] was mostly non-verbal, and he felt it was nice that she was included in a lively conversation, even if she couldn't contribute verbally herself. He said she seemed very engaged with the painting and smiling at people.*

*- Fieldnotes, site 2*

Allowing for different ways of engaging may mean carers dominating conversations is not preventing all people with dementia from engaging, if engagement means something more non-verbal to them. It was not possible to determine what ‘engagement’ meant to individuals in the sessions I attended as I often only saw them in that one session, and not in any other situation or setting to see if they responded differently, for example, to a different type of facilitation. This means it is not possible to determine whether they were being prevented from engaging in the way they wanted.

This theory has therefore been refined. As this research concerns the impact of including carers, the issues around needing to balance between different members of the group for other reasons, such as familiarity with museums, has not been included in the theory. However, it will be considered when discussing potential implications and recommendations from the theories in Chapter 8.

Where there is poor facilitation or the carers are particularly enthusiastic about the activity (M/res), and the person with dementia finds it more difficult to speak up in a group setting (C), carers dominate group conversations (M/res), so the person with dementia cannot engage verbally, does not have a sense of belonging in the group, and cannot gain potential positive outcomes (O).

## 6.15 Theory (n)

From the review:

*“Where carers are not in contact, or have limited contact, with other carers (C), the activity happening in a group means carers meet others in similar situations (M/res) and feel connected to others in a similar situation and the wider community (M/rea), so feel less socially isolated (O), and leads some to continue friendships outside the group (O) or join other dementia-friendly groups (O).”*

The context for this theory was only hypothesised in the review, rather than developed through direct evidence within the review papers. There was some evidence to support it in this evaluation, where the ‘shrinking social world’ means the family carer has limited contact with other carers, in interviews with staff at sites 2 and 6, and one interview with a carer at site 4.

*...because it’s hard work and can be quite isolating because people do slip away from friendships because they can’t quite handle the fact that that person, the other person, has dementia. I witnessed this with a friend who lost her husband recently and she’s my age and she was dropped beca...particularly by her husband’s male friends, they just, they slipped away. Her girlfriends rallied around. And it was hard work for her. No break, that was partly because she was committed to being the carer, and it’s jolly hard work.*

*- Facilitator interview, site 6*

The same carer from site 4 and two members of staff at sites 3 and 4 suggested that carers feel less isolated through meeting others in a similar situation in the group (the theory’s mechanism resource).

*But I do think in the session that a lot of people find quite a comfort in meeting other people who are also caring for someone with dementia so that’s quite a nice addition.*

*- Manager interview, site 4*

*And it also helped me seeing people with similar problems and, you know, realising that you’re not alone.*

*- Carer interview, site 4*

Staff interviews at sites 4 and 6, and session observations at sites 3 and 5, suggested that carers also feel less isolated through sharing information, such as other groups they might find interesting.

*[The carer] also spoke to the [carer] who came alone and at the end told her about some volunteering she did near to where the person who came alone lived, and that she thought she would really enjoy it if she came too.*

*- Fieldnotes, site 5*

The one family carer who was interviewed said she then joined other dementia-friendly groups as a result of coming to the museum sessions:

*In the beginning we weren't going out very much and [the museum programme] was a place to go, for him to go. And it encouraged me to get us out more and do more things.*

*No, no, I was really sort of cautious about going out, then I realised it was really sort of easy and he was fine so, so we did it more.*

*- Carer interview, site 4*

But neither she nor her husband said they continued friendships outside of the sessions. Four studies in the review did report some, though not all, planning to socialise outside the group or continuing friendships (Baker, 2014; Burnside et al., 2017; Lamar, 2015; Roe et al., 2016). This aspect of the outcome will therefore remain part of the theory, but the word "some" will also remain to indicate the difference between this outcome and the outcome of feeling less socially isolated which can be applied more widely.

*And although I see the same people often, besides coming here I don't sort of socialise with them at all, it just hasn't happened that way. But they're familiar, you know, so it's just nice to see them and say hello and see how they're getting on.*

*- Carer interview, site 4*

Staff members from sites 1, 2, and 4 suggested that repeated visits or having a regular group of attendees helped sessions to be more social, as people were able to get to know each other over time which meant they formed closer relationships and were then more supportive of each other. This will not be included in the wording

of the theory, but will be considered in the conclusions and implications drawn, particularly in terms of why some carers may socialise afterwards but others do not.

*When we did have a bigger group and there were people like Adam, like the other guy who was a musician, there was Bill and Bill's wife, and quite a big group, they were turning up and talking to each other more, so we have to do that, less of the we're making chit-chat when everybody arrives, they were sort of saying "oh how are you, what have you been doing?". And it was more social for them.*

*- Facilitator interview, site 1*

Observations of sessions at sites 1, 2, 3, and 6, and staff interviews at sites 1 and 2 suggested carers also socialise in the session with staff, not just other members of the group. This may link with the 'wider community' aspect of theory (n).

*During the tea and cake, [dyad 1 carer] talked to [facilitator] about the exhibition...[Volunteer] sat next to [dyad 4 person with dementia] and they talked to each other about both having recently moved to the area.*

*- Fieldnotes, site 1*

Theory (n) has not been altered as a result of any results from the evaluation.

Where carers are not in contact, or have limited contact, with other carers (C), the activity happening in a group means carers meet others in similar situations (M/res) and feel connected to others in a similar situation and the wider community (M/rea), so feel less socially isolated (O), and leads some to continue friendships outside the group (O) or join other dementia-friendly groups (O).

#### 6.16 Theory (o)

From the review:

"A positive experience in the museum (M/res), in the context of a 'shrinking world' for the dyad (C), makes the dyad feel the museum is a 'safe place' they can return to (M/rea), so they intend to return outside of the group (O) and feel less socially isolated (O)."

The studies in the review which contributed to the development of this theory all described participants *intending* to return to the museum, rather than having any evidence they actually did. As well as providing further evidence of dyads intending to return, this evaluation found some dyads actually did return.

Both dyads who were interviewed said they used to go to the museum prior to dementia, often when they were younger, but, since coming to the programme, now come regularly outside of sessions. One staff member at site 3 also described meeting a person with dementia and her family who had returned to the museum outside of the session.

*But that one lady [with dementia] who had the bottle [in an object-handling session], she held the bottle for ages and there was a second bottle that was similar, and then the next month she didn't come, but I saw her in the galleries, in the [gallery]. And I said "Oh it's really nice to see you again. Who are you here with today?" And she said "Oh I'm here with my family, it's my birthday".*

*- Manager-facilitator interview, site 3*

*Yeah every once in a while we would come [to the museum]. Not very often, but we would bring the kids here or if we had a visitor we would bring them. But we come a lot more now [since coming to the sessions].*

*- Carer interview, site 4*

One staff member at site 1 said carers would tell her they would come outside of the session to use the café as a place to meet, suggesting the museum had become a safe place to return to:

*We've had couples who've started coming when the person with dementia is not so severe and then as time goes on, and I think people's social circles often get smaller and people get, both people can get more timid about going out or being in new spaces. And people have said that because they've carried, they've started going to the museum programme, at a certain point that's still a space that they can go out. And say if they're going into town that they can meet friends at the museum café, for example.*

*- Manager interview, site 1*

As illustrated by the previous quote, there was some suggestion that the museum becoming a 'safe place' becomes more important as a person's dementia progresses and the 'shrinking world' of the dyad increases. Where the dyad have had experience of the museum in sessions when the person with dementia's dementia was more mild, it is a familiar place they could return to, and a place in which the carer already has knowledge of the space, logistical access, and level of

support. One of the dyads tracked at site 1, who seemed to be in a transition of needing more support and increasingly struggling to go out, was also mentioned in a staff interview who suggested the museum had become one of very few 'safe places' for them:

*...and now I think, I think he's the one that pushes them to come. I think, one, because he enjoys it, and also because there's fewer and fewer things he can persuade his wife to do and that they can get to....So I do feel like that's quite a social lifeline for that couple now.*

*- Manager interview, site 1*

A staff member at site 3 also described examples of care home staff returning outside of a session with other residents, opening up the museum to people with dementia who had not attended the programme themselves, and suggesting it was perceived as a safe and interesting place to go with the people with dementia they support.

*Because one of the care homes, I saw a few months later, they came back [outside the session] but with different people.*

*- Manager-facilitator interview, site 3*

A staff member at site 2 said professional carers reported they intended to return to the museum outside of their caring role, such as visiting with family members. However, she, and all staff members, acknowledged it was difficult to get evidence of whether people do actually return. As most museums, and all museums in this research, do not require anyone to sign in, there is no record of who has visited the museum when. Staff members therefore only know if someone has returned to the museum if they tell them or they happen to be working on the same day and see them, as per the manager of site 3 quoted above.

The sessions may also open up the museum for professional carers in particular. Professional carers who work at a residential home, for example, do not necessarily choose to come to the museum sessions, but attend as part of their job role. There was some evidence from descriptions in staff interviews at sites 2, 3, and 6 of professional carers who were disinterested in the museum, but then enjoy the session, and return either with other residents or outside of their caring role.

*[Volunteer] said when she greeted the group from the care home she thought “this is going to be a hard sell”. She said before they came in they stood outside and the carers had a cigarette, and she heard them saying they wished they could stay outside in the sunshine and weren’t looking forward to the visit. When they came in, [volunteer] said she tried to enthuse about things they were passing on the way the lift but the group were “completely silent and didn’t respond”. But said she was pleasantly surprised in the way the carers totally opened up once they got settled into the session. She said that every time they run this sort of programme there are always one or two who she gets that feeling with but then they always leave feeling energetic and full of enthusiasm.*

*- Fieldnotes, site 2*

This theory also links with the ideas around the carer controlling access to the sessions in section 5.5 of Chapter 5. If carers control the access for the dyad, then the carer feeling comfortable in the space not only helps them both to attend the session initially, but the feeling that it is a ‘safe place’ is also the mechanism which leads them to return outside of the session. If the person with dementia attended the group alone, it would be unlikely to become a safe place for the carer, and so unlikely the dyad would go to the museum outside of sessions.

Theory (o) has not been revised in the light of evidence from the evaluation, but a new theory has been developed specifically related to disinterested professional carers:

A positive experience in the museum (M/res), in the context of a ‘shrinking world’ for the dyad (C), makes the dyad feel the museum is a ‘safe place’ they can return to (M/rea), so they intend to return outside of the group (O) and feel less socially isolated (O).

Professional carers who would not choose to come to the museum and are not interested in it (C), experience an engaging, participatory session where carers are included (M/res), so feel the museum is an enjoyable or interesting place (M/rea), and return outside of the session (O). They return in two ways:

- a) Personally outside of work roles (such as with family)
- b) Professionally with other residents who did not attend the session (the museum becomes perceived as a good place to visit with the people with

dementia they support more generally, and the sessions indirectly open up the museum to people with dementia who did not attend a session themselves).

#### 6.17 Theory (p)

From the review:

“A positive experience in the museum (M/res), in the context of a ‘shrinking world’ but where the carer does not have capacity to include leisure in day-to-day life (C), means the carer does not see the museum as a place they can return to (M/rea), so they do not intend to return and do not feel less isolated (O).”

Museum staff at sites 1, 4, and 6 described instances where carers (and so dyads) had not returned to the museum due to a lack of capacity or resources to do so:

*[Support staff] also said that as [the dyad] left to get into the taxi, [carer] gave her a big hug and said “thank you so much for this”. She said in the session [carer] had said [person with dementia] doesn’t get to go out very often as her family can’t pay for wheelchair-accessible taxis, so she usually only goes out once a month, so that’s why she’s so happy being here. [Contextual note: site 2 pays for participants’ travel to the sessions]*

*- Fieldnotes, site 2*

As described in section 5.3 in Chapter 5 on caring responsibilities, although carers always have some responsibility for the person with dementia, the programme also always takes some responsibility from carers in terms of the structure of the session, logistical support within the museum, and the activity and its clean-up if required. Going to the museum outside of sessions means going to the museum without this additional support, which may mean the level of caring responsibilities is too much for the carer. One staff member at site 4 also pointed out that many museums do not have a quiet rest area, so dyads could not take a break if needed during a trip, whereas the tea and coffee room can be used for this purpose during a session.

*I think also I can imagine organising a visit to a museum that’s outside of that kind of structured format where you’re kind of looked after by a group of people must be quite stressful and kind of depends on how people are feeling that day and it’s, I guess there must be a bit of a sense of “okay, we can come here and then we’re*



*going to get told where to go and what to look at". Because it's quite an overwhelming building and there's lots of stuff in here, and you can get lost very easily.*

*- Manager interview, site 6*

The theory from the review was therefore revised as follows:

A positive experience in the museum (M/Res), in the context of a 'shrinking world' but where the carer does not have capacity to include leisure in day-to-day life or who need the additional logistical support of a session (C), means the carer does not see the museum as a place they can return to outside of sessions (M/rea), so they do not intend to return and do not feel less isolated (O).

#### 6.18 Final developed programme theories from the evaluation

The programme theories developed through the literature review (Chapter 3) and the evaluation (Chapters 5 and 6) will be used to develop a reusable conceptual platform in Chapter 7 (explained further in Chapter 7). Table 4 lists all twenty-eight of the refined theories from Chapters 5 and 6, and allocates them a 'theory number' so that they can easily be referred to in Chapter 7.

Table 4. Numbered list of refined programme theories

Theory number	Refined programme theory
1	When the carer wants to enjoy the session separately (C), high staffing levels (M/res) mean the staff are able to support the person with dementia when needed (M/rea), so the carer has fewer responsibilities (O) and is able to enjoy the session alone (O).
2	When the carer wants to enjoy the session separately but the person with dementia wants to be close to them (C), then either: a) High staffing levels (M/res) mean the staff support the person with dementia (M/rea), so the carer can enjoy the session alone (O) but the person with dementia is unhappy or stressed (O). b) The carer supports the person with dementia (M) so the dyad stays together (O), but the carer is unhappy or stressed (O).
3	When the carer has always enjoyed the session through being separate (C), but the person with dementia's support needs have increased as their dementia progresses (C), the carer provides more support in the session (M), and is unhappy or stressed as they can no longer use the session for traditional respite (O).
4	In the context of the carer being the one who finds out about the programme and decides whether to attend (C), the person with dementia (dyad) does not attend (O) when the programme does not provide the resources needed to support the carer to feel comfortable or able to attend (M).
5	Where the carer is trying to hold on to the person with dementia's previous identity/interests (C), they try to make the person with dementia engage in a particular way tied to this (M). The person with dementia does not want to (M) and feels annoyed and cannot engage in the way they want to (O).
6	<i>Where the dyad is unsure of new activities to try or often does the same type of activities (C), coming to a new/different kind of activity that the person with dementia enjoys/engages in (M), means the carer seeks out similar activities or replicates them at home (O). In care home groups, the activity is replicated with other residents who did not attend the session (O), extending the impact to those people with dementia outside of the session itself.</i>
7	<i>Where the dyad's home interactions are mainly about caring tasks or with limited leisure activities (C), doing a shared activity outside of caring routines (M) means they have new things to talk about and share with others after the session (as well as during) (O).</i>

8	Where carers are unsure if the session is for them or are feeling stressed at the beginning of the session (C), museum staff serving them tea (M/res) helps carers to feel they can also participate, they do not hold all of the responsibility in the session, and gives them space to relax (M/rea). The carer then feels less stressed and welcomed (O).
9	When the facilitation enables the person with dementia to 'maximise capacity' to participate in an activity outside of their usual routine (M/res), the person with dementia responds in a new or unexpected way (M/rea). Where the carer's expectations of the person with dementia are low (C), and/or others in the group highlight the person with dementia's capabilities (C), the carer sees the individual person with dementia in a new way (O) or reconsiders the activities in which people with dementia in general are capable of engaging (O).
10	Professional carers who only have a relationship with the person with dementia in a work context with limited opportunities for shared or social activities (C), take part in a shared activity outside of the work context (M/res) and are able to get to know the person with dementia beyond dementia (M/rea), which builds their relationship.
11	Where dyads do not know each other well, or the person with dementia has changed some of their interests or aspects of their identity (C), sharing an experience outside of their usual routine on an equal basis (M/res) means they have meaningful or new communications and interactions (M/rea) which helps the carer to see the person with dementia in a new way (O) and build their relationship (O).
12	In dyads where the carer does not know the person with dementia well (C), is unsure how to support the person with dementia (C), or has fallen into habitual patterns of interacting (C), staff interacting with the person with dementia in a new way (M/res) means carers learn new ways to interact with them and new strategies (M/rea), which builds their relationship through improved communication and a focus on process rather than product (O).
13	Where the person with dementia has anxiety, or is anxious about new activities or new people (C), the carer reassuring or modelling taking part in a shared activity (M/res) helps the person with dementia to feel comfortable/able to take part (M/rea), so the person with dementia is able to participate without anxiety (O), but the carer cannot be separate within the session (O).
14	Where the dyad's home interactions are mainly around caring and they want to spend time together (C), enabling facilitation of an activity not about dementia in a community setting, in which the carer only has to provide the level of care for the person with dementia that they want to (M/res), means the dyad can participate on an equal basis (M/rea), which leads to the dyad experiencing shared respite from dementia/caring roles (O), which also helps strengthen their relationship (O).
15	Shared respite (C) means the dyad can interact and communicate outside of dementia roles (M), which builds their relationship (O) and also feeds back into enjoying the activity together (O).

16	The participatory activity with a 'product' that is outside of their daily routine (M/res), <i>in the context of high carer expectations or a dyad struggling to accept dementia (C)</i> , means the family carer compares the person with dementia's current abilities to their former abilities or with other people with dementia in the group (M/rea), which leads to the group highlighting losses or reinforcing limitations (O).
17	Where the family carer feels respite in the session (C), they realise they are missing other activities they enjoy (M), and this highlights personal losses for the carer (O).
18	When personal losses are highlighted for the family carer (C), they realise they need to find activities just for them and seek them out (M), and then join other groups without the person with dementia (O) if they have the capacity to do so.
19	<i>Where the family carer has high expectations of the person with dementia (C)</i> or the group highlights losses (C), the carer does not perceive the person with dementia's capabilities or feels upset (M), so the carer does not feel respite (O) and does not see the person with dementia in a new way (O).
20	When the carer has high levels of caring responsibilities in the session (C), they cannot engage with the activity (M), so they do not feel respite or enjoy the activities (O).
21	Anxious carers (C) intervene on the person with dementia's behalf (M), so the person with dementia cannot engage fully (O) and the carer has no respite (O).
22	Where the person with dementia struggles with speaking or finds it stressful (C), the carer answers for them in the group or translates their answers for others (M), so the person with dementia is able to engage in a way which is comfortable for them (O).
23	Professional carer-person with dementia dyads have only had a caring/work relationship so find it harder to step out of caring roles (C), or museum staff perceive professional carers to only have a caring, and less participatory, role (C). This means the carer intervenes on the person with dementia's behalf or does not participate themselves (M), and the person with dementia and/or professional carer cannot engage fully (O) or gain potential relationship-building outcomes (O).
24	Where there is poor facilitation or the carers are particularly enthusiastic about the activity (M/res), and the person with dementia finds it more difficult to speak up in a group setting (C), carers dominate group conversations (M/res), so the person with dementia cannot engage verbally, does not have a sense of belonging in the group, and cannot gain potential positive outcomes (O).

25	Where carers are not in contact, or have limited contact, with other carers (C), the activity happening in a group means carers meet others in similar situations (M/res) and feel connected to others in a similar situation and the wider community (M/rea), so feel less socially isolated (O), and leads some to continue friendships outside the group (O) or join other dementia-friendly groups (O).
26	A positive experience in the museum (M/res), in the context of a 'shrinking world' for the dyad (C), makes the dyad feel the museum is a 'safe place' they can return to (M/rea), so they intend to return outside of the group (O) and feel less socially isolated (O).
27	Professional carers who would not choose to come to the museum and are not interested in it (C), experience an engaging, participatory session where carers are included (M/res), so feel the museum is an enjoyable or interesting place (M/rea), and return outside of the session (O). They return in two ways: a) Personally outside of work roles (such as with family) b) Professionally with other residents who did not attend the session (the museum becomes perceived as a good place to visit with the people with dementia they support more generally, and the sessions indirectly open up the museum to people with dementia who did not attend a session themselves).
28	A positive experience in the museum (M/Res), in the context of a 'shrinking world' but where the carer does not have capacity to include leisure in day-to-day life or who need the additional logistical support of a session (C), means the carer does not see the museum as a place they can return to outside of sessions (M/rea), so they do not intend to return and do not feel less isolated (O).

### 6.19 Conclusion

This chapter mapped findings from the evaluation to the theories developed in the review, and refined those theories where the evaluation evidence suggested. Four new theories were also developed related to review theories (h), (k), and (0). A complete table of all twenty-eight programme theories refined in Chapters 5 and 6 was given at the end of the chapter. Chapter 7 will use the use the programme theories developed in Chapters 5 and 6 to create a reusable conceptual platform (explained further in Chapter 7).

## Chapter 7 - Conceptual platform

### 7.1 Introduction

The results of the evaluation were discussed in Chapters 5 and 6. From these findings, 28 programme theories were developed on how including carers in museum programmes for people with dementia has an impact. This chapter will develop a reusable conceptual platform based on these programme theories. I will first discuss what a conceptual platform is and why it is useful, and then discuss the core processes of the platform in relation to UK policy and wider literature on dementia, caregiving, and museums. The implications, potential areas for further research, and limitations will be discussed in Chapter 8.

### 7.2 Conceptual platform of including carers in museum programmes for people with dementia

Programmes are rarely, if ever, built on entirely new ideas, but evaluations of those programmes often start anew each time. This is an issue in evaluating complex interventions or programmes as no one evaluation can cover absolutely every aspect of that complex system (Pawson, 2013). Programme theories can lie on continuum between higher levels of abstraction (generalisability) and higher levels of specificity (relevance to particular setting), and Pawson (2013) has used the term ‘programme theory’ to refer to both more specific and more abstract theories (Shearn, Allmark, Piercy, & Hirst, 2017). In realist terms, this can be thought of as being in the ‘middle-range’ of abstraction to a greater or lesser extent. In order to test programme theories in other evaluations and in other contexts, they need to be in the middle-range of abstraction, so the essential components, or core processes, of those theories must be identified (Pawson, 2013; Pearson et al., 2015). This is the conceptual platform. The conceptual platform allows theories to be tested in different programmes that share core processes, which means evaluations of different programmes can build on one another, and gives evaluations a starting point. For example, Pawson discusses the investigation of Megan’s Law, an “intervention designed to reduce predatory sex offences by identifying released, former offenders to the communities in which they settle” (Pawson, 2013: p93). He links this to the programme theory ‘public

disclosure', which is common across many different interventions, and identifies the component processes by which 'public disclosure' works, such as "the performance or behaviour in question must be identified and measured reliably and without ambiguity or error", "that data/information needs to be disseminated clearly and efficiently to the appropriate public", and so on. These could then inform the evaluation of Megan's Law by considering, for example, how the optimum boundaries of the 'appropriate public' to release the information to was defined, or how and whether that 'public' acts on that information. The results of the evaluation of Megan's Law could then be considered in an evaluation of another intervention which involves public disclosure. Pawson's example is of situating the programme under evaluation within an existing conceptual platform (in order to inform the evaluation). However, evaluations of specific programmes have also been used to develop a conceptual platform where there was little existing explanatory research in the area of interest (Pearson et al., 2015).

I am not evaluating how museum programmes for people with dementia work in general, but rather the impact of including carers in them. This gives my conceptual platform a small but significant difference to that proposed by Pawson. As stated in Chapter 1, many programmes and interventions for people with dementia include carers to some extent, so this could be considered a 'core process' of those programmes. However, there is often little thought given to the implications of this, and how it could impact, negatively or positively, the participants involved, as discussed in Chapter 1. This is why my focus is on this one process, rather than the more general processes of the programme. The difference, therefore, in my conceptual platform to that proposed by Pawson is that the core processes of my conceptual platform occur within the context of the core processes of how the museum programmes work in general, rather than standing alone. Though there may be similarities, there may also be differences in the impact of including carers in programmes which do not, for example, try to promote equal participation for both the carer and the person with dementia. This will be discussed further in Chapter 8 on implications and potential areas for future research.



### 7.2.1 Analysis methods

There is no specific, prescribed method for developing a conceptual platform. As described above, the conceptual platform should be at a level which is generalisable to other programmes or contexts. For this reason, I approached the development of my conceptual platform through abstraction and casing. Abstraction is the ‘process that allows us to understand an event as an instance of a more general class of happenings’ (Pawson, 2013: p89). This means using inductive reasoning – making broad generalisations from specific observations or data through focusing on commonalities in the phenomena being studied (Swedberg, 2019). This technique of abstraction has been used in realist research to ‘case’ the data to connect ideas and theory (Astbury, 2018). In this context, ‘casing’ refers to Ragin’s (Ragin & Becker, 1992) definition of it being a research activity which makes the linking of the theoretical and the empirical possible through inductively grouping ideas and deciding what evidence is the most relevant to use. It is therefore closely linked to the idea of abstraction. In practical terms, I used an iterative process of refinement. Firstly, I developed my question of “what are the core processes involved when carers are included in museum programmes?” This gave my analysis focus, particularly as conceptual platforms are usually created to represent how a programme works overall, whereas I was interested in a specific component that sat within how museum programmes work. I then listed the key concepts or ideas from each of the programme theories developed in the review, for example, “professional carers get to know the person with dementia outside of their caring role”. I then annotated this list to refine the language and case similar ideas into more general ones, such as the previous example becoming part of the idea of building the relationship between the carer and the person with dementia. Through this refinement I iteratively moved between the draft core processes and the programme theories to ensure the work was grounded in evidence. Following refinement, I also annotated the final list of core processes with the links between them, for example “carers bringing knowledge of the person with dementia which helps the museum staff to support them” linking to “the carer can enable the person with dementia to participate”. Processes which were

closely linked were not combined where they also provided unique perspectives or insights in their own right.

#### 7.2.2 Core processes

This analytic method led to the development of twenty-three core processes involved when carers are included in museum programmes for people with dementia. They include impacts on the person with dementia, the carer, and the relationship between them, as well as both positive and negative impacts. These core processes do not stand alone, but sit within the context of the processes of how these museum programmes work – equal participation, in-the-moment wellbeing, not being about dementia, enabling facilitation, and held in a community-based, valued place.

- a. Carers hold the ultimate responsibility for the person with dementia (so the museum does not have to).
- b. The carer's level of responsibilities in the group can prevent them from engaging in and enjoying the activity.
- c. High staffing levels and the session structure take some responsibilities from the carer.
- d. Serving tea to carers helps them to feel the session is also for them, to socialise, and to relax after a stressful journey.
- e. The carer can enable the person with dementia to participate.
- f. Carers bring knowledge of the person with dementia which helps the museum staff to support the person with dementia.
- g. Museum staff can have differing expectations of different carer types, impacting the carer's experiences.
- h. Some dyads enjoy the session together, but others use it as an opportunity for traditional respite from one another.
- i. The dyad can experience shared respite from dementia and their caring roles.
- j. There can be mismatch in the way the carer and the person with dementia wants to use the session, which can cause tension or distress.
- k. Carers control whether the dyad (and so person with dementia) attends and/or returns.

- l. Carers can prevent the person with dementia from engaging fully.
- m. Carers can dominate the activities or discussions.
- n. The session can highlight losses for the family carer.
- o. The family carer can compare the person with dementia to other people with dementia in the group or with their past selves.
- p. The impact of the programme can extend beyond the session or with other people with dementia who did not attend.
- q. The session can build the relationship between the carer and the person with dementia.
- r. The session gives the dyad new things to talk about outside of caring tasks.
- s. Carers can learn new ways of interacting with the person with dementia and/or new strategies for working with them.
- t. The carer may reconsider what the person with dementia (or people with dementia generally) are capable of doing, or see the person with dementia in a new way.
- u. Carers can meet others in similar situations and feel less isolated.
- v. The museum becomes a safe place for the dyad to return to in the future.
- w. The museum is opened up as an enjoyable and interesting place to visit for previously disinterested professional carers.

Table 5 below maps all of the programme theories developed in Chapters 5 and 6 to these core processes. For brevity, theory numbers from Table 5 at the end of Chapter 6 have been used rather than the describing the whole programme theory.

*Table 5. Programme theories mapped to core processes*

<b>Core process</b>	<b>Programme theory number</b>
Carers hold the ultimate responsibility for the person with dementia (so the museum does not have to).	2
The carer's level of responsibilities in the group can prevent them from engaging in and enjoying the activity	2, 20, 23
High staffing levels and the session structure take some responsibilities from the carer	1, 2

Serving tea to carers helps them to feel the session is also for them, to socialise, and to relax after a stressful journey.	8
The carer can enable the person with dementia to participate	2, 13, 22
Carers bring knowledge of the person with dementia which helps the museum staff to support the person with dementia.	22
Museum staff can have differing expectations of different carer types, impacting the carer's experiences	20, 23
Some dyads enjoy the session together, but others use it as an opportunity for traditional respite from one another	1, 2, 3
The dyad can experience shared respite from dementia and their caring roles	14, 15
There can be mismatch in the way the carer and the person with dementia wants to use the session, which can cause tension or distress	2, 3, 13
Carers control whether the dyad (and so person with dementia) attends and/or returns	4, 26, 27, 28
Carers can prevent the person with dementia from engaging fully	5, 21, 23, 24
Carers can dominate the activities or discussions	24
The session can highlight losses for the family carer	16, 17, 18, 19
The family carer can compare the person with dementia to other people with dementia in the group or with their past selves	5, 16, 19
The impact of the programme can extend beyond the session or with other people with dementia who did not attend	6, 7
The session can build the relationship between the carer and the person with dementia	7, 10, 11, 12, 14, 15
The session gives the dyad new things to talk about outside of caring tasks	7, 11, 15
Carers can learn new ways of interacting with the person with dementia and/or new strategies for working with them	6, 9, 12
The carer may reconsider what the person with dementia (or people with dementia generally) are capable of doing, or see the person with dementia in a new way	6, 9, 11
Carers can meet others in similar situations and feel less isolated	25
The museum becomes a safe place for the dyad to return to in the future	26, 28
The museum is opened up as an enjoyable and interesting place to visit for previously disinterested professional carers	27

The core processes will now be discussed in more detail, with reference to their corresponding programme theories and wider literature, including middle-range and substantive theories. As discussed in Chapter 2, there is overlap in the definitions of 'middle-range' and 'substantive' theory. Middle-range theory refers to theory which is "specific enough to generate hypotheses (for example in the form of propositions) to be tested in a particular case, or to help explain findings in a particular case, but general enough to apply across a number of cases or a number of domains" (Wong, Westhorp, Pawson, & Greenhalgh, 2013; p15). Substantive theory, however, is described in the same training materials as "existing theories within particular disciplines...For example in the social sciences, theories may deal with topics such as 'cognitive development', 'deviance control', 'incentivisation' or any of the wider ambitions of interventions." (Wong et al., 2013; p15). Substantive theory is thus also in the middle-range of abstraction, but may be considered a more established or overarching theory. A conceptual platform is at the 'middle-range' level of abstraction, as it aimed to apply to both the specific programmes in this research and to other programmes (Pawson, 2013). However, it also needs to be situated within existing research and theory, and the wider context, which means considering other studies, policy documents, other middle-range theory, and substantive theory.

For ease of discussion, the core processes have been grouped into seven sections: caring responsibility, session function, controlling access, preventing engagement, losses and comparisons, long-term impact, and reduced social isolation.

### 7.2.3 Caring responsibility

Core processes:

- a. Carers hold the ultimate responsibility for the person with dementia (so the museum does not have to).
- b. The carer's level of responsibilities in the group can prevent them from engaging in and enjoying the activity.
- c. High staffing levels and the session structure take some responsibilities from the carer.

- d. Serving tea to carers helps them to feel the session is also for them, to socialise, and to relax after a stressful journey.
- e. The carer can enable the person with dementia to participate.
- f. Carers bring knowledge of the person with dementia which helps the museum staff to support the person with dementia.
- g. Museum staff can have differing expectations of different carer types, impacting their experiences.

As discussed in section 5.3 of Chapter 5, museum staff stated that carers were included in sessions due to their caring role and the responsibilities the museum could not hold. There are legislative reasons why carers (both professional and family) held the ultimate responsibility for the person with dementia in the sessions. The Care Act (Care Act 2014) defines a person as an at-risk or vulnerable adult if they need care and support (whether the local authority provides that care or not), is experiencing (or at risk of) abuse or neglect, and as result of their care and support needs is unable to protect themselves from abuse or neglect. Similarly, the definition of 'vulnerable adults' in the UK government's Safeguarding Vulnerable Groups Act (Safeguarding Vulnerable Groups Act, 2006) includes people living in care homes or sheltered housing, and people who require assistance in the conduct of their affairs. People with dementia may therefore be classed as at-risk or vulnerable adults if they live in a care home or if they need support with activities of daily living such as managing finances, personal care, or leaving the house. It could be argued that all people with dementia in my research were vulnerable adults as they all had carers, given the Care Act does not require that a carer be a professional or formal carer for the definition to apply. In the UK, people are required to have an enhanced Disclosure and Barring check (DBS check) if they do any regulated activity with a vulnerable adult, which includes activities such as personal care or supervising personal care (Disclosure & Barring Service, 2018). As providing personal care is not a usual activity of a museum staff member's role, it may be unlikely that they have the required DBS check to support a person with dementia with personal care should they require it. These caring tasks are also not part of a museum staff member's job description, so there is no expectation that they would

undertake these tasks. Additionally, there may be other issues related to a person with dementia potentially being classed as a 'vulnerable adult'. For example, if a person with dementia decided they wanted to leave a session early, not having a carer present who is ultimately responsible for the person and knows them may put museum staff in a position of needing to assess whether that person is vulnerable and/or needs support to safely return home. In a typical public programme, such as a guided tour, the museum has a safeguarding responsibility but does not need to take a formal responsibility for assessing who is a 'vulnerable adult'. This, again, is beyond the scope and training of a typical museum staff member's role.

However, these responsibilities around regulated activity and vulnerable adults do not encompass all of the different kinds of responsibilities carers held, and do not mean that museum staff can hold no responsibilities. A less formal definition of 'caring responsibilities' includes supporting the person with dementia to participate in the activity by, for example, explaining the activity in a new way or repeating instructions. Some of these responsibilities can, at times, be held by museum staff. For example, in section 5.2 of Chapter 5 on session function, museum staff discussed supporting the person with dementia with the activity so the carer could enjoy the session separately. One of the ways programmes indicated to carers that they did not hold all of the responsibility was by serving them tea. A study on memory cafes also found that part of carers' enjoyment of the cafes came through a feeling of being looked after by the volunteers (Greenwood, Smith, Akhtar, & Richardson, 2017a), or not needing to do all of the 'looking after' themselves. However, museum staff taking some of these responsibilities was not always possible, for example if the person with dementia specifically wanted or needed the carer to provide that support (as discussed in section 6.6 of Chapter 6). This will be discussed further in section 7.2.4 on core processes about session function.

Core process (g) refers to staff expecting more of a caring and support role from professional carers than family carers. As previously discussed in Chapter 6, attending the session is part of a professional carer's working day, rather than part of their leisure time, which is perhaps why museum staff

expect them to be in more of a caring role (i.e. working), and why professional carers sometimes find it hard, or do not expect, to step out of their caring role. This may also be related to ideas around what 'person-centred care' means. 'Person-centred care' is a commonly used term in the UK care sector but it is often poorly defined and can have different meanings for different people (Brooker, 2003). In the UK National Service Framework for Older People (Department of Health, 2001), person-centred care is one of the key standards of care, and is focused around treating people as individuals. Likewise, guidelines on supporting people with dementia includes this focus and states person-centred care should be a part of the training of professional carers (National Collaborating Centre for Mental Health, 2011). This may imply, in care work, it is the individual with dementia which is the sole focus. However, models of person-centred care also have a relational element (McCormack, 2004), implying relationship-building between the person with dementia and their professional carer is also a part of person-centred care. National guidelines focus more on the individual aspects of person-centred care, but less on the relational aspects, which may also reflect Kitwood's (1997) lack of attention to the person with dementia's ability to reciprocate in the relationship, rather than simply personhood as something that is 'done to' them (Bartlett & O'Connor, 2007). It would therefore be unsurprising that some museum staff have an expectation that professional carers do not participate in activities because their relationship with the person with dementia is not given the same emphasis. There may also be differences in how professional carers themselves view or enact person-centred care as different carers define it differently, and care homes have differing organisational cultures which can impact issues such as how it is implemented and how well staff are supported to provide person-centred care (Kirkley et al., 2011). As mentioned in Chapter 3, a study found some residential staff were hesitant to engage with interventions promoting closeness because they feared getting emotionally attached to the person with dementia (Rapaport et al., 2017). This may mean that, even if a professional carer believes their relationship with the person with dementia does form a part of person-centred care, they still may not engage fully with the activities in the session. If this hesitation is common, this may also



influence the view of museum staff that professional carers are in more of a supportive, rather than participatory, role.

Despite the relationship between the person with dementia and the carer being important for all dyads, different dyad types may, at times, need to be treated differently as they may need different kinds of support. As discussed in Chapter 3, the socio-relational challenges faced by different dyad types are likely to be different (Rausch et al., 2017). Additionally, the programme theories which highlighted possible areas of distress in sessions for carers all related to family carers, not professional carers, due to the nature of their closer or more long-standing relationships. Differing expectations is therefore not necessarily negative, as it may link to needing to view different dyad types differently in order to provide the most appropriate support. However, there may be an impact on outcomes such as relationship-building, or the museum being opened up to professional carers, where staff do not expect or encourage professional carers to participate in the activities with the person they support.

#### 7.2.4 Session function

##### Core processes:

- h. Some dyads enjoy the session together, but others use it as an opportunity for traditional respite from one another.
- i. The dyad can experience shared respite from dementia and their caring roles.
- j. There can be mismatch in the way the carer and the person with dementia wants to use the session, which can cause tension or distress.

Respite is usually defined as giving the (family) carer a break from their caring responsibilities and the stresses of caregiving, with the aim that this will allow the carer to continue in their caregiving role for longer and to provide better care, as well as improving the relationship between the carer and the person with dementia (Maayan & Lee, 2014). UK government policy on carers includes providing or improving respite services for carers as a priority (Department of Health and Social Care, 2018a; National Collaborating Centre

for Mental Health, 2011), and research conducted for these policies report carers stating accessible respite care would significantly improve their lives (Department of Health and Social Care, 2018b). However, despite respite care being a priority for both providers and carers themselves, there is relatively low use of respite services (Phillipson, Jones, & Magee, 2014). Carers and service providers may be conceptualising 'respite' differently, with services focused on respite as a physical break, but carers focused on the psychological break from caring (O' Shea et al., 2019). Because carers need to experience a psychological break from caring to feel respite, conceptualising 'respite' as simply a physical break from the person with dementia is inadequate and may contribute to the low uptake of services (O' Shea et al., 2019).

Chappell, Reid and Dow (2001) proposed conceptualising respite as an outcome, not a service, to put carer experiences at the centre. As discussed in Chapter 5 (section 5.2), Chappell, Reid and Dow's (2001) conceptualisation of respite included 'internal respite', in which the carer feels respite, or that they are taking a break, whilst remaining in the caregiving situation – i.e. the carer can feel respite without having a physical break from the person for whom they are caring. This also links with the idea of shared respite (Burnside et al., 2017), in which the dyad has a break from their caring/cared-for roles with a focus on the relationship not defined by dementia. Additionally, although respite is almost always about a break for family carers, shared respite, with its focus on the relationship, is also relevant to professional carers and building their relationship with, and knowledge of, the person they support. Shared respite also considers respite for the person with dementia from 'dementia' and their cared-for role, whereas other conceptualisations and means of respite are focused solely on the carer and the break (physical or psychological) for them. Dyadic programmes, such as the museum programmes which are the focus of my research, could therefore also be considered a place of respite, despite not meeting the traditional, policy definitions of respite as a physical break.

There are a number of reasons why carers do not always use traditional respite services or find them helpful. For example, family carers sometimes

use traditional respite services to complete other tasks (such as chores) that they struggle to do when the person with dementia is present, so it does not actually serve as the break they need (Parahoo, Campbell, & Scoltock, 2002). Experiencing respite may therefore be easier for some carers on museum programmes, as it is not about doing other tasks but enjoying the activities as a psychological break. This may also link with the finding that carers are more likely to feel respite when they feel the person with dementia is being engaged in meaningful occupation rather than 'busywork' (Hochgraeber, von Kutzleben, Bartholomeyczik, & Holle, 2017), and when the carer perceives there is a mutual benefit from a respite service for themselves and the person with dementia (O' Shea et al., 2019). It may be that the carers in museum sessions who appeared to find respite through being separate to the person they support in the session, were able to do so because they felt the activities were meaningful for them both.

Research has also suggested that carers need to give themselves permission to accept and use respite services (Strang, 2000). A study examining the use of day centres for respite by carers of people with dementia found that this self-permission process could be impacted by the day centre staff – either facilitating this process and subsequent use of the service, or reinforcing beliefs that the service was not a good fit and subsequent withdrawal (Phillipson & Jones, 2012). This may mean it is important for museum staff to recognise that carers use the session for respite in different ways (either together or separately from the person with dementia), and to demonstrate that they support this in order to allow carers to give themselves the permission they need. Serving tea (core process d in the previous section) is one way some already do this by demonstrating the session is also for the carer to enjoy.

One of the aims of experiencing respite is to improve or maintain the relationship between the person with dementia and the family carer (Maayan & Lee, 2014). One of the potential impacts of museum programmes found in my research is about relationship-building between the carer and the person with dementia (for both professional and family carers). This relationship-building was theorised to link to shared respite and interacting outside of their

caring/cared-for roles. This will be discussed further in section 7.2.8 on processes related to longer-term impacts.

Discussions of respite are normally centred on family carers needing a break from their responsibilities, likely because professional carers' responsibilities are part of their job and are time-limited to that job. However, as discussed earlier, shared respite can also include dyads with professional carers, and can be a positive process of learning new things about one another and relationship-building, which could contribute to better person-centred care (as considered in section 7.2.3). Additionally, professional carers are often low paid with limited formal training in dementia and they may also be at risk of burn-out due to the challenges of caring (Ballard et al., 2000). Shared respite whilst 'on the job' may therefore not only contribute to person-centred care, but also support the mental health of professional carers in the same way it may support the mental health of family carers.

Mental or emotional health has been found in a scoping review to be the most identified need of family carers with dementia, but studies did not offer many specific solutions to address this (Queluz et al., 2020). Respite is aimed to support the mental health of carers through having a break (Maayan & Lee, 2014), and has also been suggested as a key external resource for supporting the resilience of carers (Parkinson, Carr, Rushmer, & Abley, 2016). Parkinson et al (2016) also suggested a key component in resilience-building for family carers was safeguarding the carer's quality of life, including sustaining their hobbies and interests. Museum programmes, and other similar dyadic programmes, could support carers in this way through respite – both shared respite and when carers enjoy the session separately. However, this does then depend on both the carer and the person with dementia wanting to use the session in the same way, and for there to be adequate staffing levels to support the person with dementia if needed. For example, if attending the session and enjoying activities separately supports the carer's quality of life, it will be difficult for them if they are not able to do this when the person with dementia's needs increase and they then need to be with them to support them. This may be one reason why carers may struggle in sessions during

times of transition, as found with one couple in this research (discussed in section 5.2 of Chapter 5).

Finally, Silverman (2019) suggested that experiencing respite can also be an outcome related to place, rather than simply a mental or physical break from care. She argues that being in favourite places can facilitate a feeling of connection to themselves, others, and their environment, which can be a restorative experience. In this way, the museum as a space could in itself become a prompt and context for respite, beyond the session or programme. If the museum was previously a 'favourite place', attending the session and experiencing respite may be linked with being in the space, rather than simply the activities or style of facilitation. Alternatively, through attending the sessions, the museum may become a valued space which then becomes a prompt for respite when the dyad returns in the future outside of sessions (returning to the museum will be further discussed in section 7.2.9). This may also be linked with previous research on these museum programmes which found the museum being a valued, public place was a key component of how they facilitated positive outcomes (Camic et al., 2016). Therefore the core processes around respite may have additional power within spaces which are seen to be valued, become valued, or have architectural or design features the person enjoys (such as particular light fixtures; Silverman, 2019).

#### 7.2.5 Controlling access

##### Core processes:

- k. Carers control whether the dyad (and so person with dementia) attends and/or returns.

As discussed in Chapter 5 (section 5.5), carers enable the people with dementia to attend the session through being the person who finds out about and books the museum session, and the person who deals with the logistics of getting to the session, such as managing travel, parking, and navigation. This means that if the carer does not have the knowledge or resources to do these things, the dyad does not attend, and suggests programmes need to consider what could make it accessible or comfortable for carers, even where the person with dementia is the main focus of the session.

There have been increasing calls to create 'carer-friendly' environments. The UK Government has issued the National Carers' Strategy (Department of Health and Social Care, 2008) and the Carers' Action Plan (Department of Health and Social Care, 2018a) which detail plans and proposals for supporting carers. These include encouraging businesses and services to have flexible working arrangements to allow carers to remain in paid employment if they wish, or to make appointments to use those services around caring responsibilities. Charities such as Carers UK have also emphasised the need for 'carer-friendly communities' across health, education, employment and local communities (Carers UK, 2016). These strategy documents largely apply to family carers rather than professional carers, however some of the issues, such as access to timely information about community services, may also apply.

How programmes like the museum sessions in this research become 'carer-friendly' in practical terms is a little less clear from the strategy documents. For example, flexible appointment times are not appropriate for group sessions where there does need to be set start and finish times. One way of considering how to make programmes carer-friendly is to examine what makes them not carer-friendly – in other words, what causes stress or difficulty for carers in attending, and what do they worry about before attending. This research did not specifically ask carers or staff what it is that makes a programme carer-friendly or not carer-friendly. As discussed in the prologue, prior to the pandemic, the final stage of this research was intended to include speaking to carers and people with dementia who were aware of their local museum programme but did not attend. This may have helped to uncover some of the reasons why dyads did not want to attend, including if there were barriers related to the carer. Despite this gap, there was some evidence on reasons why carers may struggle to attend.

Firstly, there was evidence of carer stresses. In the evaluation, as discussed in sections 6.11 and 6.12 of Chapter 6, there were two main reasons suggested why carers may feel stress. Museum staff suggested carers can be stressed at the beginning of a session from the logistics of getting to the museum, which may be from supporting the person with dementia to get

ready and leave the house, or from the journey to the museum. Museum staff also suggested carers can have general stresses in their caring role or lives which are then brought into the session. Though these were staff perceptions, rather than directly from carers themselves, these suggestions are supported by a study included in the literature review (Chapter 3) which reported carers feeling stressed due to the logistics of getting to/from or around the museum and the person with dementia's behaviour (Lamar, 2015; Lamar & Luke, 2016).

Secondly, having the time for activities like the museum sessions were also highlighted as a barrier. As discussed in the review, one carer in a study by Camic, Tischler, and Pearman (2014) stated they would not find the time to come to sessions in the future due to the day-to-day tasks of caregiving. Relatedly, cost was also an issue for some attendees. Only one programme in the evaluation (site 1) charged participants for the session, but participants had to meet the other costs of attending such as transport in all but one programme (site 2). Family carers in the UK have higher rates of poverty than non-carers (Joseph Rowntree Foundation, 2020) which means it may be difficult to pay for the transport to a free museum session. Additionally, care homes vary in their budgets for outside activities, and may depend on individual residents having adequate personal budgets. For example, one person with dementia discussed in section 6.17 of Chapter 6 lived in a care home and rarely went on outside trips due to lack of personal funds for accessible taxis.

Finally, comfort with, or knowledge of, the museum space and session activities may also be a factor. As discussed in Chapter 5, section 5.5, some carers at site 5 stated they would not have booked onto the sessions prior to an outreach session as they were not sure how suitable the tours or setting would be. Managers at site 4 and 5 sent carers pre-session information specifically because they felt it helped carers to feel more comfortable to attend by giving them information such as navigation, session content, and the setting. However, this information was only given *after* carers booked, which meant carers must have enough comfort or knowledge to book in the first place. Those who need that knowledge in order to book never receive it.

Access to information has also been highlighted as an issue in both government policy and academic research. For example, lack of information was found to be a factor in why carers do not use support services (Brodaty, Thomson, Thompson, & Fine, 2005), and, in the UK Government's call for evidence, providing information was a key theme across a number of the carers' suggestions for improvements to carer support, such as having an updated directory of what local services are available (Department of Health and Social Care, 2018b).

These issues suggest that 'carer-friendly' in this context means giving carers the knowledge and support they need to attend. Museums (and other programmes) need to consider for following:

1. The programmes need to be advertised to carers.

As the carers are the ones who book, they are the ones who must also be targeted by advertising.

2. Information about what will happen in the session and facilities available (such as accessible toilets).

This may help carers to feel less anxious about whether the physical space is accessible to the person they care for or themselves, and what the session will entail.

3. Support with, or information about, the logistics of getting to the session

As both the cost and the logistics of getting to the session could be a barrier or source of stress for carers, programme funding could include funding for participants' transport costs. Information could also be provided about transport and navigation, such as local bus stops, most convenient building entrance for the session, and building navigation maps.

4. Support to feel comfortable in the museum space

If the carer does not feel comfortable in the museum space, they are unlikely to book onto the session. This is beyond simply what will happen in the session (point 2), but broader expectations about museums. For example, some carers worry whether the person with dementia's behaviour will be



appropriate for a museum, or whether they themselves belong there. The narratives around museums, both as a whole and for individual museums, can perpetuate this feeling of exclusion among certain groups of people (Coffee, 2008). These wider narratives need to be taken into account in how sessions are advertised or described to potential attendees. This will be addressed in more detail in section 7.2.9 on opening up the museum.

#### 7.2.6 Preventing engagement

Core processes:

- l. Carers can prevent the person with dementia from engaging fully.
- m. Carers can dominate the activities or discussions.

These core processes were derived from theories which included the carer trying to make the person with dementia engage in a way they do not want to, carers intervening unnecessarily on the person with dementia's behalf, and carers dominating group discussions.

As discussed in Chapter 1, excess disability is disability or loss of ability caused by something other than the dementia itself (Brody et al., 1971). This can be caused by a carer doing too much for the person with dementia. Excess disability has also been linked to a negative impact on identity as being treated as incompetent or incapable can make the person with dementia feel they are not capable or make them question their identity as a capable person (Beard & Fox, 2008).

Excess disability could prevent some people with dementia from engaging fully in the activities, if others are doing tasks for, or answering for, the person with dementia when they are able to do so themselves. As discussed in Chapter 1, a benefit of museum programmes may be the support and maintenance of the identities of both the person with dementia and the carer beyond dementia and their caring roles. However, instances of excess disability may limit the programme's ability to do this, and in fact have the opposite effect. Although most discussion of excess disability relates to the person's carer, any person supporting the person with dementia can be the 'other' in their psycho-social environment. This means programme staff need to be aware of not only the potential of carers to create excess disability, but

also themselves. This means not making judgements about what 'a person with dementia' is capable of, but responding to the individual person. In this research, staff discussed that an important reason for including carers was that they could bring knowledge of the person with dementia and how best to support them. This may be a key way of understanding a person and their needs within a short space of time. However, this also needs to be balanced with the fact that carers may be underestimating a person's capabilities. Staff did report interacting differently with people with dementia than their carer, in ways which suggested mitigating excess disability. This will be discussed further in section 7.2.8 on long-term impacts.

As well as excess disability potentially being a threat to the person with dementia's identity, one theory developed in Chapter 5 was about the carer trying to get the person with dementia to engage in a way more consistent with their previous identity or interests. This may be linked with Kitwood's (1997) conceptualisation of malignant social psychology, particularly the elements of 'imposition' and 'invalidation'. However, it may also be linked with the carer feeling losses or grief. This will be discussed further in the next section on comparisons and losses.

Finally, as discussed in section 6.14 of Chapter 6, people with dementia may find it more difficult to speak up in a group setting as issues such as word-finding difficulties are common (Klimova & Kuca, 2016). This may mean carers dominate group discussions where the carers are particularly enthusiastic about the activities or where there is poor facilitation (theory 23). Aside from basic facilitation strategies such as allowing people more time to speak, some groups have found ways of supporting people with dementia to speak. For example, Innovations in Dementia is a charitable organisation in the UK which focuses on rights for people with dementia. Together with people with dementia, they created 'I want to speak please' cards to support people to speak in group meetings (Innovations in Dementia, 2019). Though there is no formal research on their use, they are currently used in their support and activism groups for people with dementia, and have featured on 'Dementia Diaries', a site where people with dementia can upload audio diaries of their experiences (for example Dementia Diaries, 2018). Facilitation

strategies such as these may be useful in supporting people with dementia to speak in groups where they may find it more difficult. Innovations in Dementia state that it is important that everyone in a meeting uses the cards, not just the people with dementia, to ensure people feel equal (Innovations in Dementia, 2019). Most museum programmes aimed to treat the person with dementia and the carer equally, so it would be important to use any strategies such as this across the whole group. Additionally, staff in this research suggested there was not only a need to balance between people with dementia and carers, but also people who had differing levels of experience (and confidence) in a museum, for example, so strategies applied across the group may help encourage more equal participation more generally.

#### 7.2.7 Comparisons and losses

##### Core processes:

- n. The session can highlight losses for the family carer.
- o. The family carer can compare the person with dementia to other people with dementia in the group or with their past selves.

These core processes relate to the carer forcing the person with dementia to engage in a particular way that is more consistent with their past self, the carer comparing the person's current abilities to their past abilities, and losses being highlighted for the carer. This section relates specifically to family carers, as these issues are more likely to apply to them (as discussed in Chapter 6, section 6.9).

Grief may be an overarching concept which links these ideas. Anticipatory grief is grief for someone prior to their death. Anticipatory grief is a common experience for family carers of people with dementia, and this grief involves multiple and ongoing losses for both themselves and the person with dementia (Chan, Livingston, Jones, & Sampson, 2013). Blandin and Pepin (2017) suggested that grief for carers of people with dementia is different than anticipatory grief experienced by dyads in other terminal illnesses. Because dementia impacts a person's communication and insight, carers are unable to have a joint sharing of feelings of grief, or an opportunity for conflict resolution about incidents in the past. Due to these differences, Blandin and Pepin

(2017) proposed the Dementia Grief Model which offers a dementia-specific grief process. In the Dementia Grief Model, grief for dementia carers is a cycling of three states – separation, liminality, and re-emergence. Separation is the state of experiencing a loss – a separation from the person with dementia, their past life, or an anticipated future. This loss may be a single specific loss (such as no longer being able to attend a particular event), a general loss (such as a slow change in the person with dementia's personality), or multiple losses experienced in a short space of time or before previous losses have been resolved. Liminality is the ambiguous state of transition between the previous and emerging situation. Re-emergence is the state of acceptance. Each state has a mechanism that can hinder or facilitate movement through the states. These mechanisms are acknowledging loss, tolerating difficult feelings, and adaptation to the reality of the loss. The idea that adaptation is the mechanism that resolves the difficulty of the grief is supported by work by Nay et al (2015). They examined the social participation of family carers of people with dementia and suggested the process of adaptation was key for carers in moving from their pre-carer role, through losses associated with becoming carers, to creating new meaning.

Where the museum session highlights losses for the carer, this may be linked to this kind of grief reaction. A loss being highlighted, such as realising they no longer have enjoyable activities for themselves or realising the person with dementia is no longer able to write, may mean the carer is thrust into a state of separation within the session. This means they are dealing with the acute difficult feelings associated with the loss, so it is unsurprising some become upset during the session. Dealing with these feelings may also mean the carer is focussed on the negative (what has been lost) rather than the positive (the person with dementia's capabilities), which links with the mechanism of theory 18 below:

Where the family carer has high expectations of the person with dementia (C) or the group highlights losses (C), the carer does not perceive the person with dementia's capabilities or feels upset (M), so the carer does not feel respite (O) and does not see the person with dementia in a new way (O).

As described in Chapter 6, section 6.9, the session can highlight personal losses for the carer, such as no longer having enjoyable activities or time for themselves. In the two examples described in Chapter 6, both carers became upset in the session, but one then sought out and joined another group for herself. This could be linked to adaptation and, for that carer, a state of re-emergence as that loss was resolved at that time. However, as Nay et al (2015) discuss, adaptation is more difficult if the carer does not have the resources available to adapt – in this case the knowledge of other suitable groups, the time and the financial capability to attend, and the person with dementia having other sources of support if needed while she attends. If that carer had not had the available resources to join another group after realising the loss of her social life, adaptation to that loss may have been much more challenging and could have potentially gone unresolved.

These models of grief may also be linked to carers forcing the person with dementia to engage in a particular way (theory 5) and the carer comparing the person with dementia's current abilities with their past abilities (theory 15). In developing their Dementia Grief Model, Blandin and Pepin (2017) discuss the idea of the 'receding of the past self' – that there will be changes in the memories, abilities, and personality characteristics of the person with dementia, and eventually the carer will experience the person with dementia "express themselves as though they are someone else, someone new, or otherwise not who they used to be" (Blandin & Pepin, 2017; p70). If the carer has not yet processed these changes (losses) or they have recently noticed a new change, this may be why they struggle within the session to respond to the person with dementia's wants or abilities 'in the moment'.

As well as models of grief, social comparison theory may also be relevant in considering losses and comparisons by family carers in the museum sessions. Social comparison theory, first proposed by Festinger (1954), suggests that people compare themselves to others, particularly those who they perceive to be similar to them, in order to evaluate their own position. People can make downward comparisons (comparing their situation with someone who they perceive to be in a worse situation), and upward comparisons (comparing their situation with someone who they perceive to be

in a better situation). Either form of comparison can be negative or positive for the person, as it is their interpretation, not the perceived relative states of those being compared, which is key (Buunk, Collins, Taylor, VanYperen, & Dakof, 1990). For example, a carer may compare themselves with another carer who they perceive to be in a worse position than them. They may interpret this comparison positively and feel relief that they are coping better, or they may interpret this negatively and feel worry about a potential negative future as the person with dementia's illness progresses.

My research found potential negatively interpreted comparisons. For example, in Chapter 6, section 6.9, I discussed findings from the literature review that carers make downward comparisons of the person with dementia they support with other people in the group (i.e. that others in the group were less severely affected), and findings from the evaluation that carers make upward comparisons of the person with dementia they support (i.e. that others in the group were more severely affected). Both of these types of comparisons were interpreted negatively, and no positively interpreted comparisons were found. However, other research has found carers of people with dementia making positively interpreted comparisons as a coping mechanism. For example, one study of teleconferencing support found carers made social comparisons, but only when they perceived their situation as being more manageable than other carers and the comparison was interpreted positively (McHugh, Wherton, Prendergast, & Lawlor, 2012). Other studies have suggested a mix of negatively and positively interpreted comparisons. For example, Greenwood, Smith, Akhtar and Richardson (2017) examined carers' experiences of dementia cafes and reported carers interpreting comparisons positively (as normalising of dementia and their experience) and negatively (as a potential negative future).

Only having findings of negatively interpreted comparisons in my research may be due to only two carers being interviewed and discussing this issue, with the remaining evidence from staff perceptions. Staff may be more attuned to negative comparisons as this may be more likely to have an overt impact, such as the carer becoming upset when losses have been highlighted and discussing what upset them when the staff member speaks to them. Research

which includes more interviews with carers may uncover positively interpreted comparisons.

The context for theory 15, which includes the mechanism of comparisons, is about the dyad, or carer, struggling to accept dementia. This may be linked with the models of grief discussed previously. Where a carer is not yet in a state of acceptance about a particular loss, they are dealing with difficult feelings and in a state of ambiguity about the outcome (Blandin & Pepin, 2017). This may make them more likely to be focussed on the negatives of their own situation, and so be more likely to make negatively interpreted comparisons with others. This may also relate to findings that making social comparisons can be related to a negative adjustment to chronic illness due to a lack of control over the illness and any positively interpreted downward comparisons representing a possible negative future (Dibb & Yardley, 2006). For example, if a carer is actively in a state of loss, it may be likely they are also feeling a lack of control.

The final aspect of losses being highlighted is due to the museum activities being outside of the dyad's usual routine, so, for example, the person with dementia is asked to do things they do not usually do, such as writing, and the carer realises they have lost that skill. The mechanism for this kind of loss may be linked to the ideas of excess disability and the shrinking social world. As discussed in section 7.2.6 on preventing engagement, excess disability is disability, or loss of skills, caused by something other than the dementia itself but by, for example, someone else doing the task for the person unnecessarily (Brody et al., 1971). It may be that skills, such as writing, were lost unnoticed prior to the session because the carer took over the administrative tasks at home. The person with dementia then stopped writing, which may have meant they lost this skill earlier than expected through lack of use. It may also be due to the shrinking social world experienced by people with dementia and their cares (Duggan et al., 2008) which has meant they are doing less outside of the home, and so there are fewer opportunities for these realisations to occur.

### 7.2.8 Long-term impact of in-the-moment activities

#### Core processes:

- p. The impact of the programme can extend beyond the session or with other people with dementia who did not attend.
- q. The session can build the relationship between the carer and the person with dementia.
- r. The session gives the dyad new things to talk about outside of caring tasks.
- s. Carers can learn new ways of interacting with the person with dementia and/or new strategies for working with them.
- t. The carer may reconsider what the person with dementia (or people with dementia generally) are capable of doing, or see the person with dementia in a new way.

This research had no long-term follow-up of participants, so the processes and outcomes in this section are ones which may be suggestive of a longer-term impact, but this was not tested empirically. Additionally, although this section focuses on potential long-term impacts, as discussed in the introduction chapter something does not need to have long-term impact to have worth – simply enjoying in the moment can be enough (Beard, 2012; Woods et al., 2016).

One of the potential longer-term impacts of museum programmes found in my research is about relationship-building between the carer and the person with dementia (for both professional and family carers). This relationship-building was theorised to link to shared respite and interacting outside of their caring/cared-for roles. As discussed in section 7.2.4 on session function, relationship-building is one of the aims of respite for family carers (Maayan & Lee, 2014). As respite is prioritised in UK government policy for support for carers (such as Department of Health and Social Care, 2018), this may suggest building relationships is at least a secondary priority in family dyads. Relatedly, as discussed in section 7.2.3 on caring responsibility, person-centred care is a key feature of policy on professional caregiving (Department of Health, 2001), which again may suggest relationship-building in professional dyads is also a priority. However, both respite and person-



centred care is largely individualised in policy, despite both having relational aspects, so relationship-building is not explicitly a priority from a policy perspective.

There is a lack of research generally on the role of relationships on outcomes for the person with dementia and the carer, despite a focus on person-centred care (Edwards et al., 2018). However, as discussed in the introduction chapter, there is evidence the relationship is important. In the introduction chapter, current models of family caregiving relationships were discussed, which may suggest interventions which could help to support or maintain the relationship would be useful. For example, Leung, Orgeta, and Orrell (2017) proposed a revised model of Pearlin et al's (1990) Stress Process Model of dementia caregiving in which they added dyadic interpersonal interactions, opportunities to engage in pleasurable activities, and cognitive support, as mediators of the stress process. This suggests supporting the relationship through enjoyable activities may mediate stress in caregiving. Similarly, Benbow, Tsaroucha, and Sharman (2019) use their model of dementia caregiving relationships to suggest how interventions could support and maintain the dyadic relationship. They list interventions which explicitly address relationship factors, such as counselling, but dyadic arts interventions such as museum programmes could also support this in a less formal or non-medical way, or as a supplement to the formal, explicit help of interventions such as counselling. This may link with social prescribing which uses non-medical or social activities to support people, and is becoming more common in the UK (Husk et al., 2020). Social prescribing will be discussed further in section 7.2.9 on opening up the museum.

Professional caregiving relationships in dementia have not been given the same focus as family relationships in terms of models or interventions for the relationship beyond the policy and training focus on person-centred care, or models of nursing care. This research indicated museum programmes could help the professional carer to get to know the person with dementia, both in terms of who they are outside of dementia, and through others interacting with them in a new way. As having good knowledge of the person being cared for has been listed as central to person-centred care for professional carers

(National Collaborating Centre for Mental Health, 2011), programmes such as these could be a way supporting relationships in professional caregiving dyads. Social prescribing schemes which aim to support family dyad relationships could therefore be usefully opened up to professional care dyads as a way of supporting their relationships.

The process of the carer reconsidering what the individual person with dementia, or people with dementia more generally, can do may be linked with the ideas around excess disability discussed in section 7.2.6 on preventing engagement. Sabat (2006) discussed how people with dementia can be 'positioned' in the minds of others according to stereotypes or pre-existing ideas they have about dementia. Others then interpret the person with dementia's behaviour or respond to them according to that positioning, for example interpreting anger as emotional lability or a symptom of dementia rather than a reasonable reaction to something that is happening. Sabat (2006) links this to Kitwood's (1997) notion of malignant social psychology, in that if a carer positions the person with dementia according to these stereotypes, it means the carer treats them according to that positioning, so may, for example, assume they are incapable of a particular task and so do it on their behalf (excess disability). Sabat (2006) also suggests that people with dementia have more difficulty rejecting the positioning imposed upon them and repositioning themselves due to communication difficulties, for example, which further compounds the problem. MacRae (2011) links this idea with that of 'master attributes', in which dementia can become the main attribute people use to interact with and judge a person, rather than other aspects of identity. This then impacts their interaction in the manner Sabat (2006) described, and impacts the ability of the person with dementia to maintain their identity (MacRae, 2011). As staff members in my research described perceived shifts in carers' thinking in terms of what people with dementia are capable of, it may suggest that the sessions help to 're-position' the person with dementia (and people with dementia more generally) in the carers' eyes. Getting to know the person outside of dementia and their caring roles, particularly for professional carers, may challenge dementia being the 'master attribute' used to view and interact with the person. Dyadic programmes such as museum

programmes which involve shared respite from caring roles and dementia may therefore help to promote person-centred care through challenging (often unconscious) stereotyping of individuals due to dementia.

#### 7.2.9 Reducing social isolation and opening up the museum

Core processes:

- u. Carers can meet others in similar situations and feel less isolated.
- v. The museum becomes a safe place for the dyad to return to in the future.
- w. The museum is opened up as an enjoyable and interesting place to visit for previously disinterested professional carers.

As discussed in the introduction chapter, dementia can lead to a shrinking social world for both the person with dementia and their carer (Duggan et al., 2008). The UK Government strategy on loneliness states that becoming a family carer may make you particularly vulnerable to loneliness, and specifically discusses carers as a group targeted by their strategy (Department for Digital Culture Media and Sport, 2018). Prevalence of loneliness amongst family carers of those with dementia is high. A recent study found 62% of family carers of people with dementia reported moderate or severe loneliness; carers with smaller social networks were more likely to report being lonely, and carers with a better relationship with the person with dementia less likely (Victor et al., 2020). The same study concluded that interventions aiming to improve the dyad's relationship quality and carer resilience may be more effective at addressing loneliness than those focussed on loneliness explicitly (Victor et al., 2020). Dyadic programmes such as the museum programmes in this research may therefore improve carer loneliness, despite many programmes' focus on the person with dementia, through increasing the carer's social network in meeting others and through supporting the dyad's relationship (as discussed in the long-term impact section).

Although dementia and difficulties are not explicitly discussed in the museum sessions, a key feature for family carers may be meeting others in similar situations. The 'shrinking social world' also includes shrinking friendships, as some carers feel their caring situation is not well understood or tolerated by

existing friends, or they feel they have been ‘dropped’ by old friends (Lilly et al., 2003). As family carers often experience loss in many aspects of their previous social lives and in their capacity to find new ways of participating (Nay et al., 2015), dyadic programmes may be one way of supporting their social participation. Research on memory cafes, for example, has found that they can function as a social club but one in which being a carer or person with dementia is normalised, accepted, and understood, and this could help attendees feel a sense of belonging and connection to others (Greenwood, Smith, Akhtar, & Richardson, 2017b). However, some people with dementia have stated they do not like the term ‘dementia-friendly’, nor having groups that are separated from the mainstream public offerings (Alzheimer Europe, 2017). This may also be the case for some carers. Although having a programme with only people with dementia and carers may be normalising and welcoming for some, it may be frustrating or stigmatising for others. Views on “dementia-only” groups should be a factor considered in whether the programme is suitable for a dyad, particularly if it is linked to a social prescribing scheme (discussed later in this section).

Unlike programmes or support groups which meet in multi-purpose public venues, such as community centres, the museum is open and can be revisited outside of when the session is running. This may mean that, through attending the sessions and becoming familiar, the museum can become a safe place to return to in the future. For some, the museum could become a ‘Third Place’ – a place where connections are made that are not home or work (Oldenburg, 1989). Museums do not fit the criteria for Oldenburg’s (1989) original definition as being ‘neutral’ spaces which are not explicitly about anything, and museums could be seen as delivering a service rather than specifically facilitating engagement between regular attendees (Tate, 2012). However, more recent work which builds on Oldenburg suggests that Third Places should be conceptualised by how the space is used and the interactions within it, rather than how the place defines itself (Purnell & Breede, 2018). In other words, not all museums will be Third Places, and a single museum will not be a Third Place for all people; it will depend how the person experiences and uses that space – Third Places are constructed by

the users. Through attending programme sessions, some dyads may come to view the museum as a “safe, relaxed space outside the home” (Tate, 2012; p280) where they feel meaningful connection that they can return to.

Oldenburg (1989) suggests that if people have a Third Place, it also helps to make them feel more a part of the community, so the museum becoming a Third Place may help isolated dyads to have a greater sense of connection to others. It may also link to Silverman’s (2019) notion that a place can in itself become a prompt for feelings of respite, as discussion in section 7.2.4 on session function.

However, the museum being opened up as a Third Place, a safe place to return to, or prompt for respite, is dependent on the carer’s capacity to return. As discussed in section 7.2.5 on controlling access, the venue needs to be carer-friendly and for the carer to have the means to return, such as the ability to pay for transport. Furthermore, some may need the additional support given by staff or the session structure to alleviate some of their caring responsibilities in order to attend (section 7.2.3 on caring responsibilities).

As discussed in section 7.2.8 on potential long-term impacts, dyadic programmes such as museums programmes may be able to support the dyad as a whole and the carer as an individual, either in a less formal way or as an adjunct to medical interventions such as counselling. Social prescribing is the prescribing of non-medical or social activities to support a person’s wellbeing (Husk et al., 2020). As described in Chapter 1, social prescribing has recently received further funding in the UK and there are planned increases in its use within primary care (NHS England, 2019b). None of the museum programmes in this research were linked with any local social prescribing schemes, if those schemes existed at the time. However, given the planned increases in prescribing schemes, programmes could usefully become a part of those schemes. They may be particularly useful given that attendees can visit the museum outside of the sessions if they become places of respite, and many museums in England can be accessed for free. However, it is important to consider who the programmes may work, and not work, for, and not to assume that the museum sessions will be a positive and supportive experience for everyone. For example, as described in section 7.2.7, a carer

who is struggling with grief about losses associated with dementia may find this is worsened by attending the sessions, particularly if they do not have the capacity or resources to practically address, for example, social losses. As discussed in the introduction chapter, there is a lack of theoretical work around family carers' needs, and there is a need to develop a specific and thorough measurement tool to assess carers' needs alongside a framework for how to meet those needs (Bangerter et al., 2019). This means it may be difficult to quickly assess which carers may or may not benefit from attending programmes, and to appropriately match carers to programmes. Social prescribing schemes also need to ensure they support carers with what they need in order to attend, such as transport costs or detailed information about a setting (Fixsen et al., 2020 and as considered in section 7.2.5 on controlling access).

Finally, as mentioned in section 7.2.5 on controlling access, the narratives around museums can perpetuate a feeling of exclusion among certain groups (Coffee, 2008). For example, museums are also more likely to be attended by people from higher socio-economic groups without a disability or long-term illness (Matthews et al., 2016). Some museum staff in my research said that balancing different needs in the group was not always about a balance between the needs of people with dementia and carers, but between people with different levels of comfort or experience in a museum setting (section 6.14 of Chapter 6). Camic and Chatterjee (2013; p66) write about how museums could be ideal partners for public health interventions, and state that "While museums can sometimes be intimidating places, they are nearly always non-stigmatising settings in that they are not institutions where diagnosis and treatment of medical and mental health problems occur, nor are they settings where one experiences embarrassment, shame or criticism for attending". However, this does not acknowledge that, for some, a museum can be a place where a person feels embarrassment or shame while attending if they are concerned they do not know the social rules, that they are 'not smart enough', or are caring for a person with dementia whose behaviour may be unpredictable or 'inappropriate' for the setting. This links to the idea of 'cultural capital'. Bourdieu defined cultural capital as the familiarity with a

society's culture, and differentiated three forms: embodied (e.g. mannerisms and ways of speaking), objective (e.g. museum objects and books), and institutionalised (e.g. university qualifications) (Bourdieu, 1979, cited in Hanquinet, 2017). Bourdieu suggested that the reason museums are visited by a small, relatively privileged portion of the population, despite being open to all, is linked not only to inequality of economic capital, but to an inequality of cultural capital (Fyfe, 2015). As cultural capital can be dependent on the person's family background and environment (Newman & McLean, 2006), people who do not grow up in an environment which includes museum visits or discussion are likely to have less cultural capital as relates to museums, and so less comfort in the museum space. That some carers worry about the 'appropriateness' of the person with dementia's behaviour in the museum space may link to worries about embodied cultural capital (the way museum participants are 'expected' to behave and speak), which could be the case for both those with relatively low capital (unsure of the 'rules' due to lack of experience) and relatively high capital (experience of the 'rules' and how the person may break them).

In my research, the museum programmes appeared to challenge some of the narratives around museums for professional carers in particular. This may be because they did not have a choice in attending as it was part of their work day, whereas a family carer likely would not book if they did not feel initially comfortable attending. Social prescribing schemes and link workers also need to consider these wider narratives around the programmes and settings they refer carers and people with dementia to, as some may be reluctant to attend because of this. This may include 'hidden' information which may be taken for granted, such as reassurance about expected or 'allowed' behaviour (embodied cultural capital), or simply what the museum is like through photographs or virtual tours. Museums are increasingly working to include and engage previously excluded communities and groups, though there is still work to be done. Some research has found that users and non-users of museums tend to describe them in similar ways, with the difference being the personal or active connection users draw between themselves and the museum, such as describing the museum as 'place where old objects are

kept' versus 'a place where I can learn about old objects' (Coffee, 2008). This meaningful connection to museums and their collections includes both the cultural significance (such as of being about a particular group of people or era), and the personal significance (such as being linked to past experiences or expressing personal experiences) (Froggett, Farrier, & Poursanidou, 2011). It may therefore be important for museums, and any social prescribing schemes, to focus on finding the meaningful connections between museums and communities (or the individual carer). For some, if those meaningful connections are created and they are supported in practical terms, the museum could become a safe place to return to and expand the carer's (and person with dementia) shrinking social world.

#### 7.2.10 Summary of conceptual platform on including carers in museum programmes for people with dementia

The core processes of the conceptual platform have been discussed in relation to wider literature and UK policy. The implications of the issues raised, and areas for further research, will be considered in more detail in Chapter 8.

### 7.3 Conceptual platform on including carers in programmes

As discussed in section 7.2, the development of a conceptual platform allows theories to be tested in different programmes that share core processes, so evaluations of different programmes can build on one another (Pawson, 2013). The conceptual platform was developed from my research at six different museum programmes, with the aim that it can be further evaluated and refined at other museum programmes (to be discussed further in the implications and further research sections of Chapter 8). However, as discussed in the introduction chapter, most other kinds of programmes for people with dementia, such as NHS reminiscence groups, support groups, memory cafes, and singing groups, also include carers. There are also many other reasons, beyond dementia, why an adult may be a carer or may need a carer, for example other progressive illnesses such as Parkinson's disease or non-progressive illness or disability. Additionally, although all parents are carers, those who care for a disabled or chronically ill child have additional responsibilities and caring tasks (Roberts & Lawton, 2001). The core processes described in section 7.2.2 are specifically written about people with



dementia, their carers, and museum programmes, and exist within the processes of how those programmes are run. However, there may be some similarity or overlap in the core processes involved when including carers in different kinds of programmes or from different dyad types. In order for future research to consider these ideas, it may be useful to have a version of the conceptual platform which is not specific to people with dementia or museums. This conceptual platform is derived from the processes in section 7.2.2. I therefore do not suggest it to be conclusive or exhaustive, but a starting point for further research and other evaluations in wider settings and with other people with care needs (which will be discussed further in chapter 8).

For these core processes, the carer is referred to as the caregiver and the person cared-for as the care-receiver.

Core processes:

- a. Caregivers hold the ultimate responsibility for the care-receiver (so the programme/venue does not have to).
- b. The caregiver's level of responsibilities in the group can prevent them from engaging in and enjoying the activity.
- c. High staffing levels and the session structure take some responsibilities from the caregiver.
- d. The caregiver can enable the care-receiver to participate.
- e. Caregivers bring knowledge of the care-receiver which helps programme staff to support the care-receiver.
- f. Programme staff can have differing expectations of different caregiver types, impacting the caregiver's experiences.
- g. Serving tea to carers helps them to feel the session is also for them, to socialise, and to relax after a stressful journey.
- h. Some dyads enjoy the session together, but others use it as an opportunity for traditional respite from one another.
- i. The dyad can experience shared respite from their caring roles.
- j. There can be mismatch in the way the caregiver and the care-receiver wants to use the session, which can cause tension or distress.

- k. Caregivers control whether the dyad (and so care-receiver) attends and/or returns.
- l. Caregivers can prevent the care-receiver from engaging fully.
- m. Caregivers can dominate the activities or discussions.
- n. The session can highlight losses for the family caregiver.
- o. The family caregiver can compare the care-receiver to other care-receivers in the group or with their past selves.
- p. The impact of the programme can extend beyond the session or with other care-receivers in a care home who did not attend.
- q. The session can build the relationship between the caregiver and care-receiver.
- r. The session gives the dyad new things to talk about outside of caring tasks.
- s. Caregivers can learn new ways of interacting with the care-receiver and/or new strategies for working with them.
- t. The caregiver may reconsider what the care-receiver (or care-receivers generally) are capable of doing, or see the care-receiver in a new way.
- u. Caregivers can meet others in similar situations and feel less isolated.
- v. If it is a publically accessible space, the venue becomes a safe place for the dyad to return to in the future.
- w. If it is a publically accessible space, the venue is opened up as an enjoyable and interesting place to visit for previously disinterested professional caregivers.

#### 7.4 Chapter summary

A conceptual platform was developed of the core processes involved when carers are included in museum programmes for people with dementia. These core processes were discussed in relation to UK policy and wider literature on dementia, caregiving, and museums. A second version of the conceptual platform was also created, which re-words the processes so that they could apply to other dyad types and other programmes. The implications of the conceptual platforms and potential areas for future research will be discussed in Chapter 8.

## Chapter 8 - Discussion and conclusions

### 8.1 Introduction

This chapter will discuss the strengths and limitations of this thesis, and consider the implications of the findings for research, policy, and practice. This is then followed by a consideration of the ways in which my positioning may have shaped and impacted the research. Finally, it will conclude with how the thesis makes an original contribution to research and ways it may be disseminated.

### 8.2 Revisiting research aims

This PhD had an overarching research question of:

How does including carers in museum programmes for people with dementia have an impact on people with dementia, their carers, and the relationship between them?

Through a realist literature review (Chapter 3) a number of secondary research questions were also developed for the evaluation:

- Dyadic context:
  - What is it about the context of the dyad that leads to positive / negative outcomes?
  - How socially active are participants outside of the museum activities? (And does this change following attending the museum?)
  - How does the dyad type have an impact? (spousal, parent/child, consistent paid carer, changing paid carer)
  - How does amount of past experience with museum settings have an impact?
- Does ‘shared respite’ fluctuate over time?
- Does the amount of caring responsibility the carer has in the group have an impact?
- Is the impact different for different types of activities?

In answer to these questions, twenty-eight programme theories were developed related to the impact of including carers. These were then used to

develop a conceptual platform of core processes involved when carers are included in museum programmes for people with dementia. This included processes about caring responsibility, session function (how dyads use the session), carers controlling access, carers preventing engagement, comparisons made and losses felt by carers in a session, the potential long-term impact of including carers, and reducing social isolation and opening up the museum. The secondary questions do not have separate findings but are incorporated into these theories and the platform. For example, how the amount of caring responsibility the carer holds in the group has an impact is embedded throughout, but particularly in thinking about session function. However, not all of the secondary questions could be addressed, or were only addressed in a limited way. This will be discussed further in the limitations section of this chapter.

### 8.3 Strengths

To my knowledge, this is the first study to examine the impact of including carers in museum programmes for people with dementia. I also believe it is one of very few studies to specifically consider the processes around including carers in programmes such as these. This thesis highlighted that the inclusion of carers does have an impact – it is not a neutral act and careful consideration needs to go into how to support people with dementia and carers, and whether this will change the way a programme is run.

The realist framework provided a way of approaching process and causation, but the lack of prescribed methodology meant I could fit the study design to the setting and my available resources. The ‘for whom, in what circumstances, and how’ of realist work meant I did not just look at what the impact may be, but the underlying processes and causes of those impacts, and how it may be different for different people. This enables clearer practice, further research, and recommendations, for example, rather than ‘some carers can get upset in sessions’, it is ‘carers can get upset when losses are highlighted which may be linked to processing grief’. The ‘for whom’ of realist thinking means acknowledging that the programme will not have the same impact on everyone. This may be particularly important with the increase in social prescribing and considering who may benefit (or not benefit) from referral to

which community or cultural initiative. Additionally, the iterative nature of data collection and analysis meant emerging findings could be constantly tested and refined through the evaluation. For example, at site 1 the idea of session function became apparent as potentially important, and I then included testing this idea in interviews and observations at other sites. Finally, the realist concept of demi-regularities (semi-predictable outcomes or causal pathways; Jagosh et al., 2012) provided a framework for considering the same processes across different sites, rather than treating each as a separate evaluation. This was particularly useful as data was limited at individual sites and it would have been difficult to treat each as a self-contained evaluation such as in a case study approach.

Using six different sites enabled me to compare and contrast findings and consider whether a particular finding was related to the specific context of that specific programme, or could be applied more generally. An additional strength was the range of museums included, in terms of location, size, funding, and type of collection (for example primarily art-based or history-based). This also supported the generalisability of the findings. The combination of interviews and session observations enabled triangulation of the data. This was particularly important as I mainly had staff interviews, rather than interviews with carers or people with dementia, so I could use the session observations to see if staff assertions were actually apparent in sessions. For example, the manager at site 1 said the sessions were about a shared experience, but in sessions I observed some dyads using the session to have separate experiences.

The research design enabled programme theories and a conceptual platform to be developed which are specific to museum programmes but could also be applied to other dyadic programmes for people with dementia and their carers, and potentially other dyad types. The findings of this thesis are theoretical, which may be particularly important given there is limited theoretical work about carers' needs (Bangerter et al., 2019). However, the thesis is also rooted in practical application for museum programmes and dyadic programmes more generally, as well as policy. In this way, the impact of this thesis could provide instrumental, conceptual, and persuasive uses of

knowledge (Straus et al., 2010). This will be discussed further in section 8.5 on implications.

#### 8.4 Limitations

As discussed in Chapter 2, in realist philosophy all knowledge is considered partial (Maxwell, 2012). As such, this thesis represents **one** interpretation of the impact of including carers. This should be emphasised more so here than in some other academic work as the nature of PhD research means it was not completed as part of a team, but as a lone researcher. As described in Chapter 4, I did attempt to mitigate this by seeking out alternate explanations, for example by taking raw anonymised data to a qualitative analysis group for discussion. However, the work was largely my own, partial, perspective.

Although the literature review (Chapter 3) used a realist framework, it could be argued that it was 'realist-informed' rather than 'truly realist' as all included studies were specifically on the type of museum programme being investigated, rather than scoping wider for literature related to developed mechanisms. I did deliberate for some time on how and whether to include similar programmes or related literature, particularly on models of caring relationships. However, I decided there was enough richness in the included studies to develop theories on my area of interest. Importantly, the review theories were not the 'finished product' but would be used as the initial programme theories to be tested in the evaluation. Relevant middle-range theories, such as models of grief, were identified following the evaluation when processes were more refined. The final programme theories and conceptual platform are therefore the combination of the review, the evaluation, and wider literature. However, wider literature could have been considered at the review stage to strengthen those initial programme theories, which may have provided additional insight for the evaluation.

Despite the strengths of the realist framework, it also posed some difficulties. Researchers new to realist approaches often find them challenging, particularly in terms of analysis and determining the relevant components of context-mechanism-outcome (CMO) configurations (Marchal et al., 2018). This was also a challenge for me, and will be discussed further in section 8.6 on reflexivity. One way this challenge may have limited the research is

through the sheer number of programme theories developed and included. I was unsure how to choose which theories may be the most 'important' and which to discard, which may in part be due to my inexperience with the methodology. More time and resources may also have allowed me to work with stakeholders (including museum staff and programme participants) to prioritise theories from the review to investigate in the evaluation. However, as there was little existing theoretical work on the impact of including carers, I did not want to exclude anything that could be potentially useful. There were ideas, such as reassurance-seeking, that had evidence from only one study in the review, that were then well-supported by the evaluation and consequently led to specific research and practice recommendations (see section 8.5). However, if I had discarded some theories and focused only on, for example, theories about relationship-building, I may have been able to develop more detailed theories and examine more closely models of dyadic relationships. As such, the breadth of this research limited some of its depth.

Due to recruitment difficulties, the evaluation included few interviews with carers and people with dementia (two of each). Although their perspectives were included in session observations, and through descriptions in staff interviews, their direct opinions and views could not be included in theory development. This is a key limitation, particularly for those theories which include the thought processes of carers or people with dementia, which could only be hypothesised or gained indirectly (for example from observations). Additionally, this means a large proportion of the interview data relies on staff perceptions, and so triangulation using session observation is essentially testing staff perceptions, rather than carer perceptions. It is possible museum staff were overly positive in talking about the programme and its impacts because they wanted to present it in a good light, or non-managerial staff were concerned about any negative comments being taken to, or overheard by, their managers. Arguably this was mitigated, at least to an extent, as some negative impacts (such as upset carers) were discussed. All staff were interviewed in a private space away from other staff, and before recording started it was re-iterated that all interviews were confidential and anonymous. The realist framing of the interview and the questions may also have helped.

For example, emphasising in the introduction that I was interested in their views and expertise, and normalising negative impacts by asking directly about them such as “some studies have found this, has this been your experience here?” (see Appendix 3 for an example of a staff interview schedule and framing of questions).

Similarly, most professional carer dyads could not be included in interviews or observations in the evaluation due to ethical approval restrictions, so most theories about them are less evidenced or rely more heavily on staff perceptions as there could be little triangulation with session observations. A lack of research on professional carer dyads was also noted in research on museum programmes in the review (Chapter 3), and in the discussion of elements of the conceptual platform (Chapter 7).

I could also only include dyads who attended the programme, so the diversity of my sample is limited by the diversity of the museum programme participants at my study sites. For example, there were no couples in same-gender relationships and very few non-white dyads, despite this not being representative of the geographical location of the included museums. This suggests people from these groups are not attending the programmes, which is an important finding in itself. It may be linked with who museums are seen as being for (Coffee, 2008), but also dementia services being viewed as predominantly for heterosexual and white people. For example, there is limited research on LGBT caring dyads, but discriminatory experiences from service providers in the past may prevent LGBT carers from accessing services (Willis, Ward, & Fish, 2011). This means LGBT carers may be reluctant to participate in a museum programme if they have experienced micro or macro aggressions in their caring role in the past, and fear or predict the same will happen in the museum setting. This means the results of my research cannot be generalised to all dyads, as there may be different or additional processes involved for dyads with different personal characteristics. This may be particularly important in considering what makes a programme ‘carer-friendly’, as there may be some specific issues related to identity which have not been covered by this PhD research.



As the research only includes people who already attend programmes, they are more likely to be positive about their experiences as they have chosen to attend. Despite this, some negative impacts were found in interviews with carers and people with dementia, and witnessed in session observations. However, there may be other negative processes which were not found, particularly in how or whether someone chooses to attend in the first place, or those which cause dyads not to return.

This research may be limited by not verifying the diagnosis of the people with dementia, nor what form of dementia they were affected by. Different forms of dementia impact people differently, and so may impact their experience of the programme and their carer's experience of supporting them. For example, some studies have found family carers of those with dementia with Lewy bodies experience higher levels of stress than carers of those with other forms of dementia due, in part, to cognitive fluctuation, unpredictably of the person's needs, and subsequent difficulty in planning and maintaining routines (e.g. Lee, McKeith, Mosimann, Ghosh-Nodyal, & Thomas, 2013). As discussed in Chapter 7, some carers have concerns about the 'appropriateness' of the person with dementia's behaviour in the museum space. If this 'appropriateness' is unpredictable, this may make carers less likely to attend. It may also be linked to session function, for example carers may feel more stressed or unable to have physical respite in the session due to the need to "remain vigilant...to the [person's] variable requirements" (Lee et al., 2013; p140). Further research should examine whether the type of dementia has an impact on the processes involved when carers are included. There may be limitations in the ability of programmes to tailor their provision based on a person's specific diagnosis, for example due to having a mixed group or the fact dementia is often not explicitly discussed. Further research related to different forms of dementia should also therefore consider any practical or ethical barriers when proposing recommendations to programme developers and facilitators.

The evaluation had no long-term follow-up so the potential long-term outcomes are tentative. For example, there was some evidence of some professional carers coming back to the museum outside of the session, but

not for whether they actually replicate the activities in the care home with residents (just that they planned to).

One aspect of the impact of including carers which was not addressed by this research was whether all people with dementia want carers to be included. It was implied that some do, for example those people with dementia in sessions who wanted support specifically from their carer, but others may not. At the 2019 Dementia Congress conference, I attended a presentation discussing some research on an arts-based programme. Some people with dementia in the audience stated in response that they would not want carers to participate in the programme with them, and wanted a space that was just for them. Some practitioners in the room argued against this, perhaps because they need the carer to hold ultimate responsibility (as discussed in Chapter 7). Shakespeare, Zelig and Mittler (2019) argue that current dementia activism from people with dementia is similar to the early stages of other disability rights movements. They suggest dementia should be considered within other disability rights contexts, such as taking a functional capacity approach in activities (such as these museum programmes), rather than assuming the diagnosis means there are particular limitations (such as the person needing a carer present to take responsibility). This will be discussed further in the implications for practice section of this chapter.

Finally, the limitations described in this section meant some of the secondary questions of this research could not be addressed. For example, due to few interviews with carers or people with dementia, it is not clear how the dyad type has an impact, beyond 'family' or 'professional'. There may be differing impacts for dyad types within these categories, such as spousal, parent/child, or between professional carers who work in a care home and those who work in the community. This will be discussed further in the implications for research section.

#### 8.5 Implications for research, policy and practice

This section will consider the implications of the research, as applied to research, policy, and practice.

### 8.5.1 Implications for research

This section discusses implications for research, and is organised into sections on further research to address limitations, further research from findings, and implications for methodology.

#### 8.5.1.1 Further research to address limitations

As discussed in the previous section, there were limitations of this research. Future research could build on this PhD by addressing those limitations. For example, similar research could include more interviews with people with dementia and carers and a more diverse range of dyads, such as LGBT family dyads or dyads whose ethnicities are not white. There also needs to be more research with professional caring dyads in particular as the lack of research with this group was also highlighted in the literature review (Chapter 3) on current research on these museum programmes. This should include examining the processes for different professional carer types, such as carers working in a care home with a number of different residents, and carers who work on a one-to-one basis with the person in the community. Socio-relationship processes may be different for different dyad types (Rausch et al., 2017), and there were some outcomes and processes which were specific to professional or family dyads in this research. However, these groupings should be further broken down to consider these different professional carer types as well as different family carer types (such as spouse, friend, or adult child), as their differing relationship dynamics may have an impact beyond simply 'family carer' or 'professional carer'.

As well as including a wider range of dyads, further work could also include people who do not attend sessions to examine why they do not, which may give further insight into barriers such as narratives around museums or finances and time. As discussed in the preface, there was a further study planned for this thesis which involved recruiting dyads from local memory cafes who had received outreach sessions. Public groups such as these, which have received outreach or taster sessions, could be useful to involve in future work about reasons why people do not attend, as they are aware of the museum sessions and live locally, but most do not then attend the session at the museum. It may simply be lack of interest beyond the outreach session,

but aspects such as barriers and what makes a venue or activity 'carer-friendly' may be usefully explored.

To address the limitations of this research, further work should also include a long-term follow-up. This would enable potential long-term processes to be examined further, such as change in session function as the person with dementia's condition progresses and they need more support in sessions. It would also allow for the potential long-term impacts of 'in the moment' programmes to be investigated, such as whether a carer does change how they interact with the person or whether professional carers replicate activities in the care home. As 'relationship-building' was a key outcome in a number of programme theories, a long-term focus on this could examine how or if this works in the longer-term and for whom, including professional caring dyads who are not 'dyads' within a care home setting.

Similarly, further research could examine processes in more depth. As discussed in the limitations section, a large number of programme theories were included due to the lack of previous work in this area. Although this was a strength of this thesis, it also meant some depth about individual processes was sacrificed for breadth. For example, future research could take just one process, or group of processes such as 'reducing social isolation and opening up the museum', and study those in more depth, rather than applying the conceptual platform as a whole.

#### 8.5.1.2 Further research from findings

As mentioned in the strengths section of this chapter, there are a number of potential instrumental, conceptual, and persuasive uses of the findings of this research. According to Straus et al (2010; pE94), "use of knowledge can be instrumental (i.e. concrete application), conceptual (i.e. changes in understanding or attitude), or persuasive (i.e. as ammunition)". The programme theories and conceptual platform developed in this thesis could be used to consider the ways museum programmes include carers and the ways the session is facilitated (instrumental use). This will be discussed in depth in section 8.5.3 on implications for practice. Persuasive uses of the findings to influence policy change will also be discussed later, in section 8.5.2 on implications for policy. The conceptual uses of the findings are in

understanding the impact of including carers, particularly that it does have an impact and is not a neutral act for the person with dementia or the carer. Future research could test and refine the conceptual platform in different museum programmes and with different dyad types, as discussed in the previous section on research to address limitations. The platform could also be used as a starting point to evaluate the impact of carers in other types of dyadic programmes and activities for people with dementia, such as singing groups or memory cafes. This could include examining whether the conceptual platform as a whole, or a specific process of interest, is reliant on the overarching processes typical in museum programmes. For example, the museum programmes included in this research aimed to promote equal participation for the both the carer and the person with dementia (though varied in how much this was enacted). Investigating whether, and how much, the conceptual platform applies to programmes which do not have these overarching processes would enable understanding of the extent of its generalisability. As well as different types of programmes for people with dementia, it would be useful to test and refine the conceptual platform in programmes for people who do not have dementia, but have other support needs. For example, there may be differences in processes if the illness or disability of the person cared-for was acquired in adulthood or had been life-long, or is progressive or not. Processes such as losses being highlighted for the carer may not be a key component where there is less change to adapt to, or it may still be a key component due to ableism and a lack of accessibility of other types of programmes in the same venue. Further research on the conceptual uses of the platform developed in this thesis could therefore be conducted in other museum programmes for people with dementia and their carers, non-museum dyadic programme for people with dementia, and in programmes for other types of caring dyads. This would enable further development of general, middle-range theory on the impact of including carers in programmes.

As previously discussed in this thesis (Chapters 1, 3, and 7), there needs to be more research and theoretical work on the dyadic relationship and the impact of the relationship in dementia, rather than simply the impact of

dementia on the relationship (Edwards et al., 2018). Although there are some models of relationships (e.g. Ablitt, Jones, & Muers, 2009; Benbow, Tsaroucha, & Sharman, 2019; Leung, Orgeta, & Orrell, 2017), a comprehensive model which also takes into account different dyad types could be used to consider how activities such as the museum programmes could build relationships, and for whom this may work or not work. This should also include professional caregiving relationships; not only models of nursing, but integrating this with models of person-centred care (such as Kitwood, 1997) and how person-centred care and relationships intertwine. This should account for different professional carer types, such as a carer who only works occasionally with the person with dementia, or a carer who works one-to-one regularly.

Relatedly, as Bangerter, Griffin, Zarit, and Havyer (2019) suggest, there is a need for more theoretical work around family carers' needs and the development of a specific and thorough measurement tool to assess those needs, alongside a framework on how to address them. This kind of theoretical work could be usefully integrated with the work of this thesis, to understand further how these programmes may, or may not, meet those needs, and for whom they may work best. As suggested in Chapter 7, this may also better support social prescribing efforts.

This thesis supports previous research suggesting there may be many forms of respite, beyond simply carers having a physical break from the person they care for (e.g. Chappell, Reid, & Dow, 2001). This thesis discussed the complex interaction between caring responsibilities and the carer's ability to feel respite (Chapter 6). Using Burnside et al.'s (2017) definition of shared respite as a break from caring roles and a relationship defined by dementia, shared respite could be usefully linked with research about relationship identity (such as 'spouses') discussed in Chapter 1 (e.g. Colquhoun & Moses, 2017; Wadham, Simpson, Rust, & Murray, 2016). Similarly, individual respite within sessions, such as a carer experiencing respite while remaining in the caregiving situation (Chappell et al., 2001), could be linked with research on individual identity. For example, carers can experience 'role engulfment', in which the number of caregiving responsibilities leaves little time for other

activities and as so there is a loss of personal identities other than 'carer' (Eifert et al., 2015). It may be that internal moments of respite in activities, such as the museum sessions, help the carer to re-discover or maintain their other personal identities, while also being 'carer'. However, as discussed in Chapter 7, for some carers this may link to a realisation of loss and a grief reaction, particularly when they do not have capacity or resources to find other ways of maintaining those 'non-carer' identities. Further research could usefully consider the relationship between different forms of respite and identity, and the ways in which dyads and individuals could be supported to maintain their identities through other forms of respite. The ways respite is conceptualised will be considered further in the section 8.5.2 on policy implications.

#### 8.5.1.3 Implications for methodology

This thesis developed a conceptual platform for one programme element (including carers) rather than the programme as a whole, which is a novel use of the methodology. Future research could also develop focused platforms as a way of building middle-range theory where there has been little theoretical work previously.

This research used realist interviewing techniques with people with dementia. There is increasing qualitative work with people with dementia (McKeown et al., 2010), including co-produced research (e.g. Wang, Marradi, Albayrak, & van der Cammen, 2019). However, there can be difficulties in gaining people with dementia's views directly, rather than solely interviewing their carer, due to concerns about communication difficulties or memory for the programme. For example, in their study on museum programmes, Eekelaar, Camic, and Springham (2012) had difficulty obtaining the perspectives of the people with dementia from residential homes due to a lack of memory for the session. However, using carers as a proxy can be problematic, as carers can have different perspectives to the person they care for, even when they know them well (Bannerjee et al., 2009; Moyle, Murfield, Griffiths, & Venturato, 2012). Other studies have also used realist interviewing techniques with people with dementia, such as McConnell et al's (2018) evaluation of a member-led dementia empowerment service. This thesis adds to the evidence that realist interviewing techniques can be effectively used with people with dementia,

though it is limited by only including two interviews with people with dementia. Realist interviewing techniques may be a particularly effective method, as useful data and perspectives can still be obtained even if the person does not have memory for the programme in question, due to the focus on mechanisms and demi-regularities. As illustrated by the example interview schedule in Appendix 6, you could, for example, ask the person about what helps them, or makes it more difficult, to speak in a group, rather than a specific instance in a museum session. Their answer can still contribute to theory development, even if it is not specifically about the programme. Further qualitative research could therefore consider using a realist framework to investigate and evaluate programmes with people with dementia, particularly where there are concerns that the person may not have good memory for the activity or programme. Should more research also find this a useful approach, it could then be included as a methodological option in guidelines for interviewing people with dementia, such as those by Quinn (2017).

#### 8.5.2 Implications for policy

Policy implications of this research could be considered persuasive use of knowledge (Straus et al., 2010), in that it could be used in support of policy change or amendment. Research can influence government policy in a number of ways, including identifying problems and considering the benefits and harms and consequences of policy (Clancy, Glied, & Lurie, 2012). However, using academic research to create change at a policy level can be challenging for a number of reasons, from both the perspective of academics, and from the perspective of policymakers. Recent research in the UK has found the government uses academic evidence inconsistently when they are forming policy, and this is more apparent for the arts and social sciences than the 'hard' sciences (Sasse & Haddon, 2018). There are a number of barriers to the consistent use of academic evidence in policy, such as research being behind paywalls, lack of personal connections between academics and policymakers, frequent changes in government personnel, and policy-making being complicated by politics (e.g. Cairney & Oliver, 2020; van der Arend, 2014). Because there are a number of barriers, it is therefore important to set out clearly what the policy implications may be, rather than expecting



academic research to be automatically absorbed in policy-making. This also links with how and where research is disseminated, which will be discussed further in section 8.8.

This research concurs with previous research, such as that by O'Shea et al (2019), that there may be a misalignment between conceptualisations of respite in policy, and carers' conceptualisations of respite. Respite is more than just a physical break from one another, but can also be shared (a break from caring roles), a psychological break while remaining in the caring situation, or a psychological break that may be related to place (Chapter 7). UK policy on supporting carers, such as the Carer's Action Plan (Department of Health and Social Care, 2018a), could expand to include other forms of respite, beyond physical breaks. Embedding multiple forms of respite in policy, to suit the varied wants and needs of different dyads, may make it more likely that other forms of respite will be adequately funded and supported as policy is "a statement of the government's position, intent or action" (Gov.uk, 2012).

As discussed in Chapter 7, this research could also have implications for social prescribing. This may be particularly important given the planned increase in social prescribing in the UK over the next few years (NHS England, 2019b). The museum programmes examined in this research may be a good candidate for linking in with local social prescribing schemes, but there is a need to consider 'for whom, in what circumstances' they would be appropriate. The findings of this thesis gives some indications, but could also be used as the basis of further research which examines their role in social prescribing specifically. For example, my findings suggest the museum programmes could benefit family dyads who want to do activities together but are struggling to know what to do, or where the carer needs the additional support that the museum staff and session structure provide. Conversely, the sessions may be more challenging for carers who are experiencing acute grief, where the sessions may highlight losses. As discussed in the introduction chapter, much of the research on these museum programmes focus on the positive outcomes, so it is important that link workers are also aware of potential negative impacts for some. As well as considering for

whom the programmes may not be beneficial, this may mean link workers providing signposting to other kinds of support, such as counselling, where needed. Social prescribing schemes also need to be aware of potential barriers to attending the programmes so that they can provide appropriate support, such as the hidden costs of free programmes like travel, or the stress for carers of organising how to get there. There also needs to be a consideration given to the narratives around museums. Some dyads may already feel comfortable in the setting, whereas others may be intimidated or 'put-off' by the museum. Research such as Coffee's (2008) suggests that it may be useful for link workers to think about how to find the connection between the person and the museum venue or its contents.

Additionally, social prescribing schemes, and museum funders, need to consider the longevity of these types of programmes. A dyad may attend a museum session, either through social prescribing or of their own volition, and it becomes an activity they enjoy, a way of feeling socially included, or it opens up the museum as a safe place in a shrinking social world (Chapter 7). However, it may then be difficult for them if the programme is time-limited (Daykin et al., 2020), particularly if they need the support within the sessions to attend the museum. This forced abrupt end may be due to either their attendance being time-limited through social prescribing, or because the programme itself does not have sustainable funding. For example, the programme at site 2 was only funded for four weeks, with no source of funding for any further sessions. At site 1, after my research ended, the sessions were reduced from monthly to quarterly, with a greater focus on outreach which was seen as more sustainable financially (the implications of this will be further discussed in section 8.5.3 on practice implications). In my research I initially had some difficulty in recruiting museums, as programmes would run at a particular museum for a short time and then disappear again. It often appeared as though a museum would receive funding for a dementia-friendly initiative when there had been none previously, but this funding was only ever short-term, and other sources had to be found for the programme to survive beyond this initial 'dementia-friendly' funding. Lack of funding is a common barrier to the sustainability of arts programmes (Goulding, 2014). If arts-based

programmes, such as the museum programmes in this research, are to be integrated into social prescribing schemes, the funding for those schemes needs to include funding for the programmes so that the process of social prescribing is sustainable for the participants and the schemes themselves. However, there also needs to be sustainable sources of funding outside of this, as the vast majority of those currently attending programmes do not do so through social prescribing. This research found repeated visits could be helpful for both the dyads and the staff supporting them, for example through museum staff getting to know the person so they could respond to their needs more effectively (Chapters 5 and 6). The building of staff-dyad relationships through repeated visits may be lost if programmes can only be short-term. Additionally, some of the potential long-term outcomes found in this research include a connection to place, such as the museum becoming a safe place, and to meeting in a group, such as reducing feelings of social isolation. If a dyad can only attend the museum through the support of the programme, these longer-term outcomes and means of supporting people with dementia and carers may also be lost when programmes are unsustainable.

This research found potential benefits for professional caring dyads, such as the discussions on building relationships and person-centred care in Chapter 7, and suggests more allowance in budgets and time for relationship-building activities for professional caring dyads could be beneficial. Although spending more time on these kinds of activities may appear to be a 'practice' implication, it is actually a policy one. Lack of funding and understaffing can result in a focus on basic care needs in care homes as staff have few resources to provide choice and person-centred care in enjoyable activities (Eyers, Arber, Luff, Young, & Ellmers, 2012). Eyers et al (2012) note this as a conflict between policy rhetoric and reality, and that policy must drive change in care homes. Relatedly, in Chapter 7, I discussed how person-centred care policy is rightly focused on the person with dementia, but misses the relational aspect of that care. As well as allocating more specific social care funding to enjoyable and relationship-building activities, the concept of social prescribing could be expanded to include care home groups and professional caring dyads, which may be one way of easily funding and integrating this.

Finally, the concept of ‘dementia-friendly’ practices, venues, and programmes has had increasing attention in recent years (Alzheimer’s Disease International, 2017). This thesis argues for the need to embed ‘carer-friendly’ practices within dementia-friendly practices, particularly as it is often the carer who controls access to activities or programmes due to the responsibilities they take (Chapters 5 and 7). Currently, “dementia-friendly” and “carer-friendly” both have policies within the UK, but they are treated as separate issues, despite caring being relational. These policies and practices need to be integrated where appropriate, considering that carers and people with dementia will also have specific needs or a desire for their own spaces. This is particularly important where carers are required to attend a programme or activity, as their needs also need to be considered, even if the sole focus of the programme is on the person with dementia. As stated in Chapter 5, this is not necessarily conflicting, as the person with dementia can come first in the design and facilitation of a session, but that does not mean the carer is not given any focus at all. As I have argued in this thesis, including carers is not a neutral act, and can have an impact on both the carer and the person with dementia, so considering their needs in isolation when both attend a session is not the most effective means of support.

### 8.5.3 Implications for practice

The implications of the research for practice can be considered instrumental use of knowledge (Straus et al., 2010). Straus et al (2010) suggest that the impact of use of knowledge on outcomes for participants, providers, and systems is of most importance, rather than simply that the knowledge is used. Therefore, this section also links to a need for further research which examines the impact of applying these implications to practice, such as making dyadic programmes specifically carer-friendly as well as dementia-friendly. As described in section 8.5.1, the core processes may also be relevant for other types of programmes, so these implications may also be relevant to the practice within those programmes.

The implications discussed here derive from both the programme theories and the conceptual platform (the programme theories provide detail of the processes of the platform). This section will be organised into sections on

carers having an impact, understanding carers' needs, session function, mitigating potential negative impacts of including carers on people with dementia, opening up the museum, and implications for outreach and online work.

#### 8.5.3.1 Overarching implication – carers have an impact

Regardless of whether the programme is intended to be for carers as well, or they are only included to support the person with dementia, including carers will have an impact on the processes within the session. This means practitioners need to carefully consider in what ways including carers could have an impact in their programme and consider if there are ways they need to alter, for example, facilitation style or session structure, as a result.

#### 8.5.3.2 Understanding carers' needs

All museums in this research gave museum staff working on the programmes some basic training in dementia with the aim of helping them to understand what people with dementia's needs may be. Some basic training in carers' needs should also be integrated with this when carers are included in the programme. Museum staff are not healthcare or social workers, so this does not need to be a comprehensive study of relationship dynamics, for example. In the same way most of the training on dementia provided a basic understanding of the symptoms of dementia and ways people may need to be supported, training on carers could provide a basic understanding of the caring role (for both family carers and professional carers) and how they may need to be supported. This could include the implications for practice covered in all of section 8.5.3.

All staff who work within the session itself could be made aware of the occasions carers may need individual support, or that there may be issues which highlight losses for the carer. For example, staff should be aware that, for some carers, enjoying the activity could prompt upset if it makes them realise they have lost this kind of enjoyment in their life. This does not mean carers should be discouraged from participating, but staff being aware of this possibility may enable them to be better prepared to respond to it, for example by having information leaflets they can use for signposting. Having this knowledge may also reassure staff that the activity in itself was not negative,

and in fact it is related to the broader difficulties of a caring role. Similarly, as the basic training on dementia includes that it is a progressive condition, and so a person with dementia's needs may change, training on caring could include that the carer's support needs may also change, as their role changes in response. This may be particularly apparent during times of transition, when the carer must change the way they use the session (as discussed in the next section on session function).

When designing programmes, managers need to be aware of structural issues related to carers' needs. For example, procedures in the session may imply to carers whether the session is also for them or not, such as only having feedback forms for the person with dementia, or whether they are also served tea by the staff. This may be important for those carers who assume they are only included for their caring role, rather than also as a participant, and may help them to take part. Relatedly, serving tea does serve an important function for carers, offering an opportunity to relax after a potentially stressful journey, and showing them the session is also for them to enjoy. As discussed in section 8.5.2, there can be limited funding for these programmes, and tea and biscuits may seem an unnecessary expenditure which could be cut. However, as this research found serving tea does serve a number of important functions, the time and funding for a tea break should be included in session design wherever possible.

As discussed in Chapter 7, programme design needs to consider what makes a programme or venue 'carer-friendly' to give carers the knowledge and support they need to attend, particularly as this research indicated it is the carer who controls access to the session. Chapter 7 discussed some issues programme designers could consider, including ensuring programmes are advertised to carers, giving pre-booking information about what will happen in the session and available facilities (such as accessible toilets), support or information on the logistics of getting to the session, and support to feel comfortable in the museum space. However, as this research did not specifically examine what would make a programme carer-friendly, these points are speculative based on what museums currently include in their pre-

session information packs and the reasons carers told managers they were unsure about attending.

#### 8.5.3.3 Session function

As discussed in Chapter 6, the carer's ability to enjoy the session may be linked to session function and the match (or mismatch) between how the carer *wants* to use the session and how they are *able* to use the session. This match (or mismatch) is dependent on the expectations museum staff have of the carer and how much responsibility the carer must take in the session, the level of support the person with dementia needs, and whether this support is within the limits of what museum staff can provide. Whether there is a match or mismatch in session function for the carer, there are a number of implications for practice from this idea. Firstly, staff need to be aware that people use the session in different ways, and not all dyads want 'togetherness' and shared respite, even where this is the aim. Evidence from this research does suggest that most staff recognise this. Secondly, staff need to be clear on what their boundaries are on the types or level of support they can provide to the person with dementia. Although all programmes in this research had a clear boundary around personal care, other boundaries were less clear and did vary between museums and individual staff members, such as whether they were able to push wheelchairs. Clarity around these boundaries may help carers to have clear expectations of their role in sessions. Thirdly, staff may need to provide more support to carers who previously enjoyed the session separately, but now must increasingly stay with the person with dementia to support them as their needs increase. This may mean ensuring they spend some time with them talking, or supporting them to participate in other ways, such as bringing favourite objects to them as they may not be able to go to them themselves. Finally, although funding can be an issue for these programmes, high staffing levels are needed, even where the carer is expected to take most of the responsibility. This means staff can support the person with dementia, when appropriate, so that the carer can enjoy the session separately if they wish, or they can spend individual time with a dyad when they are participating together (whether by choice or by need).

#### 8.5.3.4 Mitigating potential negative impacts on people with dementia

This research found there could be negative impacts of including carers on the person with dementia. It may be useful for staff to be aware that carers can dominate group conversations through their enthusiasm and because people with dementia may find it more difficult to speak in a group. Asking a person a direct question was one way staff in programmes tried to include some people with dementia specifically, however it may be useful to trial other facilitation techniques, such as the 'I want to speak please' cards (Innovations in Dementia, 2019), to see if they are appropriate to the activities and setting. It may also be useful for staff to be aware that excess disability can be an issue (carers unnecessarily intervening on the person with dementia's behalf). However, this is more complex than the issue of a person dominating conversations, which is common in facilitating all kinds of groups (Prendiville, 1995). As discussed in Chapter 6, intervening on the person's behalf can also be a supportive practice, for example where the person with dementia finds speaking in the group stressful. Museum staff may only be meeting the dyad for the first time at the session, and are not trained in health or social work, so it is difficult for them to know whether an intervention by a carer is necessary or creating excess disability. Some staff in this research discussed ensuring they give the person with dementia space and that they model comfort with long pauses to help in possible instances of the carer intervening unnecessarily (Chapter 6). It may therefore be useful to include in staff training the idea that carers can intervene unnecessarily on occasion, preventing the person with dementia from participating fully, and that techniques such as modelling comfort with silence can be useful, but this should also be tempered with the idea of necessary, supportive intervention. It may also be useful to reiterate that staff are not expected to be health, social care, or relationship specialists, but that being led by the dyad as a whole (rather than just the carer), may be a useful approach.

In MacPherson et al's (2009) evaluation, when it was suspected that carers were creating excess disability, they were asked to move out of sight, and were not then involved with the activity but just supported the people with dementia to move from one artwork to the next. This is one solution to



potential excess disability. However, it is not an appropriate solution for those programmes which aim for the carer to also participate or benefit, as it reduces their role to support-only and they are unable to experience potential shared and individual outcomes of participating. Nevertheless, there may be programmes where the person with dementia is the sole focus. As discussed in section 8.4, this research did not address whether people with dementia want their carer to be involved, and there may be some people who would prefer a dementia-only group. Additionally, as discussed in section 5.3 of Chapter 5, requiring a carer to attend means that those people with dementia who do not require their support and would like to attend alone are unable to do so. However, taking a functional approach to capacity in activities for people with dementia (Shakespeare et al., 2019) may be more complex in community or cultural settings than healthcare settings. Museum staff are not trained in health or social care, which means they should not be expected to be able to judge whether someone has the capacity to decide to attend alone. This means they would need to be led by the individual (and their carer). However, there may then be an issue of how they manage a session when someone attends who needs more support than they can offer. As discussed in the session function section previously, it may be helpful for programme managers to be explicit in what support they can and cannot offer (such as whether they can help someone sit-to-stand or push a wheelchair). This may make it easier for the person with dementia and their carer to make an informed decision, and may be particularly important in programmes which decide not to include carers. If the programme is affiliated with a social prescribing scheme, link workers may be able to support this decision-making prior to referral, as they may have more training in, and links with, healthcare, particularly as many will be based in GP practices (NHS England, 2019b).

#### 8.5.3.5 Opening up the museum

One of the programme theories and core processes was about how the museum could be opened up as a safe place for the dyad to return to in the future, but that some may have limited capacity to return. There is little museums could do to alleviate the number of caring tasks carers have which can act as a barrier to leisure activities (such as for the carer quoted in the

literature review from Camic, Baker, and Tischler's evaluation; 2016). However, they may be able to reduce some of the other barriers to visiting the museum outside of the sessions. For example, as transport costs could be a barrier, museums could partner with local public transport and passenger transport companies to offer reduced fares to the museum. Providing a quiet break room in the museum, as has become popular to support disabled people at events and conferences (for example Fife Centre for Equalities, 2017; Social Care Institute for Excellence, 2012) may also be useful, as in-house tea rooms can be busy and noisy. It may also be beneficial to ensure information is provided on other events in the museum, other groups and programmes, and on how the dyad could be supported to return outside of the session (such as quiet hours, a break room, transport initiatives, and reduced price of entry). This would not only be useful for family dyads who may have barriers to returning, but also to those professional carers who intend to return, either in a personal capacity or with other people with dementia who did not attend the session. As this research suggested the sessions particularly opened up the museum to professional carers who were previously disinterested, information on how or when to return may be particularly important, as they had not attended the museum previously and may not already have had this knowledge.

The manager at site 6 suggested it was important to embed the dementia-friendly programme in the whole museum, rather than just containing the training to those members of staff directly involved.

*When we were developing this we brought in security, visitor experience, we brought in everyone that we could think of just so that everyone knew what this was, so that people are kind of supported from the moment they step in, they're not faced with someone being like [yelling angrily] "open your bag, let me search your bag now" or like, at least people are aware that that's what's happening today. ...kind of fitting it into that broader infrastructure and making sure that everyone's aware of it. That's really key, because you don't want*

*someone to kind of step right inside the building and the suddenly feel  
unwelcome or stressed or confused*

*- Manager, site 6*

A whole-museum approach such as this may also support dyads to return outside the session as more staff will have training and awareness of dementia. Despite the increases in basic awareness training on dementia such as Dementia Friends (Alzheimer's Disease International, 2017), there is a lack of research into what, if any, impact it may have on the experiences of people with dementia and carers in community settings (Hebert & Scales, 2019). However, initiatives such as Dementia Friends are fairly well-known in the UK (Alzheimer's Disease International, 2017), and organisations often display a logo or individuals wear pin badges once they have completed the training. It may be that carers and people with dementia see this visible sign that staff have undertaken this training, and feel more confident attending the venue. However, although some people with dementia feel education and awareness training on dementia would be beneficial to their community engagement (Smith, Gee, Sharrock, & Croucher, 2016), others feel terms such as 'dementia-friendly' can inadvertently increase stigma due to a focus on diagnosis and are a paternalistic means of support as people with dementia are not often involved in the training itself (Rahman & Swaffer, 2018). Taking a whole museum approach to 'dementia-friendly', rather than containing it to the specific programme, may therefore also support some dyads to return (though more research is needed on the impact of these initiatives), but museums should work with local groups of people with dementia and carers to ensure the training supports their needs.

#### 8.5.3.6 Outreach and moving activities online

Many museums who provide the programmes investigated in this research also have outreach sessions to memory cafes, care homes, and other groups. For example, the programme at site 2 had funding for four in-house sessions, and then the remaining funding was for the development of activity boxes which could be loaned to groups to work through on their own. In contrast, site 1's outreach sessions involved a facilitator taking museum objects to a group and running an object-handling session, though with no other staff support.

Given the funding difficulties described previously in this chapter, these outreach sessions appeared to be a way of museums having an offer for people with dementia without the high staffing costs of in-house sessions, to reach those who may otherwise be unable to experience the activities, or as a way of publicising the sessions and encouraging people to attend the museum (Morse et al., 2015; Smiraglia, 2015). There is some research on the effectiveness of these kinds of activities in care homes (for example Smiraglia, 2015; Thomson & Chatterjee, 2016), and on how care homes can be a different and complex environment for artist-facilitators within which to adapt their way of working (Evans, Garabedian, Bray, & Gray, 2020). My research did not examine processes in activities outside of the museum, however some of the developed concepts may be applicable. For example, session function may also play a role in outreach sessions. The sessions in the museum have a high staffing level and take some responsibilities from the carer through the structure of the session and staff support. A carer may use the museum sessions as a form of physical respite from the person with dementia, with the museum staff providing the person with dementia with the support they need to participate. An activity box or outreach session without the same high staffing level may have less impact or be less enjoyable to that carer, even if the activities are identical, because they lose that support and ability to have separate respite time. Conversely, a dyad who enjoy the session together as shared respite, may still gain positive outcomes from these outreach initiatives, as they are still sharing an activity together that is not about dementia or their caring roles, with a box or sole facilitator that provides some structure (though some may struggle if they also require that additional support from staff). Further research is needed on how concepts such as session function apply to these outreach activities.

The Covid-19 pandemic meant many museums closed and, at the time of writing this thesis, programmes for people with dementia and their carers have not yet resumed. This has brought outreach programmes, particularly those online, into greater focus. Indeed, some museums have found ways to run their dementia-friendly programmes virtually through downloadable activity packs or on online video platforms such as Zoom (for example Exeter City

Council, 2020; Museum of London, 2020). Family carers of those with dementia may be under additional stress during the pandemic due to reduced access to respite care or support (Carers UK, 2020; Giebel et al., 2020), or progression in the person with dementia's condition (Canevelli et al., 2020). Professional and family carers of those living in residential homes may also have concerns about the spread and risk of Covid-19 in care homes, the risk of this to themselves, or being unable to visit their loved one (Killen et al., 2020; Maben & Bridges, 2020). Outreach sessions may be supportive of those who want more activities and ideas they can do within the home with the person for whom they care (Vaitheswaran, et al., 2020). However, for those who feel in greater need of more traditional, physical respite from their caring role due to the increased demands during the pandemic (Giebel et al., 2020), online outreach may have less impact, much like those who want to use the in-person session for physical respite. At-home activities also mean the carer holds all of the responsibility, including some they do not have in the museum such as cleaning up after the activity, which may be challenging for carers who rely on the support of the staff to do, and enjoy, these kinds of activities. Additionally, the online sessions may not have the same level of socialising, which is often cited as a key outcome for carers of these kinds of programmes (e.g. Camic et al., 2016; Flatt et al., 2015; Lamar & Luke, 2016). When programmes are able to resume, programme managers may need to consider how the issues of the pandemic may impact those processes of the session. For example, if there is an increased desire for physical respite after having little access to it, museum programmes may need to further increase the staffing levels, to allow more dyads to enjoy the session separately if they wish. However, this may be challenging due to the financial impact of the pandemic on the arts sector.

Providing sessions online may open up the activities to those who previously could not visit in person due to difficulty attending the session, such as transport costs and availability, or living far from a museum. As only those people who already attended programmes were included in my research, the impact of these online activities on those who could not attend in-house programmes is worth exploring, particularly so that they can continue post-

pandemic if they are valued. However, in removing barriers for some, online sessions create barriers for others, such as lack of internet access or digital literacy. For example, although internet use has been growing amongst older people, in 2019 twenty-nine percent of people aged sixty-five or over had never used the internet (Office for National Statistics, 2019). For those that struggle to access online sessions, the impact of their lack of access may be compounded by most other activities also moving online during the pandemic (Centre for Ageing Better, 2020).

One finding of this research was about the programmes, and museums themselves, becoming safe places for the dyad to go and enjoy themselves, away from dementia. This may become of greater importance post-pandemic, after not being able to leave the house or do group activities in a long time. However, some people with dementia have found their dementia has progressed more rapidly during the pandemic due to losing normal routines and activities (Canevelli et al., 2020), which may mean it is harder for the dyad to resume activities, like the museum programmes, they enjoyed previously.

#### 8.6 Reflexivity and reflection

The preface to this thesis briefly discussed my positionality prior to this research, including my personal view of museums, experience of professional care work, professional training, and experience of dementia and chronic illness. This section will consider the issue of positionality in more depth, through defining reflexivity and how it applies to this research.

Research is context-bound. No research can be truly objective because the characteristics of the researcher influences what questions they ask, what methods they choose, and what they draw out from the findings, shaping the overall conclusions (Malterud, 2001). Findings do not 'emerge' from data, but are actively constructed (Braun & Clarke, 2019a). This subjectivity of research includes the researcher's personal characteristics, such as personal experiences, beliefs, and theoretical stances (Berger, 2015). It is also psychosocial, as the researcher is part of the social world they study, interacts with participants, and is in turn influenced by that social world (Gough & Madill, 2012; Hammersley & Atkinson, 2007). A strictly positivist approach to research responds to this subjectivity by attempting to control and eliminate it,

but, given a researcher's characteristics will influence the shaping of the research (such as what to study and how), complete objectivity is impossible (Maxwell, 2012). Qualitative approaches have been increasingly considering subjectivity as a resource in understanding data and producing knowledge (Braun & Clarke, 2019a; Finlay, 2002; Gough & Madill, 2012). This fits with the epistemology of a realist framework, in which knowledge is viewed as partial and constructed, and thus the researcher's perspective inevitably impacts the research and its findings (as discussed further in Chapter 2).

Reflexivity is the active process of recognising your positioning within the research, and considering the impact this may have on all aspects of the research process and its outcomes (Berger, 2015). Thus, reflexivity aims to enhance the quality and credibility of research through transparency of the researcher's subjective role (Berger, 2015; Gough & Madill, 2012). This transparency is not just for the reader of the research, but also for the researcher themselves, so that they can deliberately and consciously consider their role throughout the research process, with the aim of understanding and handling their data better (Berger, 2015).

#### 8.6.1 Strategies for reflexive practice

Despite the recognised importance of reflexivity, there is less guidance on *how* a researcher can be reflexive and what strategies may be most effective (Dean, 2007; Maxwell, 2012). Reflexivity cannot be a one-time process and must be considered throughout the research, given that positionality impacts all stages of research and that the researcher's position is also fluid, such as how relationships with participants can change over time (Berger, 2015). Additionally, as reflexivity is about implications, it is not enough to simply describe personal experiences, but those descriptions must be used to explain, interpret, and make explicit the links between the research and its context (Finlay, 2002; Gough & Madill, 2012). In other words, it is not simply about *what* may be having an impact on the research, but *how* it may be having an impact.

There were a number of strategies I used to take a reflexive approach to my research. However, it is worth noting again that I, as for all researchers, do not necessarily have conscious access to everything that may impact or influence

the research, nor is it possible to describe and explain every potential impact to every process or interaction (Emmel, 2013; Gough & Madill, 2012; Mason, 2007). Therefore I used these strategies to be as reflexive as possible, and the following description of ways my positioning may have impacted the research is also limited by that positioning.

I tried to embed a reflexive approach in my research methods and practice. Firstly, as described in the preface, this thesis is written in the first person in order to make myself as researcher overt in the process for the reader. Secondly, my training as a clinical psychologist included the practice of reflexivity in therapy sessions, and I used this means of reflexivity in research interviews. It involved paying attention to my own thoughts, feelings, and ideas while listening to the interviewee, in order to unpick my reactions to ensure I was not imposing my own framing on the interviewee (this parallel between reflexivity as a therapist and as a researcher has been described by other researchers, such as Berger, 2015; Tolman, 2001). This may be particularly important in realist interviewing, as it involves testing and presenting theory. This not only means considering how you ask questions to test theory (as described in Chapter 4 on evaluation methods), but also how you interpret responses and ask follow-up questions in the moment. This 'in the moment' reflexivity helped me to consider if I was imposing a framing on an interviewee's responses which fit with my existing theories, or if I was listening, and being open, to alternative explanations in the way I responded or asked questions. Relatedly, as described in Chapter 4, I also sought alternative explanations and disagreement from others in the analysis of that data (Barbour, 2001) through taking raw anonymised data to a qualitative analysis group. The benefit of this group to other aspects of reflexivity will be discussed further later in section 8.6.2.

A key tool I used to aid my reflexive practice was keeping a research diary, which I began during the search phase of my realist review (Chapter 3), and continued through the evaluation and data analysis. A research diary has been used by a number of PhD students to aid their research process, for example Borg (2001), Engin (2011), and Li (2018). A research diary offered ongoing time and space to be reflexive and have an ongoing conversation



with myself about my thinking, ideas, and decisions (Nadin & Cassell, 2006). I used it in a number of ways. Firstly, I used it as a log of my activities, such as describing what I had been working on or reading, alongside my thoughts and ideas for what I needed to do next. Secondly, I included my thought processes on any decisions I had made such as whether to include a particular area of research in the review. Thirdly, I included moments of analytic insight, such as connections between what I was reading and data, or ideas and questions that arose while coding data. Finally, I included difficulties or moments of 'stuckness' in the process of conducting this research. The research diary not only allowed a 'thinking on paper', but also documented my processes so I could return to them at a later date if I was unsure why I had done something in a particular way, or wanted to revisit the decision in the light of new information, data, or thinking. Much like Engin (2011), this opportunity to re-read and re-visit supported my reflexive practice in acting as a mediator in my understanding of my role in the research, though being able to have a conversation with the thoughts and ideas of my past and future self.

#### 8.6.2 Reflexive statement

Using the reflexive strategies described previously, I considered the impact my positionality had throughout this research. This section considers some of the potential key impacts (with the previously stated caveat that my positionality will also impact what I view as 'key').

As stated in the preface to this thesis, my background is in psychology, specifically through training as a clinical psychologist, and then working in health research. Within clinical psychology, I aligned myself with systemic approaches to therapy, in which a person and their mental health is understood not only on an individual level, but within their social, cultural, and societal context. This is an approach which I have carried through in my work since, particularly in more recent disability activism work at my university. In the context of this research, this disciplinary approach means I would have been trying to place stories people told me or behaviours I witnessed within a context, particularly as context is a key component of realist approaches (Sayer, 2000). However, there may be two potential issues with this. Firstly, as I did not interview most of the participants in the sessions I observed, I was

making assumptions about their personal context based on my knowledge of dementia, caring, and perceptions of dementia in society. As I will discuss later, my experience of these issues is limited, and mostly not a lived experience, so I needed to be mindful of when I was making assumptions. Secondly, I have no background in museum work or as an artist-facilitator, which meant I needed to be aware of my assumptions about the museum context and the context of those who work within sessions. Spending time working with the team at Site 1 for approximately 10 months prior to starting my evaluation (during my literature review work), was an important way of learning about the museum context, for example how programmes such as these are funded, the training and various roles and responsibilities staff members have, and how museums are located within national funding and arts structures. I was working from the museum offices one day per week, usually on my PhD work unless there was a dementia programme session that week. As well as adjusting my initial assumptions about museums and how they are run, embedding myself in the museum in this way also meant I had easy access to staff members who I could ask questions and check my assumptions or assertions. When I visited other museums for the research, I could also then ask questions to check whether issues, such as how museums link to social prescribing schemes, were the same or different at different museums. Although I was not sharing data, it was a way of obtaining the views of people from a museums background on ideas I was generating from the data. Seeking alternative explanations and disagreement is important for the rigour of qualitative research (Barbour, 2001). Given PhD research is conducted alone, rather than as a team, seeking these alternative explanations was of additional importance. As well as speaking to museum staff about broad ideas being developed, I also took raw anonymised data to a qualitative research group. This group comprised researchers conducting qualitative research from a range of disciplinary backgrounds, including sociology, psychology, medical sciences, and education. None were using realist approaches. This meant I could gain perspectives on my data and developing findings from those with different disciplinary and theoretical backgrounds to highlight and challenge any hidden assumptions I was making

based on my own background, and find different ways of reading the same data.

My work background also involved some professional care work. As I was unable to include most professional care dyads in this research, this was important in bringing some knowledge that was not visible in the sessions, such as the nature of work in care homes, the way different care homes have different cultures, and the very busy nature of a care worker's day. However, my experience was not of dementia care, and was over a decade ago, so I may have imposed assumptions based on my experiences which were not relevant to those attending museum sessions. For example, through my research diary, I realised I expected professional carers to be excited or interested in attending the session, because these were the kind of activities I enjoyed as a carer and I enjoy talking about artwork with others. My observations at site 2 demonstrated that this was not the case for all professional carers, and reminded me of the stress that also came with supporting someone to go out, travel, and go somewhere you are unfamiliar with at a specific time. As well as examining my assumptions through my research diary, I also tried to ensure I mitigated any potential assumptions through reading research and accounts of working in care homes, and including literature related to this in my theory development.

Prior to the research, I had very little personal experience of family caring or dementia, aside from friends talking about their experiences of having parents with dementia. Over the course of my PhD, my gran developed dementia, and I had a few one-off days of caring for her. One of these days included taking my gran to a dementia-friendly museum session, just prior to beginning my evaluation. Although we went because I thought she would be interested in the specific activities scheduled for that session, rather than for research purposes, I had a number of reflections from this experience which had an impact on the evaluation. Firstly, because it was a new and different experience for her, it became a 'special day out' she has mentioned frequently since, and became a shared experience that we could talk about in later conversations. Secondly, I realised that it did not feel like a 'shared experience' as such during the session. I noticed my focus was always on her,

her needs, and what she was enjoying, and only realised afterwards that I completed the evaluation sheet based on her experience rather than my own, even though she had her own evaluation form which staff helped her complete. This also led me to realise how I describe the visit as 'taking her' to the session, rather than 'going together'. This also fits with my experiences of days caring for her, where even 'shared activities' like watching a film together were very focused on tasks of caregiving, such as helping her to readjust her position or getting her a drink. The idea of 'shared respite' had arisen in the review, and felt like an important idea to investigate further. However, these reflections also made me see the appeal of an 'enjoying together', but also the difficulty of stepping out of a caring role, and how at times it is not possible to do so. I was not my gran's main carer, so the dynamic was different to those who attended the museum sessions, however I also witnessed the impact of the caring role on her main family carer, and how this became increasingly difficult as my gran's needs progressed. This brought more into focus the systemic factors affecting carers, such as the difficulty of accessing support services and the impact a lack of social care support can have, and how this may manifest in shared activities. Although the idea of session function quickly became apparent during my evaluation observations, these experiences likely also improved my ability to see the ways different dyads used, and acted within, the sessions.

This also links to the idea of the emotional labour of research. As quoted in Chapter 6, one volunteer at site 3 did not go to any further sessions because it made her consider her possible (negative) future as a carer. This was not the case for me, perhaps because I was not my gran's main carer and already had a good understanding of how dementia progresses from my clinical work. However, this does not mean there was no emotional impact from the research. There is increasing interest in the emotional impact of research, but much of the research on this examines 'sensitive research', or that which may be likely to cause harm to those involved (Dickson-Swift, James, Kippen, & Liamputtong, 2009; emerald & Carpenter, 2015). However, it is not possible to anticipate emotional challenges as they may arise only indirectly from the research topic itself (Hubbard, Backett-Milburn, & Kemmer, 2001). In

qualitative research in which you are working with people, there is a constant negotiation and re-negotiation of the balance between closeness and detachment with research participants (Gilbert, 2001). There is not a complete detachment, which means I was not completely detached from my participants. As two of my participants noted, some people who previously regularly attended the museum session stopped attending when the person with dementia's condition progressed. There were some I came to know fairly well through repeated visits. I could not help but think about and wonder how they were coping, particularly one carer who informed the museum they would no longer be attending because his wife, who had been suddenly taken into hospital, would be coming home to die. All the people I met were also on my mind when the pandemic arrived and I knew they would have lost many of their usual sources of support. This was not 'distress' in the way 'harm from research' has been discussed elsewhere (Bloor, Fincham, & Sampson, 2010). However, it was an unanticipated emotional impact. I was surprised by its unanticipated nature, given my experience with distressing issues in clinical work and my expectation there that my clients and their stories do stay with me. There can be a tendency in research to 'write the researcher out' of anticipated potential emotional impacts, and focus on the participants and the research itself (Dickson-Swift et al., 2009; emerald & Carpenter, 2015; Hubbard et al., 2001), and I think this is what happened for me too, particularly as my topic (museum programmes) is not one which is 'sensitive'. Knowing emotion is part of research can lessen its impact (Hubbard et al., 2001), and may also allow the researcher to ensure they have means of support and self-care should emotional challenges arise. It would be useful for all researchers to consider the emotional labour and impact of their research, even where their topic is not 'sensitive'. My feelings of concern for people who attended the programmes was also paralleled by the museum staff who worked on them, who told me during coffee breaks of their worry or concern for how people were coping, particularly when they stopped attending or had told them of a difficult life event. This emotional impact should also be considered for museum staff too.

Researcher emotions can be used reflexively, like data, to consider your assumptions and interpretations (emerald & Carpenter, 2015). For example, during an interview, I felt one staff member was dismissive, and did not understand the lived experience of people who were not from a wealthy background, and I felt negatively towards her. When I first read the transcript, I interpreted many of her comments negatively (i.e. that she did not understand the people in the programme). However, when I noted this negative reaction in myself, I went back to the transcript holding this reflection in mind, and found I could read a more positive interpretation of many of her comments and see a care for the people she worked with, albeit from a place of ignorance about some of their personal circumstances.

As discussed earlier, reflexivity is an ongoing process, one reason for which is the fluid and changing nature of relationships. My position, as relates to my participants, will change over time, and so it is important to consider how that changing relationship can impact the research. For example, the same staff members usually worked on each session at a museum, and I spent more time with them than dyads who attended because I was also helping to set up and clear down each session. More so than the dyads who attended, I got to know many staff members quite well which changed my positioning. For example, although I tried to ensure I introduced myself and my research from a position of curiosity and interest in the other person's expertise, some staff moved from seeing me as a 'novice' to an 'expert' on museum programmes, despite my lack of museums experience. The manager at site 3 asked me for my opinion on their evaluation forms, how they could be improved, and what other museums were doing to evaluate their sessions. After I signposted her to some resources on creating dementia-friendly materials and where she could find what other museums were doing, the evaluation forms were altered for the next session. This highlighted that I did have an influence on the settings I was researching, although not always in such an obviously direct way. My findings cannot be separate from the fact I was present, and volunteering, in those settings. Another researcher, with a different way of working, may have had a different impact to a different degree, and subsequently developed different findings.

My relationship with museum staff could also have led me to want to find 'positive' aspects of the programmes, minimising the negative, because of their support for my research and knowing they were making an effort to make a positive difference to people's lives. I did reflect on this in my research diary, but I believe this did not have a large effect on my conclusions. I felt that my focus was, conversely, sometimes more concentrated on the negative aspects of including carers. This was because I felt this was the information that was missing from research and discourse on including carers in all kinds of programmes. Seeking alternative explanations for data, as previously discussed, also helped to mitigate this impact, as others did not have any relationship or attachment to the staff or museums in my research so would not have this potential bias. I was also clear, when first proposing my research to a new museum manager, that I was interested in both positive and negative aspects of how the programmes worked. This helped to set expectations so staff were aware my focus was also on the negative.

As discussed in Chapter 2, in realist terms, social phenomena are 'real', rather than constructions, in that they have real effects (Bhaskar, 2008). This includes research relationships, which can shape the context of the research and influence its progress and findings (Maxwell, 2012). One aspect of relationships that impacted how I conducted the research is reciprocity. During the evaluation, I was struggling to recruit people with dementia and carers for interviews, though most were happy to take part in the observations and demonstrated interest in my research by asking me questions. Part-way through the evaluation, I realised that I did not pursue interview recruitment as much as I could have, for example by not following up with a dyad at a subsequent session if they had seemed less than absolutely sure they wanted to participate in an interview. I realised I felt concerned my research, particularly the interview, was a burden to dyads who were already coping with dementia, particularly as they had not attended the session for research purposes. The observations felt less burdensome, as I was not asking the participants to do anything they had not already been planning to do, and I was less hesitant to recruit for this purpose. On reflection, I think this was in part due to feeling I could not reciprocate for their involvement and time, in a

way that I did not feel with staff as I was reciprocating by volunteering at the session. It also suggested to me that I did view caring and/or dementia as burdensome, or at least time-consuming, despite knowing there can be positive aspects to the experience of caregiving in dementia (e.g. Lloyd, Patterson, & Muers, 2016). This may also have been related to an increase in difficulties related to my own health condition worsening in the evaluation phase, during which I increasingly struggled to manage the tension between worsening my health through participating in additional activities, and wanting to offer my personal experiences of disability to other projects or activities as way of improving my experiences and those of others. This increasing feeling of personal burden when I was struggling may have meant I did not view 'the opportunity to share their perspectives' as enough of a reciprocal gain for my participants. This was an example of when I may have imposed my own story on that of the potential participants. Although recruitment for interviews would always have been limited by the low attendance of some sessions and because many dyads did not attend regularly, these factors related to my personal positioning at that time would also have had an impact (viewing my interviews as a burden due to a lack of reciprocity, participants not attending to participate in research, and that sharing experiences can be a burden rather than an opportunity when you have a number of demands on your time and your health). I attempted to address this when I released I was being hesitant in this way, and did subsequently follow-up with more dyads, but I know I remained more hesitant than I could have been. On reflection, I felt I would rather be hesitant than place burden on my participants, despite the potential negative impact on conducting the research itself.

Research relationships are most obviously apparent during interviews. My personal characteristics may have had impact on interviews, as what an interviewee says or how they describe it can depend on who is interviewing them (Gough & Madill, 2012). The notion of being an 'insider' versus 'outsider', or being 'similar' or 'different' to interviewees is not necessarily a binary concept. Insider/outsider identity has also been considered as a liquid identity in which the researcher is neither insider nor outsider but within a continuously shifting relationship (Thomson & Gunterb, 2011). And it has



similarly been considered as on a continuum of 'outsider-ness' to 'insider-ness', which can also involve multiple parallel continuums, such as being an 'insider' in terms of gender but an 'outsider' in terms of age (Hellowell, 2006). In this research, there were ways in which I was an insider (similar) and ways in which I was an outsider (different) to my participants, which may have impacted what and how they discussed their views and experiences. The times when I was viewed as an 'outsider' and unfamiliar with the museum sessions or the participants' lived experiences may have empowered participants as being the expert (Berger, 2015), which is also something I was trying to cultivate through my realist framework in interviews. This empowerment may have had particular importance in interviews with people with dementia and carers as a more marginalised group (Berger, 2015). Though this unfamiliarity could be positive in this way, it may also have led me to misunderstand or misrepresent participants' experiences (Berger, 2015). Conversely, the occasions and characteristics in which I held 'insider-ness' may have enabled participants to feel more comfortable sharing their perspectives and may have allowed me to have a different kind of understanding than if I did not share that 'insider' characteristic (Berger, 2015). However, as discussed earlier, it is important I did not impose my 'insider' experiences over the interpretations of my participants experiences and perspectives, and similarity with participants cannot be assumed to be the same thing as solidarity or comfort in the interview space (Maxwell, 2012). For example, as discussed earlier, my relationship with museum staff was fluid, and I had a 'liquid identity' in my position in interviews (Thomson & Gunterb, 2011). I was initially usually an outsider, being a researcher rather than a museum worker, though my 'outsider-ness' varied depending on how my experience doing the research was viewed as museum experience. This became more liquid during the evaluation at a particular museum, as working on the session meant I was both an insider as 'another volunteer' and an outsider as 'researcher'. When it came to staff interviews, I already had this established liquid positioning, as almost all staff were interviewed at the end of my time at a museum. This may have led staff to feel more comfortable in sharing their perspectives with me, but also they may have felt I could not truly understand their role in my limited time, or may have misunderstood their

perspective. These ideas are particularly important when considering people with dementia and carers, and what was visible and not visible in terms of my identity and experiences. I do not have lived experience of dementia and was younger than the attendees of programmes. In fact, most participants assumed I was much younger than I am, and this perspective may have had an impact as perceived generational differences can influence the interviewees response (Underwood, Satterthwait, & Bartlett, 2010). Furthermore, elements of my 'insider-ness' were hidden from participants, as I did not discuss my experiences of caring nor of having a disability (again, participants made assumptions about my health and one once asked why I sat down in one session when I was 'a fit, young thing'). Though some elements of my insider-ness may have helped me to understand perspectives, such as experiences of professional caregiving discussed earlier, I was mainly an 'outsider' in terms of people with dementia and carers in my research. This was important to work with reflexively, as the lack of interviews with these groups meant the voices of people with dementia and carers were missing outside of their utterances in sessions. I needed to constantly consider my reflexive strategies, such as using a research diary as a mediator for constant conversations with my past and future thinking, and seeking alternative explanations from others and the literature, in order to ensure I was not misrepresenting or misunderstanding that which was unfamiliar to me. This also meant I needed to use this reflexive practice to determine when I needed to be flexible in my methodology (Underwood et al., 2010). As stated in the preface, I shifted my plans in order to try to gain more perspectives from people with dementia and carers, but this became impossible during the global pandemic and remains a limitation of this research.

As well as in interviews, these fluid concepts of insider and outsider are also relevant to session observations, and specifically the writing of fieldnotes. Descriptions in fieldnotes are not a mirror to the reality of what occurred, but are constructed by my decisions on what to include or not describe, my theoretical priorities, and my experiences (Emerson et al., 2011). Therefore, my understanding, and experience, of the museum and the participants' lives (my insider/outsider-ness) will have impacted how I wrote my fieldnotes, and

so what theories I developed from the analysis of those fieldnotes. This subjectivity and reality-construction are often considered in the critical analyses of finished ethnographic research, but the act of writing fieldnotes from observations can be overlooked (Emerson et al., 2011). In recognising this impact of my positioning and my findings, I carefully considered the act of writing fieldnotes prior to entering the field, so that I had an awareness of this reality-construction and how it may have an impact from the outset. I also ensured I triangulated these notes with interview data and published literature, and did not treat the fieldnotes as an absolute 'truth'. However, there will likely be some situations a different researcher would have focussed on that I did not include, or would have interpreted and written about them in a different way, creating a different set of fieldnotes, which may have led to a different focus in the findings of this research.

Finally, as stated in the preface, I was a novice in realist research, having not even heard of the methodology prior to beginning the PhD. As described by Marchal et al. (2018), there are challenges in using the realist approach, particularly for those new to it, such as understanding the meaning of 'mechanism' in this approach; theory development; analysis and configuration of context-mechanism-outcome configurations (CMOs); and the difference between different levels of theory, such as CMO and middle-range theory. It is also challenging to quickly gain proficiency as there is no prescribed accompanying methodology or analytic 'steps'. This meant I needed to learn how to practically apply the theoretical as I conducted the research. As discussed in the limitations section, this is partly why I had a large number of programme theories, as I was unsure how to prioritise them without losing valuable insights. To improve my understanding, I attended training on using realist methods, which included a training event in which I could workshop developing theories from the review with a group of realist researchers. I also joined a realist discussion forum, which includes a number of experienced realist researchers, and followed the conversations on methodology, theory, and analysis. However, a more experienced realist researcher would not have had to do the initial work of understanding realist approaches and how to

handle data within this framework, and may have focussed the programme theories further or had different insight into how the CMOs were constituted.

### 8.6.3 Reflecting on doing the study differently

All research can benefit from hindsight, and there are a number of ways I would conduct this research differently were I to begin this PhD again. I would seek to address the limitations described in section 8.4, such as including more long-term follow-up. However, many of these limitations would still be limited by the financial and time constraints of PhD work. I would make some changes to my methodology to improve my recruitment of people with dementia and carers to interviews. As I discussed earlier, this poor recruitment was linked to low attendance at some museum sessions, many dyads only attending for one session, and my own hesitance related to research burden. I would address this in a number of ways. Firstly, as discussed in Chapter 4, my information sheets were a barrier to participation. I was unable to change the formal and difficult wording of certain paragraphs, such as information on GDPR, due to ethics committee requirements. Ethics committees can sometimes provide required or sample text which has lower standards of readability than they themselves require (Paasche-Orlow, Taylor, & Brancati, 2003). Informed consent requires that the person is able to understand the information about the study, so presenting that information in an inaccessible way prevents this. As discussed in Chapter 4, this complex language and the length of my information sheets limited the capacity of some potential participants to consent. Ethics committees need to be more flexible in allowing their required information to be re-written in a manner which is accessible to the people who need it. I, as a researcher, could have pushed back against this further to improve the experience of my potential participants and my recruitment. I could also have included some Patient and Public Involvement (PPI) work with people with dementia and carers when developing my materials in order to get their feedback on language, length, and readability. This may have improved my materials in making them more appropriate for the people for which they were intended, and given me evidence of the need to change more complex sections when the ethics committee initially refused. However, research into PPI groups with people

with dementia and carers has found aspects of PPI feedback, such as shortening information sheets, could not be incorporated due to ethics committee requirements (Miah et al., 2020). Assuming the existing requirements remained, it may have been helpful to add a front sheet with a shorter, easier to understand summary of the research. Although this would be adding another page to an already lengthy sheet, it may allow potential participants to easily understand the key ideas immediately, with more detailed information they could take away to consider in their own time. Finding new approaches to providing participants with the information they need, without overwhelming them with too much information or overly lengthy forms, is critical to include a wider range of people in research. This is not just an issue for those with dementia who may find processing a large amount of information challenging, but for all kinds of participants, particularly as most participants do not read all the information prior to giving consent (Antoniou et al., 2011).

Secondly, one of my major mistakes in recruitment was assuming that the numbers in museum sessions would remain the same, and that there would be a majority of family care dyads (as discussed in Chapter 4). In not making this assumption again, I would plan to involve more museum sites from the outset. I found that the number of programmes running at any one time varied depending on what funding the individual museum had available. If I had initially planned to include more sites, I would have recruited more museums at the beginning of the evaluation, rather than adding more as it became clear I would need them. This would have meant I would also have allowed for the evaluation to take a full year from the outset, so I could have had a more realistic idea of what would be possible within the timescales of a PhD (a pandemic disrupting the final study notwithstanding). It would also have lessened the impact of having different levels of access at different sites, such as when access to interviews was removed at site 2 due to the team deciding to conduct their own evaluation.

Thirdly, a lack of research with professional care dyads was something I identified in my literature review (Chapter 3). As discussed in Chapter 4, I did not realise that social-care funded carers could only be included in my

research if it was approved by the NHS ethics committee (HRA), rather than a university ethics committee. This was complicated by most care homes being private, but many of the people with dementia being funded by social care, so I could not include the dyad because I had to assume they were present in the session due to social care funding (and it was unrealistic to expect the person with dementia or carer to know exactly how their residential care was funded or to disclose this to a stranger in a public setting). This meant my theories about professional care dyads are limited by their lack of involvement.

However, if I started the PhD again, I would still not apply to HRA as the increasing timescales for approvals would make it too challenging to complete the research, particularly if I intended to include more museums and have a longer evaluation period from the outset. I could have instead focused solely on family carers, which would also have focused the number of theories I was managing. However, I feel including theorising about professional carers strengthened this work, as it highlighted there can be different processes for different carer types. One piece of research cannot encompass all potential avenues of work about a topic, so professional care dyads would likely remain an area for future studies.

Personally, if I began this research again, I would not underestimate the challenges of doing a full-time PhD with a chronic illness which limits the number of hours I can work to less than full-time, and would enrol at a maximum of 0.8 full-time equivalent. Some aspects of this work were delayed because of frequently needing time off for health reasons, and I may have been able to at least start my final study prior to the pandemic without these delays. This was particularly challenging as PhD students do not receive sick pay, so the choice is between losing the available time to conduct the work, or taking an 'interruption' and losing your pay (and so ability to pay rent). As of August 2019, PhD students funded by bodies under UK Research and Innovation (UKRI) can take up to thirteen weeks of paid sick leave (UK Research and Innovation, 2020). However, many students, including myself, are funded by other organisations. It is vital for universities and funding bodies to pay sick leave for all PhD students, but particularly to support the growing

numbers of disabled students to remain in their PhD (Higher Education Statistics Agency, 2020).

#### 8.7 Original contribution to research

The findings of this thesis contribute to the growing literature on museum programmes for people with dementia and their carers. Specifically, this thesis makes a significant contribution in explicitly considering the impact of including carers in these programmes. It used a realist framework to move beyond considering *whether* including carers has an impact, to examining *how*. The explanations for how carers have an impact were developed in the form of testable programme theories and a reusable conceptual platform which have instrumental, conceptual, and persuasive uses in future research, policy development, and the facilitation of museum programmes. The findings may also be applicable for other kinds of programmes for people with dementia and their carers, and to programmes for other dyad types, as a way of considering how including carers may have an impact or as a starting point for other evaluations.

This thesis also makes a methodological contribution to realist work in developing a conceptual platform on one process in a programme, rather than the programme as a whole. This kind of focused platform could be considered in future research where there has been little theoretical work previously. It also demonstrates the potential value of a realist interviewing approach with people with dementia, who are able to contribute valuable insights for an evaluation of the programme even where they have little memory for it. Given the few interviews with people with dementia in this research, this is a methodological area which could be explored in future research.

#### 8.8 Dissemination

The potential implications for research, policy, and practice, are only of relevance if those involved in research, policy, or practice are aware of the findings. This means it is important to consider how the findings of this thesis can be disseminated, and how this may be different for different audiences.

The sheer length of a PhD thesis means it is unlikely to be read by many, even those academics who are interested in the area. Journal articles are the

main way research is disseminated to an academic audience. As noted in Chapter 3, the literature review was published in the journal *Arts & Health* (Kinsey, Lang, Orr, Anderson, & Parker, 2019). Following submission of this thesis, further papers will be written from the evaluation. Conferences are also a key way academics disseminate knowledge to one another. Although findings from the review were presented at two conferences, the pandemic cancelled conferences in which findings from the evaluation were due to be presented.

However, the findings may also be relevant to non-academics, so it is important not to limit dissemination to methods which are most relevant to an academic audience. Though there is increasing work on communicating findings beyond academia to the wider public, there is little evidence for which may be the most effective method, beyond that effectiveness is context-dependant (Lafrenière, Menuz, Hurlimann, & Godard, 2013). In other words, the means of communication must match the intended audience. For my research, there are a number of “publics” which could be usefully engaged: museum practitioners (including in-house staff and freelance artist-facilitators), policy-makers, people with dementia and carers (about whom the research focuses), and the general public. It is beyond the scope of this thesis to consider the vast number of potential public engagement and research dissemination methods that could be used with these audiences. This section will instead consider two illustrative examples of how some of these audiences could be engaged, or have been engaged, in the course of this research.

### 1. Illustration and exhibition

Using the arts as a means to communicate academic research has been increasing (Lafrenière & Cox, 2013), and there are a number of examples of using the arts to communicate research about dementia and caring. For example, a research team at University College London collaborated with the Wellcome Trust on a number of art exhibits and films to explore public perceptions of dementia (Tischler, Howson-Griffiths, Hedd-Jones, & Windle, 2019; Wellcome Trust, 2019). As my work involved museums and art



galleries, using artwork or illustration to disseminate the findings may be appropriate to both the work and the setting. An exhibition of this artwork at museums could be a way of reaching a number of relevant audiences, including museum staff, people who attended the programmes, and the general public who visit museums. Digital copies of artwork could also be used to disseminate the research online, for example on websites and social media, at little to no additional cost, or as postcards to take away at the end of public engagement, or conference, talks. At an exhibition, attendees could be invited to give their own perspectives and views on the artwork, mirroring the process within the museum programmes themselves. However, the aesthetics of artwork can draw attention away from the underlying research itself, so it would be useful to include commentary alongside the artwork about the research itself so this is not lost (Bartlett, 2015). Bartlett (2015) also highlighted that the creation of artwork (whether by research participants or professional artists), adds a new layer of meaning-making to data, so the researcher is required to relinquish some control over the meaning of their research. Working closely with the artist(s) to ensure good communication of the findings and meanings would be key in not misrepresenting the research. However, as the public would also be creating their own meanings and finding their own perspectives when viewing the artwork, regardless of any accompanying text, it would be important to acknowledge this kind of dissemination is not bound by traditional academic structures, so can feel more vulnerable (Watermeyer & Chubb, 2019). Although artwork may engage people in a way academic text cannot (Weber, 2008; cited in Bartlett, 2015), people may not be taking from the artwork what you intend. A parallel evaluation of the artistic engagement work would therefore be both interesting and useful.

## 2. Public engagement talks

Rather than creating something new, public dissemination can also use existing structures of engagement. I had two main experiences of this during the PhD. Firstly, I gave a talk at the local Pint of Science event. Pint of Science (Paul & Motskin, 2016) is an annual, nationwide series of events in which researchers and academics give talks about their work in public,

relaxed spaces such as pubs. This form of public engagement gave me the opportunity to discuss developing findings with both specialised and general audiences (Tischler et al., 2019). Those who spoke with me afterwards or asked questions and identified themselves included a family carer of someone with dementia, a care home manager, an NHS development manager, academics, and members of the public who were generally interested in hearing about the topic. Secondly, I took part in 'I'm A Scientist', a science engagement activity in which researchers talk to school classes online and answer questions they may have about their work (I'm A Scientist, 2020). I took part both prior to and during the pandemic, speaking to twenty-seven classes overall, which included a range of students from ages eleven to seventeen and a range of ability levels. 'I'm A Scientist' particularly targets schools which have a high level of widening participation students, or those which are over thirty minutes' drive from a university as their own research found this distance reduced STEM engagement visits significantly (I'm A Scientist, 2017). Most of the questions I received were about dementia and museums programmes more broadly, rather than my research on including carers specifically. However, this event allowed me to reach a population I would have been unlikely to reach otherwise, or may not have even considered. Involving young people in this age group in public engagement and education about dementia may be particularly important in reducing societal stigma and improving their understanding of family members and those in the community affected by dementia (Baker et al., 2019). This placed my research in the much broader context of dementia and caring, and made me consider how to best explain complex concepts, such as shared respite, to a non-academic, younger, audience.

## 8.9 Conclusion

This thesis aimed to examine the impact of including carers in museum programmes for people with dementia – the impact on the person with dementia, the carer, and the relationship between them. The research highlighted that the inclusion of carers does have an impact, and used a realist approach to theorise how it may have an impact. Carers were usually included due to the responsibility they could hold for the person with

dementia. Most programmes sought to treat the carer as an equal participant, but this was complicated by their dual role as carer and participant. Some carers struggled to enjoy or participate in the session due to their level of caring responsibility, but others were able to both enjoy the session and support the person with dementia. Dyads also used the sessions in different ways, from experiencing a 'shared respite' from dementia, to enjoying the session separately as a form of traditional physical respite. However, there could be a mismatch in how the person with dementia and the carer wanted to use the session which could cause tension or distress, and this could be particularly apparent in times of transition as the person with dementia's support needs increased. There were other negative impacts for some carers of their inclusion, such as the session highlighting losses. Likewise, there were other negative impacts for some people with dementia, such as the carer creating excess disability or preventing their engagement in the activities. Including carers enabled the person with dementia to attend, as the carer controlled access through discovering the activities, booking a place, and handling the logistics of travel and their arrival. Including carers may extend the impact of the session beyond 'the moment', for example through relationship-building or the carer re-considering what people with dementia are capable of. Including professional carers may have opened up the museum and the activities to people with dementia in the residential home who did not attend, if the carer takes back ideas for activities or comes to view the museum as a place that it suitable to bring people to visit. For some, the sessions also appeared to open up the museum in other ways, particularly to previously disinterested professional carers and as a safe place for the dyad to return to in the future.

The developed programme theories and conceptual platform considered how these outcomes may be generated. This resulted in a number of implications for further research, for policy, and for practice. This included considering how the findings may apply in the current situation of the pandemic, in which these activities have moved online, and how they may apply to policy-funded increases in social prescribing. The findings may also be applicable beyond the museum programmes investigated in this research, and further research

could use the theories and platform to consider how including carers may have an impact in other kinds of programmes for people with dementia and in programmes for other kinds of dyads.

Too often, not enough thought goes into what it means to include carers, particularly when it is seen as 'necessary' due to safeguarding or other responsibility concerns. This thesis suggests the inclusion of carers is not a neutral act, and careful consideration needs to go into how to support people with dementia and carers, and whether this will change the way programme is run, given the variety of possible positive and negative processes which occur in sessions when carers are included. Alongside making venues and programmes more dementia-friendly, there must also be a consideration of how they can become more carer-friendly.

# Appendices

## Appendix 1. Example of annotated code document for literature review analysis

Highlights negatives about dementia for carer

Artful moments, a framework for successful engagement in an art program in the middle to late stages of dementia

The team observed that some participants with a previous interest in art, members, may have experienced some discouragement at first because their skills were not consistent with the art they produced earlier in life.

Arts intervention in dementia care (Thesis version of Camic et al 2016)

This engagement and accessibility enabled a sense of competency, although for those found comparing their current abilities to former abilities this sense of competency was diminished or not achieved.

Here, now - conceptual model of the impact of an experiential arts program on persons with dementia and their care partners

On rare occasions, frank frustration with limitations of the person with dementia was expressed by the care partner, which we viewed as a barrier to engagement of the dyad in the program.

Impacts of art (THESIS) museum-based dementia programming on the participating care partners

One CP found it to be both beneficial and difficult to be in that situation due to her mother's limited abilities. She said, "[It's] nice to be around other people in similar situations. But it was actually kind of hard; it was kind of like, heartbreaking to watch. [PWD] has a hard time with her vision due to her Alzheimer's so she had a very hard time seeing what it was we were even looking at and she really had a hard time with it and other people who appeared to be worse off than my mom as far as their Alzheimer's or dementia, were able to respond better, were able to see the picture and see whatever it was we were looking at and like, respond better to it. So it was actually pretty heartbreaking...the experience.

Another discussed the isolation felt because they could not talk about it: "He couldn't remember, he didn't connect, and have any capacity to review it afterwards. It was just an experience that he experienced at the moment and that's what the neurologist told us we would get to with this disease...In the moment I tried to have a conversation afterwards, on several occasions and it never materialized. So I think, that to me reveals a lot about the disease. Its very isolating and a lonely disease for the caregiver. The museum is certainly addressing that by having these experiences."

Finally, CPs (n=2) reported anxiety during the program, as it was a confrontation with reality: "Anxious only in that when he's not making sense, then I realize that this is real. That's the only anxiousness, that I can't get away from this disease. Not anything that the program created, any interaction, any time when I see PWD failing in a standard social sense, is stressful because I know that's the reality for him."

Others did not have the same positive unexpected experiences (n=2). One CP said, "I was surprised at how hard it is for her to do something new or different."

Impacts of Art Museum based Dementia Programming on Participating Care Partners

Further, dementia-related symptoms affected interactions with the PWD during and after the program (n = 9). ... it was actually kind of hard; it was kind of like, heartbreaking to watch. [PWD] has a hard time with her vision due to her Alzheimer's so she had a very hard time seeing what it was we were even looking at and she really had a hard time with it ...

*Handwritten annotations:*

- Green sticky note: "Highlights how through comparisons & prior abilities or confrontation w/ reality may have led to high carer expectations of PWD"
- Red bracket on "in the middle to late stages of dementia": "in PWD's performance to previous level", "Reminded CP of loss/dementia", "disappointment"
- Red bracket on "sense of competency was diminished or not achieved": "Competence amount to former ability", "CP's frustration w/ person's loss of ability", "CP's frustration w/ person's loss of ability", "CP's frustration w/ person's loss of ability"
- Red bracket on "frank frustration": "frank frustration", "frank frustration", "frank frustration"
- Red bracket on "isolation felt": "isolation felt", "isolation felt", "isolation felt"
- Red bracket on "anxiety during the program": "anxiety during the program", "anxiety during the program", "anxiety during the program"
- Red bracket on "I was surprised at how hard it is": "I was surprised at how hard it is", "I was surprised at how hard it is", "I was surprised at how hard it is"
- Red bracket on "dementia-related symptoms": "dementia-related symptoms", "dementia-related symptoms", "dementia-related symptoms"
- Red bracket on "it was actually kind of hard": "it was actually kind of hard", "it was actually kind of hard", "it was actually kind of hard"
- Red bracket on "heartbreaking to watch": "heartbreaking to watch", "heartbreaking to watch", "heartbreaking to watch"
- Red bracket on "PWD has a hard time with her vision": "PWD has a hard time with her vision", "PWD has a hard time with her vision", "PWD has a hard time with her vision"
- Red bracket on "she had a very hard time seeing what it was we were even looking at": "she had a very hard time seeing what it was we were even looking at", "she had a very hard time seeing what it was we were even looking at", "she had a very hard time seeing what it was we were even looking at"
- Red bracket on "and she really had a hard time with it": "and she really had a hard time with it", "and she really had a hard time with it", "and she really had a hard time with it"

Appendix 2. Overview of studies included in the review

<b>Document author(s)</b>	<b>Document title</b>	<b>Document type</b>	<b>Location</b>	<b>Participants</b> (N, dyad type, severity of dementia)	<b>Programme details</b> (Activity, length, location)	<b>Study design &amp; measures</b>
Baker, E.L. (2014).	Arts interventions in dementia care	Unpublished DClinPsych thesis	UK	- N=24 (PWD=12) - Dyad type not specified - Mild/moderate dementia	- 1 hr art viewing, then 1 hr art making - 8 weekly sessions - Art gallery (2 groups over 2 sites)	- Interview data, researcher blog, & field notes from Camic et al (2014) study - Facilitator interviews
Burnside, L. D., Knecht, M. J., Hopley, E. K., & Logsdon, R. G. (2017)	here:now – Conceptual model of the impact of an experiential arts program on persons with dementia and their care partners	Journal article	USA	- N=34 (PWD=13) - Mixed (carers = 11 spouse, 4 child, 3 paid, 3 other) - mild/early-stage dementia	- Monthly 90-min tour - 6-week 2hr art-making sessions - Art museum	- Dyads experience one or more tours & 3 art-making classes - Semi-structured telephone interviews 2 weeks after an activity
Camic, P. M., Tischler, V., & Pearman, C. H. (2014)	Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers	Journal article	UK	- N=24 (PWD=12) - Dyad type not specified - Mild/moderate dementia	- 1 hr art viewing, then 1 hr art making - 8 weekly sessions - Art gallery (2 groups over 2 sites)	- pre/post mixed methods - Pre & post questionnaires: PWD: Dementia Quality of Life 4 Carers: Zarit Burden Interview, Bristol Activities of Daily Living scale. - Post-intervention semi-structured interviews - Researcher field notes
Camic, P. M., Baker, E. L., & Tischler, V. (2016)	Theorizing how art gallery interventions impact people with dementia and their caregivers	Journal article	UK	Published version of Baker (2014)	Published version of Baker (2014)	Published version of Baker (2014)

Camic, P.M., Hulbert S. & Kimmel, J. (2017)	Museum object handling: A health-promoting community-based activity for dementia care	Journal article	UK	<ul style="list-style-type: none"> <li>- N=80 PWD</li> <li>- No carers included</li> <li>- Early-stage (n=50) &amp; mid-stage (N=30)</li> </ul>	<ul style="list-style-type: none"> <li>- One session only</li> <li>- 1 hr object handling</li> <li>- No carers present</li> </ul>	<ul style="list-style-type: none"> <li>- Pre/post session quantitative</li> <li>- Canterbury Wellbeing Scale (visual analogue scale)</li> </ul>
Clarke-Vivier, S., Lyford, C., & Thomson, L. (2017)	Strengths and Challenges of Arts-Based Programming for Individuals With Alzheimer's and Related Dementias	Journal article	USA	<ul style="list-style-type: none"> <li>- N=12 PWD (plus carers in museum sessions)</li> <li>- Family carers only</li> <li>- Level of dementia not specified</li> </ul>	<ul style="list-style-type: none"> <li>- 3 month programme</li> <li>- Each month is 3 weeks art-making at day centre, &amp; 1 tour at museum</li> <li>- Carers only present at museum tours</li> </ul>	<ul style="list-style-type: none"> <li>- Authors' first-person reflections on programme</li> </ul>
Eekelaar, C., Camic, P. M., & Springham, N. (2012).	Art galleries, episodic memory and verbal fluency in dementia: An exploratory study.	Journal article	UK	<ul style="list-style-type: none"> <li>- N=12 (PWD=6)</li> <li>- Family carers only (5 spouse, 1 child)</li> <li>- Mild/moderate dementia</li> </ul>	<ul style="list-style-type: none"> <li>- Three 90-minute sessions</li> <li>- 30 mins art viewing, then 1 hr art-making</li> </ul>	<ul style="list-style-type: none"> <li>- Pre/post mixed methods</li> <li>- Audio recordings during the sessions &amp; pre/post interviews</li> </ul>
Flatt, J. D., Liptak, A., Oakley, M. A., Gogan, J., Varner, T., & Lingler, J. H. (2015)	Subjective experiences of an art museum engagement activity for persons with early-stage Alzheimer's disease and their family caregivers	Journal article	USA	<ul style="list-style-type: none"> <li>- N=20 (PWD=10)</li> <li>- Family carers only</li> <li>- Early-stage dementia</li> </ul>	<ul style="list-style-type: none"> <li>- One session only</li> <li>- 1 hr tour, then 2 hrs art-making</li> <li>- Art museum</li> </ul>	<ul style="list-style-type: none"> <li>- Cross-sectional qualitative</li> <li>- Satisfaction survey &amp; focus group interview</li> </ul>

Gaugler, J.E., Mojsilov, I.K., & Gerber, C. (2010)	Final report. Contemporary Journeys pilot evaluation	Unpublished report	USA	<ul style="list-style-type: none"> <li>- N=20 (PWD=10)</li> <li>- Family carers only (all spouses/partners)</li> <li>- Early-stage dementia</li> </ul>	<ul style="list-style-type: none"> <li>- 6 weekly sessions</li> <li>- 3 tours, 3 art-making sessions</li> <li>- art gallery</li> </ul>	<ul style="list-style-type: none"> <li>- Pre/post mixed methods</li> <li>- Pre/post questionnaires: Carers: The Family Questionnaire, Family Dementia Staging Tool, Care context questionnaire, the Pleasant Events Schedule, Dementia Quality of Life, the Montgomery Borgatta Burden Scale, plus satisfaction questionnaire at post only. PWD: Ratings of effectiveness, Dementia Quality of Life, Cantril quality of life ladder, plus satisfaction questionnaire at post only.</li> <li>- Post-intervention discussion groups</li> <li>- Co-ordinator's field notes</li> </ul>
Gould, V.F. (2012)	Reawakening the mind	Report	UK	<ul style="list-style-type: none"> <li>- N=98 (PWD=52) – but people attending more than one museum counted as unique participant each visit, so true number is lower.</li> <li>- Mixed professional &amp; family carers (numbers not given)</li> <li>- Severity of dementia not measured</li> </ul>	<ul style="list-style-type: none"> <li>- 7 different museums involved in activities</li> <li>- Variable number of sessions (4-7, mode 4). All weekly, except one monthly.</li> <li>-</li> </ul>	<ul style="list-style-type: none"> <li>- Questionnaire at end of workshops for both PWD &amp; carer</li> <li>- Observation notes by lead author</li> </ul>



Hazzan, A. A., Humphrey, J., Kilgour-Walsh, L., Moros, K. L., Murray, C., Stanners, S., ... & Papaioannou, A. (2016).	Impact of the 'Artful Moments' intervention on persons with dementia and their care partners: a pilot study.	Journal article	Canada	<ul style="list-style-type: none"> <li>- N=16 (PWD=8)</li> <li>- Mixed professional &amp; family carers (professional carers = 3)</li> <li>- Middle-to-late stage dementia</li> <li>- Qualitative results from same study as Humphrey et al (2016)</li> </ul>	<ul style="list-style-type: none"> <li>- 27 weekly sessions</li> <li>- 16 sessions at inpatient hospital, 11 at art gallery</li> <li>- 1hr art viewing then 1hr art-making</li> </ul>	<ul style="list-style-type: none"> <li>- Observation using Affect and Engagement Rating Scale</li> <li>- Questionnaire for carers at end of each session</li> </ul>
Humphrey, J., Montemuro, M., Coker, E., Kilgour-Walsh, L., Moros, K., Murray, C., & Stanners, S. (2017)	Artful Moments: A framework for successful engagement in an arts-based programme for persons in the middle to late stages of dementia	Journal article	Canada	<ul style="list-style-type: none"> <li>- N=16 (PWD=8)</li> <li>- Mixed professional &amp; family carers</li> <li>- Middle-to-late stage dementia</li> <li>- Quantitative results from same study as Hazzan et al (2016)</li> </ul>	<ul style="list-style-type: none"> <li>- 27 weekly sessions</li> <li>- 16 sessions at inpatient hospital, 11 at art gallery</li> <li>- 1hr art viewing then 1hr art-making</li> </ul>	<ul style="list-style-type: none"> <li>- Observation using Affect and Engagement Rating Scale</li> <li>- Questionnaire for carers at end of each session</li> </ul>
Johnson, J., Culverwell, A., Hulbert, S., Robertson, M., & Camic, P. M. (2017)	Museum activities in dementia care: Using visual analog scales to measure subjective wellbeing	Journal article	UK	<ul style="list-style-type: none"> <li>- N=66 (PWD=36)</li> <li>- Family carers only</li> <li>- Early-to-middle stage dementia</li> </ul>	<ul style="list-style-type: none"> <li>- One session only</li> <li>- Small groups of 4-8</li> <li>- Object-handling &amp; art-viewing</li> </ul>	<ul style="list-style-type: none"> <li>- Mixed 2x4 repeated measures crossover design</li> <li>- Visual analog scales on subjective wellbeing</li> <li>- Evaluation questionnaire after session</li> </ul>

Lamar, K.L. (2015)	Impacts of art museum-based dementia programming on the participating care partners	Unpublished masters thesis	USA	<ul style="list-style-type: none"> <li>- N=29 carers (who took part in programme with PWD)</li> <li>- Mixed professional &amp; family carers (17 spouse/partner, 6 child, 2 other family, 4 professional)</li> <li>- Early-to-mid stage dementia</li> </ul>	<ul style="list-style-type: none"> <li>- 3 museum sites, all tour followed by art-making</li> <li>- Two programmes monthly, one twice monthly</li> </ul>	<ul style="list-style-type: none"> <li>- Semi-structured telephone interviews after programme</li> </ul>
Lamar, K. L., & Luke, J. J. (2016)	Impacts of Art Museum-based Dementia Programming on Participating Care Partners.	Journal article	USA	Published version of Lamar (2015)	Published version of Lamar (2015)	Published version of Lamar (2015)
Livingston, L., Fiterman Persin, G., & Del Signore, D. (2016)	Art in the Moment: Evaluating a Therapeutic Wellness Program for People with Dementia and Their Care Partners.	Journal article	USA	<ul style="list-style-type: none"> <li>- N=300 (Unclear how many PWD)</li> <li>- Mixed professional &amp; family carers (but numbers of each not given)</li> <li>- “various” stages of dementia</li> </ul>	<ul style="list-style-type: none"> <li>- 1hr art-viewing then 1-1.5hr art-making</li> <li>- Art museum</li> <li>- Groups maximum of 16</li> </ul>	<ul style="list-style-type: none"> <li>- Pre/post programme design</li> <li>- Smiley Face Assessment Scale of mood (N=312)</li> <li>- Agreement with statements of interaction</li> <li>- Telephone interviews carers</li> <li>- Observation of participant engagement in 17 sessions</li> </ul>

MacPherson, S., Bird, M., Anderson, K., Davis, T., & Blair, A. (2009)	An art gallery access programme for people with dementia: 'You do it for the moment'	Journal article	Australia	<ul style="list-style-type: none"> <li>- N=30 (15 PWD)</li> <li>- Mixed (separate groups: 8 PWD from residential care with prof carer, 7 from community with spouse or Alzheimer's Australia volunteer)</li> <li>- Community group = mild/moderate dementia, residential care group = moderate and severe dementia</li> </ul>	<ul style="list-style-type: none"> <li>- 6 weekly sessions</li> <li>- 45-60 minutes</li> <li>- Art-viewing</li> <li>- Separate groups for community and residential participants</li> <li>- Art gallery</li> </ul>	<ul style="list-style-type: none"> <li>- Mixed-subject design</li> <li>- Carer completed Clinical Dementia Rating Scale and frequency of stressful behaviour scale</li> <li>- Observation by researchers of filmed session</li> <li>- Focus groups for PWD, carers, &amp; facilitators after programme.</li> </ul>
Mangione, G. (2013)	Access to what? Alzheimer's disease and esthetic sense-making in the contemporary art museum	Journal article	USA	<ul style="list-style-type: none"> <li>- N=17 interviews with participants (5 dyads, 7 carers). Numbers participating in programmes not stated.</li> <li>- Carer type not explicit but suggests mixed</li> <li>- Severity of dementia not stated</li> </ul>	<ul style="list-style-type: none"> <li>- 2 museum sites</li> <li>- Art-viewing</li> <li>- small groups (10 total on both sites)</li> </ul>	<ul style="list-style-type: none"> <li>- Ethnographic plus interviews with some participants &amp; facilitators</li> </ul>
McGuigan, K. A., Legget, J. A., & Horsburgh, M. (2015)	Visiting the museum together: Evaluating a programme at Auckland Museum for people living with dementia and their carers	Journal article	New Zealand	<ul style="list-style-type: none"> <li>- N=16 (PWD=8)</li> <li>- Family carers only (5 spouses, 2 children)</li> <li>- Severity of dementia not explicit (just need to be able to "cope with the programme")</li> </ul>	<ul style="list-style-type: none"> <li>- 6 weekly sessions</li> <li>- 2hrs per session</li> <li>- Object handling &amp; art-viewing (varies per session)</li> <li>- Art museum</li> </ul>	<ul style="list-style-type: none"> <li>- Observation of sessions by researcher</li> <li>- Focus groups at end of programme</li> <li>- Interviews with museum staff</li> </ul>

Mittleman, M., & Epstein, C. (2009)	Meet me at MoMA Program. Research.	Report	USA	<ul style="list-style-type: none"> <li>- N=74 (PWD=37)</li> <li>- Family carers only (75% spouse)</li> <li>- early-stage dementia</li> </ul>	<ul style="list-style-type: none"> <li>- Research based on first visit to monthly programme</li> <li>- Small groups of up to 8</li> <li>- Art-viewing</li> <li>- Art gallery</li> </ul>	<ul style="list-style-type: none"> <li>- Pre/post questionnaires</li> <li>- Focus group</li> <li>- Researcher observation of session</li> <li>- Carer &amp; PWD questionnaires: Family Assessment Measure, Rosenberg Self-esteem Scale, Quality of Life-AD, Smiley Face Scale, Take home evaluation scale</li> </ul>
Roe, B., McCormick, S., Lucas, T., Gallagher, W., Winn, A., & Elkin, S. (2016)	Coffee, Cake & Culture: Evaluation of an art for health programme for older people in the community.	Journal article	UK	<ul style="list-style-type: none"> <li>- N= 8 residents of supported living, 6 residents of care homes, 11 carers (not all participants had dementia, number of PWD not specified)</li> <li>- Professional carers only</li> <li>- Severity of dementia not stated</li> </ul>	<ul style="list-style-type: none"> <li>- Separate groups from supported living and care home</li> <li>- 6 sessions monthly, across two museum sites</li> <li>- Mix of art viewing, art-making, &amp; object-handling (in separate sessions)</li> </ul>	<ul style="list-style-type: none"> <li>- Observation of sessions by researcher</li> <li>- semi-structured group interview one month after programme</li> </ul>
Schall, A., Tesky, V. A., Adams, A. K., & Pantel, J. (2017)	Art museum-based intervention to promote emotional well-being and improve quality of life in people with dementia: The ARTEMIS project	Journal article	Germany	<ul style="list-style-type: none"> <li>- N= 88 (PWD=44).</li> <li>- 25 dyads in intervention group, 19 waitlist control</li> <li>- Family carers only (56.8% spouse, 31.8% child)</li> <li>- Mild-to-moderate dementia</li> </ul>	<ul style="list-style-type: none"> <li>- 6 weekly sessions</li> <li>- 1 hr art-viewing, then 1hr art-making</li> <li>- Art museum</li> <li>- small groups of 6-10</li> </ul>	<ul style="list-style-type: none"> <li>- Randomised wait-list control</li> <li>- Control = visiting art exhibitions without facilitation / group</li> <li>- Pre/post-test measures: Mini Mental Status Examination, Alzheimer's Disease Assessment Scale-Cog, Geriatric Depression Scale, Quality of Life in Alzheimer's Disease, Neuropsychiatric Inventory, Smiley Scale.</li> <li>- Carer feedback after every session</li> </ul>

<p>Windle, G., Joling, K. J., Howson-Griffiths, T., Woods, B., Jones, C. H., van de Ven, P. M., ... &amp; Parkinson, C. (2018)</p>	<p>The impact of a visual arts program on quality of life, communication, and well-being of people living with dementia: a mixed-methods longitudinal investigation</p>	<p>Journal article</p>	<p>UK</p>	<ul style="list-style-type: none"> <li>- N = 125 PWD</li> <li>- Carers not specifically included (numbers not reported)</li> <li>- Severity of dementia variable dependent on site (more severe in care homes &amp; hospital, less severe in community)</li> </ul>	<ul style="list-style-type: none"> <li>- 12 weekly sessions</li> <li>- Separate groups at different venues: residential care, assessment unit of hospital, exhibition area, arts &amp; music venue, arts centre with gallery</li> <li>- Only hospital site did not visit a gallery/museum space</li> <li>- art-viewing then art-making</li> <li>- groups of up to 15</li> </ul>	<ul style="list-style-type: none"> <li>- Longitudinal mixed-methods repeated measures</li> <li>- Greater Cincinnati Chapter Well-being Observation Tool used by researchers week before intervention and at two sessions for each participant.</li> <li>- Carer questionnaires: Dementia Quality of Life, Holden communication Scale</li> <li>- Evaluation questionnaire for PWD at end of sessions</li> </ul>
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### Appendix 3. Interview schedule for museum staff & volunteers

*The questions asked were iterative and dependent on the way the interview developed. The schedule below gives examples of ways in which questions were asked. Theory-testing questions were based on the theories developed from a literature review, as well as theories refined and developed through other parts of the evaluation. The theories can be taken as the ‘themes’ of the interviews, though not all ‘themes’ were covered with each participant.*

#### Interview introduction

“Thank you for agreeing to an interview. As a [facilitator] on the dementia programme, I felt you might have important insights about the impact of carers being in sessions with the person with dementia. I have some ideas about it so during the interview I may introduce them for your consideration. Please free to answer honestly, regardless of whether you disagree, agree, or don’t feel you have a clear opinion. I’m really interested in finding out from your experiences and expertise. If there are any questions you don’t want to answer that’s absolutely fine, and you can stop the interview at any time. Does that sound okay? Do you have any questions before we start?”

#### Warm-up / introductory questions

- How long have you been working on the programme?
- What’s been your experience of having carers in the programme?

#### Example explicit theory-testing questions (in no particular order)

- There’s an idea that professional carers sharing an activity with the person with dementia outside of their work context helps them to see the person with dementia in a new way or learn new things about them. Has that been something you’ve noticed in your experience? In what way?
- There’s an idea that carers can sometimes do too much for the person with dementia on the programme, which means the person can’t get as much out of the sessions as they could. Do you think there’s any truth to that?  
Has this been an issue in sessions you’ve facilitated?  
What happened? Can you talk me through an example?

#### Example implicit theory testing questions (in no particular order)

- You said sometimes carers speak more in the group than people with dementia, can you tell me a bit more about that?  
Are there times it happens more and times it happens less?  
What is it about the times it happens more/less than you think makes a difference?  
Can you talk me through an example of when it happened more/less?
- What do you think it is about [*couple described with positive relationship outcomes*] that made the difference? Maybe compared to [*couple described with no positive relationship outcomes*]?
- You said people can take part without worrying about dementia. What do you think it is about the programme that means people can enjoy the activity without worrying about dementia?  
How specifically do you think that helps?

#### Appendix 4. Interview schedule for people with dementia & carers interviewed together

*The questions asked were iterative and dependent on the way the interview developed. The schedule below gives examples of ways in which questions were asked. Theory-testing questions were based on the theories developed from the literature review, as well as theories refined and developed through other parts of the evaluation. The theories can be taken as the ‘themes’ of the interviews, though not all ‘themes’ were covered with each participant.*

*Questions asked also depended on whether and to what extent the person with dementia had memory for the programme. As consent can fluctuate even during the course of the interview, I attended to visual and verbal cues of no longer wanting to participate and of fatigue.*

*The person’s own language was used in questions – for example whether they self-described as a person with dementia or a carer.*

#### Interview introduction

Thank you for agreeing to talk with me. This interview is to find out what it’s like to go to museum programmes together. It’s okay if you don’t remember exactly what happens at the museum, as I’m interested in your views on different ideas. And I’m interested in what you both think. You don’t have to answer any questions you don’t want to, and you can stop the interview at any time. Does that sound okay? Do you have any questions?

#### Example warm-up / introductory questions

- How long have you been going to sessions at the museum?
- Do you have a favourite kind of session?

#### Example questions (in no particular order)

- What’s it like going to the museum together?  
Can you tell me a bit more about that?
- There’s an idea that going to the museum can help you to learn new things about each other. Has that been true for you?  
Can you tell me a bit more about that?
- Do you do other activities together? Has that changed since going to the museum?
- A lot of people find there are good things and bad things about doing things together.  
What are some of the good things for you?  
What are some of the bad things for you?  
Can you tell me a bit more about that?

## Appendix 5. Interview schedule for carers interviewed alone

*The questions asked were iterative and dependent on the way the interview developed. The schedule below gives examples of ways in which questions were asked. Theory-testing questions were based on the theories developed from the literature review, as well as theories refined and developed through other parts of the evaluation. The theories can be taken as the ‘themes’ of the interviews, though not all ‘themes’ were covered with each participant.*

*The person’s own language was used in questions – for example whether they self-described as a carer and what they called the museum programme.*

### Interview introduction

Thank you for agreeing to talk with me. This interview is to find out what it’s like to go to museum programmes with your [husband/mother/the person you care for]. I’m really interested in your opinions and experiences. I also have some ideas which I might introduce for your consideration. Please feel free to answer honestly – you can agree, disagree, or say you don’t have a clear opinion. I’m really interested in learning from your experience. You don’t have to answer any questions you don’t want to, and you can stop the interview at any time. Does that sound okay? Do you have any questions?

### Example warm-up / introductory questions

- How long have you been going to sessions at the museum?
- Do you go to all the sessions or just particular types of activities?

### Example questions (in no particular order)

- What makes you go to the museum sessions?  
Okay, so you’re saying it’s something interesting to do that’s interesting for you as well as your wife? Have I got that right? Can you tell me a bit more about that?  
So you’re saying it’s difficult to find activities that are interesting for you and your wife since her diagnosis. So is it that it’s something you can enjoy together, or that it’s something made for you as well?  
Right, so you’re saying the museum sessions are something that’s interesting for you and you don’t need to worry about your wife while you’re there because it’s for her as well?  
Have I got that right?
- What is like being at the sessions with your [husband/mother/person you care for]?
- Are there any negative things about going to the museum with your [husband/mother/person you care for]?  
Can you tell me a bit more about that?
- There’s an idea that the sessions give you an activity to enjoy together that’s not about dementia, so you get a break from dementia together. Has that been your experience?  
Can you tell me a bit more about that? Why/why not?
- Do you do other activities together other than the museum programme?  
Have you always done those things together? When did you start?
- There’s an idea that sometimes carers find it difficult on the programme if it reminds them of what the person with dementia can’t do any more. Is that something you’ve noticed?  
Can you tell me a bit more about that? Can you talk me through an example?



## Appendix 6. Interview schedule for people with dementia interviewed alone

*The questions asked were iterative and dependent on the way the interview developed. The schedule below gives examples of ways in which questions were asked. Theory-testing questions were based on the theories developed from the literature review, as well as theories refined and developed through other parts of the evaluation. The theories can be taken as the ‘themes’ of the interviews, though not all ‘themes’ were covered with each participant.*

*Questions asked also depended on whether and to what extent the person had memory for the programme. As consent can fluctuate even during the course of the interview, I attended to visual and verbal cues of no longer wanting to participate and of fatigue.*

*The person’s own language was used in questions – for example whether they self-described as a person with dementia and what they called the museum programme.*

### Interview introduction

Thank you for agreeing to talk with me. This interview is to find out what it’s like to go to museum programmes with your [carer/husband/daughter]. It’s okay if you don’t remember exactly what happens at the museum, as I’m interested in your views on ideas. You don’t have to answer any questions you don’t want to, and you can stop the interview at any time. Does that sound okay? Do you have any questions?

### Example questions (when no memory for the programme) (in no particular order)

- What kinds of things do you do outside the house?  
So you go to a memory café and do the shopping, is that right?
- What kinds of things do you do with your [carer/husband/daughter]?  
How do you feel spending time together?  
How do you feel about your [carer/husband/daughter]?
- When you are in a group of people, what helps you to talk when you want to?

### Example questions (when (some) memory for the programme) (in no particular order)

- What’s it like going to the museum?  
What do you like/not like about it?
- You said you liked spending time with your husband. Can you tell me a bit more about that?
- Are there any negative things about going to the museum with your [husband/daughter/carers]?  
Can you tell me a bit more about that?
- You said you went to a tour of the Pop Art. Do you feel like you got to say what you wanted in the group?  
You said you sometimes wanted to talk but didn’t. Have I got that right? What made you not talk as much as you wanted?  
So, you sometimes wanted to talk, but didn’t because the conversation moved too fast?  
Have I got that right?  
Okay, so you also worried that you’d be too slow because sometimes you find it difficult to find the right words. Is that right?  
Is there something that other people could do to help you talk as much as you wanted in the group?



COLLEGE OF MEDICINE AND HEALTH

**University of Exeter Medical School  
Research Ethics Committee**

**Certificate of Ethical Approval**

**Research Institute/Centre:** Institute of Health Research

**Title of Project:** The impact of including carers in museum programmes for people with dementia: A realist evaluation

**Name(s) of Project Research Team member(s):** Debbie Kinsey  
Dr Iain Lang  
Dr Noreen Orr  
Professor Rob Anderson

**Project Contact Point:** Debbie Kinsey

**This project has been approved for the period**

**From:** 17 December 2018

**To:** 31 September 2020

**University of Exeter Medical School  
Research Ethics Committee approval reference: Dec18/B/186**

**Signature:** 

**Date:** 17 December 2018

**Name of Chair  
Ruth Garside, PhD**

Your attention is drawn to the attached paper "Guidance for Researchers when Ethics Committee approval is given", which reminds the researcher of information that needs to be observed when Ethics Committee approval is given.

Application Reference Number: 18/09/186

## **THE IMPACT OF INCLUDING CARERS IN MUSEUM PROGRAMMES FOR PEOPLE WITH DEMENTIA: A REALIST EVALUATION**

### **INFORMATION SHEET FOR MUSEUM STAFF & VOLUNTEERS**

**VERSION NUMBER 2 DATE** October 2018

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to participate.

#### **What is the aim of the project?**

It's not clear how to best support people with dementia and their carers to live well with dementia, but the relationship between them seems to be important. Museums are one place that is increasingly offering activities that focus on an 'in the moment' wellbeing, intellectual stimulation, and enjoying an activity together. This project aims to investigate how museum programmes work, particularly what it means for people with dementia and their carers to attend together.

This project is also part of a PhD at the University of Exeter Medical School.

#### **Why me?**

You have been invited to take part because you work or volunteer on a museum programme for people with dementia and their carers.

#### **What will participants be asked to do?**

There are two parts of the study that you can participate in. It's up to you if you want to participate in only one, both, or no parts of the study.

##### **1. Observation of museum sessions**

I (Debbie Kinsey) will participate in and observe programme sessions at the museum to find out what happens in them. You can request that I do not attend or observe the session if you would prefer.

##### **2. Interviews**

You will be asked to take part in an interview with me, with an option for a follow-up interview. The purpose of the interview(s) is to find out about your experiences on the programme, particularly about the impact of including carers.

#### **What are the possible disadvantages and risks of taking part?**

The interview will not be discussing personal issues, but some people can find talking about dementia emotional. However, if you agree to participate, you can stop the interview at any time, refuse to answer any question, or withdraw your data without any disadvantage to you. If you wish to do so, you can let me know without needing to give a reason.

#### **Time commitment**

Interview(s) will last no more than an hour.

### **Can participants change their mind and withdraw from the project?**

Yes. You may withdraw from participation in the project at any time without any disadvantage to yourself of any kind. If you have taken part in interviews, you can request that this data is destroyed and not included in the study. However, once the study has been analysed and written up, it will no longer be possible to remove your data, though it will be anonymised at this point with no link to you.

### **How will my information be kept confidential?**

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing [dataprotection@exeter.ac.uk](mailto:dataprotection@exeter.ac.uk) or at [www.exeter.ac.uk/dataprotection](http://www.exeter.ac.uk/dataprotection)

### **What data or information will be collected and what use will be made of it?**

In programme sessions I will be observing what happens and making notes afterwards. These notes will not contain any personal information.

The interview(s) will be audio recorded and transcribed for analysis. Any identifiable information will be removed during transcription, and the recording will be deleted as soon as it is transcribed. If anything you say is used in reports, it will be anonymised and not attributable to you individually or your museum.

This study involves an open-questioning technique where the precise nature of the questions asked have not been determined in advance, but will depend on the way in which the interview develops. Consequently, although the Medical School Research Ethics Committee is aware of the general topics to be explored in the interview, the Committee has not been able to review the precise questions to be used. If the line of questioning develops in such a way that you feel uncomfortable, you can decline to answer any particular question(s) without giving a reason.

All anonymised data is kept for 10 years on the university's secure server after the end of the project. After this time the data is destroyed.

### **What if participants have any questions?**

If you have any questions about our project, either now or in the future, please feel free to contact either:-

Debbie Kinsey  
University of Exeter Medical School  
Email: XXXXXX  
Telephone: XXXXXX

or Iain Lang  
University of Exeter Medical School  
Email: XXXXXX  
Telephone: XXXXXX

## **Complaints**

If you have any complaints about the way in which this study has been carried out please contact the Chair of the University of Exeter Medical School Research Ethics Committee:-

Ruth Garside, PhD  
Chair of the UEMS Research Ethics Committee  
Email: uemsethics@exeter.ac.uk

**This project has been reviewed and approved by the  
University of Exeter Medical School Research Ethics Committee  
UEMS REC REFERENCE NUMBER: 18/09/186**

## **Sources of Support**

### **National Dementia Helpline**

This helpline offers information and support about dementia.

Telephone: 0300 222 11 22

Open –	Monday to Wednesday	9am-8pm
	Thursday to Friday	9am-5pm
	Saturday to Sunday	10am-4pm

### **Talking Point**

Talking Point is an online support community for people with dementia, carers, family, and friends.

Visit website: <http://forum.alzheimers.org.uk>

Email: [talkingpoint@alzheimers.org.uk](mailto:talkingpoint@alzheimers.org.uk)

### **Your GP**

Your GP can help you if you are struggling emotionally or physically. They may also be able to refer you on to other services or help to develop a care plan.

### **The Samaritans**

Offer 24 hour telephone support. You can also contact them via email and the Next Generation Text (NGT) service if you are hard of hearing.

National number (free to call): 116 123

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Appendix 9. Consent form for museum staff and volunteers



**THE IMPACT OF INCLUDING CARERS IN MUSEUM PROGRAMMES FOR PEOPLE WITH DEMENTIA: A REALIST EVALUATION**

**CONSENT FORM FOR MUSEUM STAFF & VOLUNTEERS**

VERSION NUMBER: 2 DATE: October 2018

		Please initial
1.	I confirm that I have read the information sheet dated October 2018, version no. 2, for the above project. I have had the opportunity to consider the information, ask questions, and have had these answered satisfactorily.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my legal rights being affected.	
3.	I understand that relevant sections of the data collected during the study may be looked at by members of the research team or regulatory authorities, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.	
4.	I understand that data collected in the project will be retained in secure storage for up to 10 years	
	<b>Session observation</b>	
6.	I understand that taking part in session observations involves the researcher making anonymised notes to be used for the purposes of:	
6.	- reports published in an academic or media publication	
7.	- public engagement activities regarding the research	
8.	I agree to take part in this part of the project	
	<b>Interviews</b>	
9.	I understand that taking part involves audio recording and anonymised interview transcripts to be used for the purposes of:	
10.	- reports published in an academic or media publication	
11.	- public engagement activities regarding the research	
12.	I understand that an open questioning technique will be used and I can decline to answer any particular question(s).	
13.	I agree that my contact details can be kept securely and used by Debbie Kinsey to contact me for a follow-up interview	
14.	I agree to take part in this part of the project	

.....  
(Printed name of participant)

.....  
(Signature of participant)

.....  
(Date)

.....  
(Printed name of researcher)

.....  
(Signature of researcher)

.....  
(Date)

This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee

**UEMS REC REFERENCE NUMBER: 18/09/186**

## **THE IMPACT OF INCLUDING CARERS IN MUSEUM PROGRAMMES FOR PEOPLE WITH DEMENTIA: A REALIST EVALUATION**

### **INFORMATION SHEET FOR MUSEUM SESSION PARTICIPANTS**

VERSION NUMBER 3 DATE November 2018

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to take part.

#### **What is the aim of the project?**

This project aims to find out how museum programmes work, particularly what it means for people with dementia and their carers to attend together. We hope that this will help provide better support for people with dementia and their carers.

#### **Why me?**

You have been invited to take part because you are going to a museum programme.

#### **What will participants be asked to do?**

You won't need to do anything. The researcher, Debbie Kinsey, would like to come and take part in sessions to see what happens in them. She will take notes afterwards about what she saw, but won't include anyone's name or personal details. It's up to you if you want to take part. There are 3 options:

1. Agree Debbie can come to sessions and you want to take part in the project.
2. Agree Debbie can come to sessions but you don't want to be part of the research. This means any notes will not include anything to do with you and she won't ask if you want to take part in other research.
3. Ask that Debbie does not come to sessions. This means Debbie will not come to sessions that you go to.

If you agree, Debbie will also give you information about other parts of the project, to see if you are interested. Those parts involve being interviewed.

#### **What are the possible risks of taking part?**

We don't think there are any risks to taking part because you are not doing anything different than you would normally do at the programme.

#### **Can participants change their mind and withdraw from the project?**

Yes. You can change your mind at any time. It won't affect whether you can participate in the museum programme. You can also decide if it's okay for Debbie to keep anonymised information that involves you if in the future you stop being able to make the decision about taking part.

## **How will my information be kept confidential?**

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing [dataprotection@exeter.ac.uk](mailto:dataprotection@exeter.ac.uk) or at [www.exeter.ac.uk/dataprotection](http://www.exeter.ac.uk/dataprotection)

## **What information will be collected and what will happen to it?**

Debbie will make notes on what happened at the museum. The notes won't have anyone's name or personal information so you can't be identified. The notes will be kept in a locked filing cabinet. They are kept for 10 years after the project has finished and then destroyed.

## **What if I have any questions?**

If you have any questions about the project, either now or in the future, please feel free to contact either:-

Debbie Kinsey

University of Exeter Medical School

Email: XXXXXXXX

Telephone: XXXXXXXX

or

Iain Lang

University of Exeter Medical School

Email: XXXXXXXX

Telephone: XXXXXXXX

## **Complaints**

If you have any complaints about the way in which this study has been carried out please contact the Chair of the University of Exeter Medical School Research Ethics Committee:-

Ruth Garside, PhD

Chair of the UEMS Research Ethics Committee

Email: [uemsethics@exeter.ac.uk](mailto:uemsethics@exeter.ac.uk)

**This project has been reviewed and approved by the  
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UEMS REC REFERENCE NUMBER: 18/09/186**



## **Sources of Support**

### **Alzheimer's Society Devon Dementia Support Service**

This service offers to people with dementia and their families. They offer support in person, over the phone, or in writing. This includes advisors who can tell you about local support services.

Telephone: 0300 123 2029 (open Monday to Friday, 9am-5pm)

Email: [devon@alzheimers.org.uk](mailto:devon@alzheimers.org.uk)

### **National Dementia Helpline**

This helpline offers information and support about dementia,

Telephone: 0300 222 11 22

Open –	Monday to Wednesday	9am-8pm
	Thursday to Friday	9am-5pm
	Saturday to Sunday	10am-4pm

### **Your GP**

Your GP can help you if you are struggling emotionally or physically. They may also be able to refer you on to other services or help to develop a care plan.

### **The Samaritans**

Offer 24 hour telephone support. You can also contact them via email and the Next Generation Text (NGT) service if you are hard of hearing.

National number (free to call): 116 123

Local number (charged at local rate): 01392 411711

Email: [jo@samaritans.org](mailto:jo@samaritans.org)

Appendix 11. Session observation consent form for people with dementia and carers



**THE IMPACT OF INCLUDING CARERS IN MUSEUM PROGRAMMES FOR  
PEOPLE WITH DEMENTIA: A REALIST EVALUATION**

**CONSENT FORM FOR MUSEUM SESSION PARTICIPANTS**  
VERSION NUMBER 3 DATE November 2018

1.	I have an Information Sheet (version number 3, dated November 2018) about this project and understand what it is about. All my questions have been answered.	Yes / No
2.	I understand I don't have to take part. It doesn't affect whether I can go to the museum sessions.	Yes / No
3.	I know I can change my mind about taking part at any time	Yes / No
4.	I know that Debbie will make notes afterwards but they won't have any personal information. They will be kept securely for up to 10 years.	Yes / No
5.	I know that the notes might be looked at by members of the research team or regulatory authorities. I agree these people can have access to the notes	Yes / No
6.	I understand the anonymised notes may be used for reports or events about the research	Yes / No
7.	Debbie can keep any anonymised notes that involve me if in the future I stop being able to decide whether to take part	Yes / No
8.	I agree Debbie can come to sessions	Yes / No
9.	I agree to take part in the research	Yes / No
10.	I agree Debbie can give me information about other parts of the project to see if I am interested	Yes / No

.....  
(Printed name of participant)

.....  
(Signature of participant)

.....  
(Date)

.....  
(Printed name of researcher)

.....  
(Signature of researcher)

.....  
(Date)

**This project has been reviewed and approved by the University of Exeter  
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UEMS REC REFERENCE NUMBER: 18/09/186**

## **THE IMPACT OF INCLUDING CARERS IN MUSEUM PROGRAMMES FOR PEOPLE WITH DEMENTIA: A REALIST EVALUATION**

### **INFORMATION SHEET FOR INTERVIEW PARTICIPANTS**

VERSION NUMBER 3 DATE November 2018

Thank you for showing an interest in this project. Please read this information sheet carefully before deciding whether or not to take part.

#### **What is the aim of the project?**

This project aims to find out how museum programmes work, particularly what it means for people with dementia and their carers to attend together. We hope that this will help provide better support for people with dementia and their carers.

#### **Why me?**

You have been invited to take part because you are going to a museum programme.

#### **What will participants be asked to do?**

If you agree to this part of the project, you will be asked to take part in interviews with the researcher (Debbie Kinsey). These interviews are to find out about your experience of going to museum sessions, especially what it's like to go with someone else. This will involve meeting up with Debbie at a time and place that suits you. She will talk to you about your ideas and what you think about other people's ideas. She is interested in talking to you and the person you go to the museum with. If you don't want to talk to her on your own, she can talk to you both together.

#### **What are the possible disadvantages and risks of taking part?**

Sometimes people find talking about their experiences difficult, especially talking about dementia and your relationship with the other person. If you feel upset, you can stop the interview at any time without giving a reason. You don't have to answer any questions you don't want to. You can also say you don't want to take part in research any more.

At the end of this information sheet there is a page of places you can find support if you need it.

#### **Time commitment**

The interview will last up to an hour, but can be shorter if you would prefer.

#### **Can participants change their mind and withdraw from the Project?**

Yes. You can change your mind at any time. It won't affect whether you can go to museum sessions. You can also ask that I delete the interviews that you did. You can also decide if it's okay for Debbie to keep anonymised information from the interviews you did if in the future you stop being able to make the decision about taking part.

If the project report has already been written I won't be able to remove information from your interviews from the report. But any information from your interview in the report will not have your personal details or any link to you.

### **How will my information be kept confidential?**

Everything you say in the interview is kept confidential. But Debbie will need to tell someone if you tell her you or someone else is at risk of harm.

The University of Exeter processes personal data for the purposes of carrying out research in the public interest. The University will endeavour to be transparent about its processing of your personal data and this information sheet should provide a clear explanation of this. If you do have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information may be obtained from the University's Data Protection Officer by emailing [dataprotection@exeter.ac.uk](mailto:dataprotection@exeter.ac.uk) or at [www.exeter.ac.uk/dataprotection](http://www.exeter.ac.uk/dataprotection)

### **What data or information will be collected and what use will be made of it?**

I will record the interviews on a dictaphone and then write them up. While I'm writing them up, I will remove any identifying information and then delete the recording. If anything you say is used in reports, it will not be linked to you in any way.

This project uses something called "open questioning", which means the questions I ask will depend on what we decide to talk about in the interview. This means the ethics committee have seen the general ideas I will talk about but not the exact questions I might ask.

If any questions I ask make you feel uncomfortable, you can say you don't want to answer. You can also say you don't want to take part in the research any more. You don't have to give me a reason.

If I take your phone number so I can meet up with you, I will store it in my phone with a password and then delete it once we have had our last interview. The interview write-up will be kept electronically for up to 10 years after the end of the project. After 10 years it will be destroyed.

## What if participants have any questions?

If you have any questions about the project, either now or in the future, please feel free to contact either:-

Debbie Kinsey

University of Exeter Medical School

Email: XXXXXXXXXX

Telephone: XXXXXXXXX

or

Iain Lang

University of Exeter Medical School

Email: XXXXXXXXXX

Telephone: XXXXXXXXXX

## Complaints

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### **National Dementia Helpline**

This helpline offers information, advice, and support about dementia.

Telephone: 0300 222 11 22

Email: Helpline@alzheimers.org.uk

Open –	Monday to Wednesday	9am-8pm
	Thursday to Friday	9am-5pm
	Saturday to Sunday	10am-4pm

### **Your GP**

Your GP can help you if you are struggling emotionally or physically. They may also be able to refer you on to other services or help to develop a care plan.

### **Talking Point**

This is an online support forum for people with dementia, carers, family, and friends.

Site: <http://forum.alzheimers.org.uk>

Email: talkingpoint@alzheimers.org.uk

### **The Samaritans**

Offer 24 hour telephone support. You can also contact them via email and the Next Generation Text (NGT) service if you are hard of hearing.

National number (free to call): 116 123

Local number (charged at local rate): 0117 983 1000

Email: jo@samaritans.org



**THE IMPACT OF INCLUDING CARERS IN MUSEUM PROGRAMMES FOR  
PEOPLE WITH DEMENTIA: A REALIST EVALUATION**

**CONSENT FORM FOR INTERVIEW PARTICIPANTS**

VERSION NUMBER 3 DATE November 2018

1.	I have an Information Sheet (version number 3, dated November 2018) about this project and understand what it is about. All my questions have been answered.	Yes / No
2.	I understand I don't have to take part. It doesn't affect whether I can go to the museum sessions.	Yes / No
3.	I know I can change my mind about taking part at any time	Yes / No
4.	I know I don't have to answer any question I don't want to	Yes / No
5.	I understand that taking part includes recorded interviews. Anonymised write-ups of the interviews will be kept securely for up to 10 years.	Yes / No
6.	I know that the write-ups might be looked at by members of the research team or regulatory authorities. I agree these people can have access to the write-ups	Yes / No
7.	I understand the anonymised write-ups may be used for reports or events about the research	Yes / No
8.	Debble can keep the anonymised write-up of my interview if in the future I stop being able to decide whether to take part	Yes / No
9.	I understand that what I say won't be linked to me in any reports. But if I say someone is at risk of harm Debble will need to tell someone.	Yes / No
10.	I agree to take part in one interview	Yes / No
11.	I agree my contact details can be kept securely and used by Debble to contact me for a follow-up interview	Yes / No

.....  
(Printed name of participant)

.....  
(Signature of participant)

.....  
(Date)

.....  
(Printed name of researcher)

.....  
(Signature of researcher)

.....  
(Date)

**This project has been reviewed and approved by the University of Exeter  
Medical School Research Ethics Committee  
UEMS REC REFERENCE NUMBER: 18/09/186**

Appendix 14. Example of annotated code document for evaluation analysis

Page 1 of 14 of annotated data extracts related to opening up the museum.

*link to carers controlling access sheet.*

**Opening up museum**  
 Fieldnotes site 4a – tour & music

She said it was hard to find things for them to do, and that it was really important to her to get out of the house and do things.

*Difficult to find accessible activities  
 going out of the house, but like to feel like in*

**Fieldnotes site 2 – textiles**

*quote from carer in paragraph about carers outside not wanting to come in.*  
 She was pleasantly surprised in the way the carers totally opened up once they got settled into the session. Helen said that every time they run this sort of programme there are always one or two who she gets that feeling with but then they always leave feeling energetic and full of enthusiasm for the session.

*Diff. carers don't come out of choice, but family carers do.*

*quote from carer in paragraph about negotiating*  
 They also discussed how some people feel they "don't belong" in a museum, due to "intellectual snobbery" (or perceptions of), and said that people who don't feel they belong always do after spending a little time in sessions. Helen said she particularly notices this in the dementia group compared to other kinds of groups. And particularly with some professional carers who perhaps have never been to a museum before and don't think there's anything there for them.

*Engaging participants  
 involving people  
 "I'm not a museum person"*

*Emotions like that  
 I've never had that before*

**Fieldnotes site 2 – Da Vinci**

Helen said that whenever they do these sessions, every week there's a reluctant professional carer who arrives not really wanting to be there and saying the museum isn't really for them. But that they'd never had a reluctant carer go back into the taxi at the end without saying how much they had loved it as well.

*Difficult to find accessible activities  
 going out of the house, but like to feel like in*

...  
 The group talked again about the welcome, specifically about the carers. Judy said it's "like giving people a treat" and that "they're here as carers but we want them to come back in their other roles too", for example as parents or just on their own.

**Carer site 4 int**

i: It sounds like it's been a really positive experience for you coming here.

P: Yeah, it is. That's why I keep coming back! [laughs]. No, it's good. It's good. And the fact you can...we don't always stay but you can wander around [location] on your own after it which is really nice.

i: So you can kind of make a day of it if you want to.

P: Yeah, that's just nice.

*Carers don't come out of choice, but family carers do.*

*Engaging participants  
 involving people  
 "I'm not a museum person"*

**Facilitator site 2 int**

I'd be quite confident to say that there was a shift in terms of people thinking what's possible in terms of the types of activities and kind of creative responses we work with, and the value of coming to the museum.

*Carers don't come out of choice, but family carers do.*

*Engaging participants  
 involving people  
 "I'm not a museum person"*

*Emotions like that  
 I've never had that before*

*Difficult to find accessible activities  
 going out of the house, but like to feel like in*

Appendix 15. Example of mapping document for evaluation analysis

**Theory 6**

Where the dyad's home interactions are mainly around caring (C), enabling facilitation in a non-medical setting in which the carer has no caring responsibilities (M/res) means the dyad can enjoy the activity together on an equal basis (M/rea), which leads to the dyad experiencing shared respite from dementia roles/life (O), which also helps to strengthen their relationship.

**Respite from caring roles sheet**

Some different mechanisms/contexts for respite from caring roles & dementia:

- a. **Non-caring situation/activity (implying lack of caring responsibility important)**
  - a. Facilitator site 2 int
  - b. Manager site 6 int – also about it also being for carers/something for them as it's not patronising / dumbed down. This also in Manager site 1, section 3 pg 4.
  - c. Manager site 4 int (also here about how structure of session takes care of content & some of the process, so takes some of the caring responsibility)
- b. **Not about dementia / talking about dementia/difficulties**
  - a. Facilitator site 1 int
  - b. Manager site 1 int x3
- c. **Equalising – no distinction made by prog./facilitators about who is PwD/carer**
  - a. Guide 1 site 6 int x2
- d. **About it being new to both in dyad & not about reminiscence**
  - a. Learning assistant site 4 int
  - b. Manager site 1 int (2<sup>nd</sup> section pg 4) – it being new to both and outside normal routine = new conversations. Conversations also beyond session itself so shared respite outside of session itself.

Also link to highlighting losses sheet in Manager site 1 interview. Respite making carer realise losses due to caring role (lack of creative activity for her). But – this then leading her to make time for that outside session (link to opening up other activities).

**Respite from dementia sheet**

Contexts/mechanisms for respite from prof carer dyad interview site 4. PwD implied respite from positive atmosphere of group & others with dementia being positive/happy. Implies support for context/mech of programme not discussing difficulties?

**Carer gets support sheet**

FoH site 2 int – different environment & having "back-up" / support for a few hours is way of them getting a break / some respite

**Shared experience sheet**

**Resource/Mechanism of it being new to both & equalising, leading to shared experience**

- a. Manager site 3 int

**Note** – see "function of sessions" mapping for enjoying together/separately and link to caring responsibilities

**Note** – lots of notes on theory 10 sheet re level of caring responsibilities

**Commented [KD1]:** - Some evidence for non-medical / not about dementia setting as M  
 - Evidence for equalising as M for respite (with detail on how equalising achieved on equalising sheet)  
 - Link to session function – is the context about interactions mainly around caregiving and they want to do something together (to differentiate from new theory about separately?)  
 - Evidence for enjoying together on session function sheet  
 - Resource – not about lack of caring responsibilities, about some support from staff & session structure and only have to do level of responsibilities they want / are comfortable with.

**Commented [KD2]:** Also link to repeated visits helpful sheet – Mech for carer being able to let go of more responsibilities

**Commented [KD3]:** Evidence of "enjoying together" on session functions sheet.

**Commented [KD4]:** Not about total lack, but more about session function for the dyad/carer? (as per theory 10). Esp. as carers are included due to responsibilities so never a lack (see caring responsibilities sheet).

**Commented [KD5]:** M (res) – like non-medical setting but more specific?

**Commented [KD6]:** Plus evidence on equalising sheet. Some theory on enabling facilitation is non-medical on facilitation sheet.

**Commented [KD7]:** M (res) – like non-medical setting?

**Commented [KD8]:** As per bullet point d

**Commented [KD9]:** - Session always takes some responsibilities (structure of session/logistics within museum). One example of mitigating stress from logistics on facilitation sheet (still have responsibility but try to make less stressful).  
 - High staffing levels – able to take on more responsibility (to a limit) & minimise what carers have to do (to an extent). Link to able to enjoy separately if want to / can.

New theories? – organise in session function sheet  
 1. Outcome of enjoying separately – solo respite (not shared so no dyad relationship outcomes)  
 2. Resource of high staffing levels



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