CO-RESEARCHING WITH PEOPLE LIVING WITH DEMENTIA: A CO-OPERATIVE INQUIRY

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Abstract

Background

There is a growing body of research that involves people in research beyond that of being participants, particularly in areas such as mental health and cancer research. Most research in the dementia care sphere involves people living with dementia as participants but fails to involve them in the research process beyond that. The involvement of people living with dementia as partners in the research process or as co-researchers is an emerging field in dementia research but is still limited in application. To date, there are no research studies that seek to explore the facilitation of co-research with people living with dementia.

Aims

This thesis utilised the broad methodology of co-operative inquiry to explore the initiating, establishing and facilitating of an inquiry group with people living with dementia. The inquiry group had its foundation in the concept of research ‘with’ people rather than ‘on’ them and aimed to develop an action-based output based on a topic that had meaning to the group. The inquiry group was made up of six individuals including two people living with a diagnosis of dementia, three care partners and a facilitator. The inquiry group worked collaboratively through phases of action and reflection over 12 meetings.

Findings

This thesis explored the week-by-week meetings of the inquiry group and how this was facilitated. An action output of an animation was produced which was narrated by members of the inquiry group and was based on their own experiences of living with dementia and the stigma that they encountered. Three broad themes were identified by the inquiry group: Positive Experiences, Negative Experiences and a Core Message (Education). These themes were adopted into a script which involved the narration of the lived experiences of the members of the inquiry group. Based on the observations of the facilitator and an external partner, a new and dynamic model of group facilitation was presented to support the facilitation of co-researching with people living with dementia.

Conclusions

This study contributes to the emerging sphere of co-research with people living with dementia by exploring the facilitation of such research and presenting a new model that looks to address the gaps in current group facilitation theory by specifically considering people living with dementia. This model places emphasis on working collaboratively but also acknowledges when to step back and step away from the research process.

Declaration

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

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Dedication

This thesis is dedicated to the co-researchers who worked with me on this study. Without their enthusiasm to share and explore their lived experiences of dementia, this thesis would not be possible.

Acknowledgements

First, I would like to thank my supervisors, Professor John Keady, Dr Caroline Swarbrick and Professor Penny Bee for their support during this study. I am very grateful for their guidance and feedback which greatly enriched this work. I would also like to thank the ESRC for funding the studentship.

I would like to thank my colleagues from the Neighbourhoods and Dementia study and members of the Dementia and Aging Research Team for all their support throughout my time at the University of Manchester. I would also like to thank my colleagues at the University of Salford for the endless cups of tea, messages of support and kindness throughout the last year. Your support has been invaluable.

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Background to the thesis

The Personal Context

I undertook my mental health nurse education between 2010 and 2013 in Glasgow and, prior to this, I had no personal or professional experience of working with people living with dementia. However, I did have extensive experience of working with people with learning disabilities and mental illness and, although was familiar with the term ‘dementia’ and believed it to have something to do with memory loss, I had no real idea of the complexities around the condition. Working one-to-one with people was my passion and in my first year of student nurse education, I presumed that I would end up with a career providing psycho-social interventions to adults living with mental health problems.

However, that was to change in my second year of student nurse education. During this year, our cohort received a session from the Scottish Dementia Working Group with the purpose of sharing an ‘insider view’ about what it was like to live with dementia. Listening to the members of the Scottish Dementia Working Group telling their own individual stories and showing how it was possible to live well with dementia completely changed my thinking around this condition and my ambition for the future. Indeed, from that moment on, I aimed to obtain further experience in dementia care and subsequently worked with Alzheimer Scotland and the NHS. This exposure took place both during my training and following qualification/registration in 2013. After, completion of my mental health nurse training/graduation, I then undertook an MSc in Advanced Nursing (2013-2014) at Glasgow Caledonian University which allowed me to tailor my study towards my specific interests in the dementia field. With this first experience of conducting my own research study, I knew I wanted to take this understanding further and contribute towards the broad agenda on enabling people living with dementia to lead more fulfilling lives. On successful completion of the MSc in Advanced Nursing, this led to an application for a full-time PhD funded by the Economic and Social Research Council (ESRC) and which existed as part of the ESRC/NIHR ‘Neighbourhoods and Dementia mixed methods study’ [henceforward known as the Neighbourhoods and Dementia study] which was led by Professor John Keady at The University of Manchester (see: Keady and the Neighbourhoods Dementia Team, 2014). This thesis is therefore a product of my particular journey to this moment in time.

When I applied for the ESRC PhD studentship there was already a focus in place, namely, to develop a participatory project on the person with dementia's involvement in research. This is not unusual in large programmes of research, and whilst some deviation from the original direction of the ESRC PhD studentship was permitted, the main part of the study continues to fall under this original direction and be part of work programme one of the Neighbourhoods and Dementia study, which was to support people living with dementia to undertake their own neighbourhood-level research. Dr Caroline Swarbrick at The University of Manchester led this work programme and was a co-supervisor on this PhD to maintain continuity between the original vision for the ESRC PhD studentship and how this PhD work was developed. I will shortly return to work programme one but will provide a little more context to the thesis by outlining the main elements of the Neighbourhoods and Dementia study.

Background to the 'Neighbourhoods and Dementia study'

The first Prime Minister's *Challenge on Dementia* acknowledged that the financial investment into dementia research was trailing behind that of other major diseases, such as heart disease and cancer, and therefore committed to increase funding (Department of Health, 2012). This initial challenge set out three key areas for investment:

- Driving improvements in health and care
- Creating dementia friendly communities that understand how to help
- Better research

'Better research' included a pledge to double funding for dementia research to over £66 million by 2015, and a key commitment that although funds would be directed towards the prevention, treatment and cure of dementia, there would also be opportunities for social research focused on the delivery of dementia care services and on living well with dementia. Thirteen million pounds was pledged specifically for social science research on dementia (key commitment 12).

In 2013, the Economic and Social Research Council (ESRC) and National Institute for Health Research (NIHR) announced a collaboration that was awarding £20 million to six different research projects (Economic and Social Research Council, 2013), a rise of £7 million on the original pledge mentioned in the first Prime Minister's *Challenge on Dementia* (Department of

Health, 2012). The five-year Neighbourhoods and Dementia study [2014-2019] was one of the studies funded under this collaboration and explored the meanings, experiences and composition of neighbourhoods for people living with dementia, their families and carers, and other groups and individuals with whom they have contact (Keady and Neighbourhoods Dementia Team, 2014).

Facilitated through the Division of Nursing, Midwifery and Social Work, The University of Manchester, the Neighbourhoods and Dementia study is framed around *People, Spaces* and *Places*. The study aims were:

- To address the meanings, experiences, and structure of neighbourhoods for people living with dementia, their care partners and other in-contact-groups and individuals
- To learn from the process and praxis of making people living with dementia and their care partners core to the research agenda
- To encourage innovative technological advances in dementia studies and in the development of a neighbourhood model of dementia
- To build capacity within the research community and the networks of people living with dementia and their care partners
- To develop the evidence base, methods and measures for understanding the significance of neighbourhoods for people living with dementia and their care partners
- To create, test and evaluate interventions that are pertinent to a neighbourhood model of dementia (https://sites.manchester.ac.uk/neighbourhoods-and-dementia/)

The Neighbourhoods and Dementia study was made up of eight distinct yet interconnected work programmes, and this funded ESRC PhD studentship was embedded within work programme one (member involvement) of the study. Work programme one was led by Dr Caroline Swarbrick and had a vision which was developed by people living with dementia, namely: *To feel enabled and empowered to develop and facilitate our own research agenda.* Work programme one engaged with four member involvement groups taking part in the Neighbourhoods and Dementia study: the Scottish Dementia Working Group; EDUCATE in Stockport, Greater Manchester; the Open Doors Service in Salford, Greater Manchester; and the newly created Salford INSPIRE group which was funded directly by the study grant. The continuous involvement of people living with dementia across all domains and dimensions of the Neighbourhoods and Dementia study helped to facilitate a participatory approach towards research encounters. For example, Salford INSPIRE is facilitated by a person living with dementia and a support worker through Age UK, Salford. Work programme one involved academics, service providers and groups of people living with dementia working in partnership to meet collaboratively identified goals. As originally agreed through the funding structure, this PhD study will explore the involvement of people living with dementia in research using a participatory approach and I have adapted the methodology and approach to further personalise the research process reported in this thesis.

Introduction to the study

The initial title for this funded PhD was 'Exploring the involvement of people living with dementia in everyday research: A participatory study' and had a broad remit to explore participatory research with people living with dementia. Exploring participatory research in the early stages of the study showed that the voice of people living with dementia is often not evident in research, and the involvement of people living with dementia in the research process beyond that of being participants was limited. Therefore, it was agreed with my supervisory team to deepen the exploration of participatory research with people living with dementia by co-researching in partnership in the form of a co-operative inquiry. Co-operative inquiry has been successfully implemented in Work Programme One of the Neighbourhoods and Dementia study but an exploration of the facilitation of this inquiry was limited. Consequently, the primary aim of this study shifted towards how a co-operative inquiry could be formed, developed, and facilitated with a group of people living with dementia and their care partners. This study explores all aspects of a co-operative inquiry in which I participated as a member of the inquiry group and as the facilitator.

The co-operative inquiry consisted of 12 research meetings which involved cycles of action and reflection and took place over the course of 10 months and will be described in Chapters Three and Four. The ethical approval process for this study was particularly challenging and is explored in detail in Chapter Three.

This thesis includes the real names of the co-researchers involved in the inquiry as the people living with dementia and their care partners were involved beyond that of being participants, and were partners in the design, data collection, data analysis and dissemination of the research. Therefore, it was only appropriate that they were acknowledged and given due credit for their contributions. The co-operative inquiry produced an action outcome of an animation around the theme of stigma and this is presented in text and in the use of stills from the animation in Chapter Four.

Organisation of Thesis

This thesis consists of six chapters:

Chapter one introduces dementia in context for the study. This chapter explores the developing views of dementia from one of personhood, to one of citizenship and human rights. This chapter also explores the growing development of user involvement in research and how this is being applied in dementia studies.

Chapter two consists of a literature review that explores the involvement of people living with dementia beyond that of being a participant. The literature review uses thematic synthesis to identify themes and a gap in the literature that is the foundation of the main body of research reported in this study. This chapter also highlights the difficulties that occur with terminology in this emerging field.

Chapter three outlines the principles of the methodology of co-operative inquiry. This chapter explores the nature of human inquiry which is the foundation of co-operative inquiry before introducing the salient terminology that is applied in this approach. The initiating of the co-operative inquiry is explored in this chapter followed by an in-depth discussion about the ethical challenges that were presented and overcome. That chapter concludes by discussing the data collection methods that were adopted in this study.

Chapter four explores the co-operative inquiry and ‘what we did’. This chapter begins with an introduction to the co-researchers that includes a short biography written by each individual. The inquiry process is then explored on a week-by-week basis beginning shortly after ethical approval was obtained and finishing after the launch party. This chapter includes my own reflections as the facilitator of the inquiry along with reference to the four ways of knowing which are an integral part of the co-operative process.

Chapter five outlines the facilitation process of the co-operative inquiry or ‘how we did it’. This chapter begins with a discussion of the theory of group facilitation before introducing a new model of group facilitation when co-researching with people living with dementia. This new model is supported by findings from my own observations and from the perceptions of an external partner who became involved in the co-operative inquiry.

Chapter six presents the key findings from this study and the relationship to previous research that has involved people living with dementia. This chapter also considers co-researching within other fields to explore the transferability of the work. This chapter concludes by exploring recommendations and implications for policy, research, education and practice.

Definition of Terms and Writing Conventions

The following terms and conventions have been used:

- The thesis has been written in the first person to allow for an exploration of reflexivity and my role as the facilitator of the co-operative inquiry
- I have used the terms ‘people/person living with dementia’ and care partners’ throughout the text. When referring to people’s lived experience of dementia this may refer to people living with dementia or their care partners.
- The co-researchers who took part in this study are identified by their real names to ensure credit is given where due for their contributions. This was approved by the research ethics committee and with the co-researcher’s consent.
- Numbers from one to nine are written within the text in full, with numbers 10 and above written in numerical form, unless I refer to Table 1, Figure 1 or Appendix 1 for example.
- I have used the Manchester Harvard style of referencing throughout the thesis. Where there are three or more authors cited, the last name of the first author is followed by ‘et al.’ Authors are presented in alphabetical order in the bibliography.
- In-text references are given in order of most recent research and where two authors have published in the same year, these are listed alphabetically.
- Short quotes of less than 30 words are embedded within the text and are italicised with double quotation marks. Direct quotes that are more than 30 words have been indented and italicised within the text with double quotation marks.

- Interview information is given in brackets after the quotes. For longer quotes, these have been placed indented on a new line, in italics and indented.
- I have used the terms ‘people/person living with dementia’ and care partners’ throughout the text. When referring to people’s lived experience of dementia this may refer to people living with dementia or their care partners.

List of Abbreviations

AMED – Allied and Complementary Medicine Database
ASSIA – Applied Social Sciences Index and Abstracts
ESRC – Economic and Social Research Council
CASP – Critical Appraisal Skills Programme
CINAHL – The Cummulative Index to Nursing and Allied Health Literature Database
DEEP – The Dementia Engagement and Empowerment Project
GMMH – Greater Manchester Mental Health NHS Foundation Trust
HMIC – Health Management Information Consortium Database
NHS – National Health Service
MCA – Mental Capacity Act 2005
UK – United Kingdom

Chapter One: Dementia in context

1.1 Introduction

This opening chapter will introduce and give a broad synopsis of dementia and the condition's current prevalence. This will be followed by an exploration of the rise in dementia activism and the movement towards hearing and recognising the voice of people living with dementia in policy, practice and research. A discussion about user involvement in research and participatory methods will then follow, before the two topics are synthesised into a brief discussion about people living with dementia and their involvement in research. This discussion will provide a context for the substantive literature review on this topic area that is in Chapter Two.

1.2 Dementia: The Medical Model

The medical model of dementia focuses on the symptoms and the term dementia is used by professionals to describe a variety of clinical ailments which result in cognitive decline (Bond, 1992). Dementia is not a disease but a syndrome that can affect memory, orientation, thinking, comprehension, language, learning capacity and judgement (World Health Organization, 2016). There was estimated to be around 47 million people living with dementia worldwide in 2015 and is expected to increase to 66 million by 2030 (Livingston et al., 2017). However, recent studies of dementia incidence suggest that that this projection may not be as large as predicted (Matthews et al., 2016; Livingston et al., 2017). Dementia can be caused by a multitude of medical conditions or diseases. For example, in older adults (over the age of 65), neurogenerative disease such as Alzheimer's disease and dementia with Lewy bodies are the most the common causes, whilst in younger adults, brain tumours and traumatic brain injury can be a common cause (Gale et al, 2018). Dementia is recognised in the International Classification of Diseases 11th Revision (ICD-11) in two different chapters. Dementia categories are included in Chapter Six: Mental, behavioural or neurodevelopmental disorders whilst the underlying causes of dementia are recognised in Chapter Eight: Diseases of the nervous system (Gaebel et al., 2018).

Dementia is not a normal part of ageing although it is more prevalent in those over the age of 65 (Alzheimer's Society, 2014; Livingstone et al., 2017). As the population in the United Kingdom (UK), grows older, the prevalence of dementia is increasing (Alzheimer's Society, 2014) and in the UK, it is currently estimated that there are approximately 850,000 people living with dementia. This figure is predicted to increase to over one million by 2025 (Prince et al., 2014). It should be noted that around 5% of the population living with dementia in the UK are under the age of 65, equating to over 42,000 individuals (Alzheimer’s Society, 2014). Approximately 60-70% of diagnoses of dementia are associated with Alzheimer’s disease (World Health Organization, 2012) and the two terms are often incorrectly used interchangeably (Groves et al., 2000

Alzheimer’s disease is characterised the presence of amyloid plaques and neurofibrillary tangles in the cerebral hemispheres of the brain (Hobson, 2019). Along with Alzheimer’s disease, there are three other subtypes of dementia that are commonly recognised: vascular dementia, dementia with Lewy bodies and frontotemporal dementia; although it is believed that these three types of dementia are potentially underreported due to misdiagnosis (World Health Organization, 2012). Vascular dementia is caused cardiovascular events or disease, such as stroke or high blood pressure (Hobson, 2019). Dementia with Lewy Bodies is often initially misdiagnosed as Alzheimer’s disease as they present with similar symptoms, however, Dementia with Lewy Bodies is caused by miniscule deposits of a protein that appears in the nerve cells of the brain and these same proteins also cause Parkinson’s Disease (Alzheimer’s Society, 2014). Frontotemporal dementia affects the frontal-temporal lobe of the brain and often presents with changes in personality and regular behaviours (Hobson, 2019). Dementia affects every individual differently, but the common signs and symptoms of the condition can be linked to three different stages: early, middle and late (World Health Organization, 2016) and as further described in Table 1.

Diagnosing dementia can be difficult particularly during the early stages as the symptoms can be the result of other conditions such as depression, delirium and a thyroid deficiency (Alzheimer's Society, 2014). Regardless, early diagnosis is a fundamental right (Prince et al., 2011) and is essential to ensure the individual can access care and support as appropriate. It is estimated that only half of people living with dementia will receive a diagnosis in high-income countries such as the UK, and as little as one in ten people from low-middle income countries will be diagnosed with dementia (Alzheimer’s Disease International, 2018). An early diagnosis of dementia is advocated by organisations such as the Alzheimer's Society (2014) and the Social Care Institute for Excellence (SCIE) as the benefits of early diagnosis include having time to understand the condition, plan for the future, benefit from treatments and maximise quality of life (Prince et al., 2011; SCIE, 2015).

Table 1: The three stages of dementia.

Stage	**Early**	**Middle**	**Late**
Signs and Symptoms	• forgetfulness • losing track of the time • becoming lost in familiar places.	• becoming forgetful of recent events and people's names • becoming lost at home • having increasing difficulty with communication • needing help with personal care • experiencing behaviour changes, including wandering and repeated questioning.	• becoming unaware of the time and place • having difficulty recognising relatives and friends • having an increasing need for assisted self-care • having difficulty walking • experiencing behaviour changes that may escalate and include aggression.

Dementia is a progressive condition, but it will vary between person to person in the length of time it takes for the individual to progress through the three stages as described in Table 1 (Pulsford and Thompson, 2012). In the early stages of dementia, the person may develop coping mechanisms to help manage the early symptoms of their condition. For example, the person may try and cover up evidence of their forgetfulness by ‘explaining away’ the situation (Hobson, 2019). Depression, which is characterised by persistent low mood, is common in these early stages as the person begins to realise and accept that something is wrong (Orgeta et al., 2015). In the middle stage of dementia, the individual’s condition will have progressed and become more noticeable. Some assistance may be required for activities of daily living and communication difficulties may arise which may lead to frustration for people living with dementia and their care partners (Hodson, 2019). The late stages of dementia bring further dependence on others to ensure the person with dementia’s needs are met.

Whilst fluent verbal communication may be very challenging at the late stage of dementia, it is recognised that people in the late stages of dementia can still have episodes of awareness and clarity and therefore it is important to recognise their strengths and maintain independence as far as possible (Hobson, 2019). The impact of dementia on the person will vary depending on the disease causing the condition but also on their life circumstances. People living with dementia who are of working age may need to navigate additional responsibilities including child-rearing and financial obligations, but also the lack of services tailored to younger people living with dementia (Pulsford and Thompson, 2012; Rabanal et al., 2018).

Until relatively recently, dementia was predominately viewed from a biomedical perspective concerned with the narrow neurological aspects of the syndrome (Kitwood, 1997a; Bartlett and O'Connor, 2010; Mental Health Foundation, 2015). Here, dementia was considered to be predominately as a neurodegenerative disorder with a view of irreversible decline, eventually leading to death, from on-going changes in the brain (Goldsmith, 1996; Bartlett and O’Connor, 2010). Interestingly, Goldsmith (1996) suggested that by adopting this medicalised view of dementia, healthcare professionals and carers could distance themselves from the person living with dementia and reduce the burden of emotional attachment. The carers, whether professional, family or casual, are also susceptible to the situation with their own anxieties around ageing, dying and death (Kitwood and Bredin, 1992). This biomedical perspective of dementia did, however, bring some advantages in the development of scientific research towards diagnosis and treatment and with recognising that a diagnosis could mean access to benefits and services (Bartlett and O’Connor, 2010).

1.3 Going beyond the medical model of dementia: personhood and citizenship

In the late 1970s and into the early 1980s, public and research awareness about dementia began to emerge (Hirschfield, 1981, 1983; Zarit et al., 1980), but the focus of caring for people living with dementia remained largely institutional and task orientated (Keady and Nolan, 2013). In the early 1980s, reports were published by public bodies such as the Health Advisory Service and the Royal College of Physicians, that began to challenge this biomedical focus on the condition and highlight “*the importance and human worth of people living with dementia*” (Keady and Nolan, 2013, p. 215). This move from a focus on the disease to a focus on the person with the disease, was further enhanced by Tom Kitwood and his development of ‘personhood’. Kitwood did not deny the benefits of the medical perspective of dementia and its contributions (Goldsmith, 1996), but suggested the use of personhood to adopt a more holistic view of dementia, in which the PERSON (sic) living with dementia is recognised before the person with DEMENTIA (sic) (Kitwood, 1997a). Personhood was defined by Kitwood (1997a) as

> “*a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust.”* (p. 8)

This perspective of personhood does not deny the presence of a degenerative condition but reframes the perspective from a medical view to a social view (Goldsmith, 1996). Kitwood(1997a) suggested that personhood is measurable and identified five defining attributes that have an effect on the person living with dementia and their personhood – this h was presented using the following equation:

$$D = P + B + H + NI + SP$$

In this equation, D stands for dementia presentation with acknowledgment of the disease process and how it leads to cognitive impairment but emphasises the uniqueness of each individual and how dementia will impact differently from person to person (Kitwood, 1997a). It is an integral part of the remaining five components of the equation:

> P acknowledges the individual personality of each person and suggests an emphasis should be placed on this;
>
> B stands for biography and recognises how an individual’s personal history will affect the language they use, their interactions with others and their behaviour;
>
> H considers the individual’s health status which appreciates that dementia may not be the only condition that a person is living with;
>
> NI stands for neurological impairment which identifies what type of dementia a person is living;
>
> SP stands for Social Psychology which acknowledges how the person living with dementia is affected by their environment and the actions of those around them.

Kitwood (1997a) proposed that everyone has six fundamental psychological and social human needs and that these needs should all considered and fulfilled in order to enhance the person living with dementia's personhood. The six psychological needs as suggested by Kitwood (1997a) are:

- Love – Being loved and accepted is a fundamental need for our survival and everybody feels the need to love someone or something and in turn be loved. This love can involve a person, object, faith or feeling.
- Attachment – This reflects our connections in life to someone or something including our wider social groups and communities.
- Comfort – Comfort may mean different things for different individuals but commonly reflects the physical needs of being free from pain, being warm, clean, dry and having our nutritional needs met. Comfort can also include an emotional connection or bond with another.
- Identity – Defines who we are as a unique individual, from our food and drink preferences to our haircuts and choice of clothes.
- Occupation – This reflects our need to be engaged in activities in our day to day lives. This need reflects the desire to have purpose in our lives.
- Inclusion – means we do not want to be left out of anything that has meaning to us, a need to be a part of something.

By failing to address or be mindful of these needs, there can be a detrimental effect on the person living with dementia's personhood. Kitwood (1997a) used the term 'malignant social psychology' to describe the collective impact of certain behaviours of the care deliverer such as disempowerment, infantilization and ignoring, which led to an overall erosion and loss of the person with dementia's personhood. One person can activate poor practice or the 'malignancy' and if they are in a position of influence, others may copy this behaviour which introduces the 'social' element of malignant social psychology (Hobson, 2019). An inability by people without dementia to accommodate the person with dementia's world view, leads to an 'us and them' divide, where any problems are perceived to lie with the person with dementia as opposed to a lack of understanding on the part of the person without dementia (Kitwood and Bredin, 1992, p. 272). Kitwood (1997a) argued that if the behaviours of malignant social psychology can be recognised and overcome, then a person with dementia's personhood can be maintained and subsequently, the persons sense of well-being improves.

In order to facilitate this maintenance of personhood, Kitwood (1997a) proposed the notion of person-centred care. Person-centred care has its origins in the work of Carl Rogers (Rogers 1961, cited in Brooker, 2007, p. 14), however it was Kitwood (1997a) who first presented the idea in dementia care. Brooker (2007, p. 13) looked to build on the work of Kitwood and developed the VIPS model of person-centred care which consists of four elements:

- V - A value base that asserts the absolute value of all human lives regardless of age or cognitive ability.
- I - An individualised approach, recognising uniqueness.
- P - Understanding the world from the perspective of the service user.
- S – Providing a social environment that supports psychological needs

The four parts of the VIPS model were specifically called 'elements' in recognition that the different parts can stand independently of one another yet brought together define the influential ethos of person-centred care (Brooker, 2007). The lens of personhood does not distract from the fact that there is a progressive condition affecting the individual but suggests that with a purely bio-medical focus on the person, the subtle complexities that makes a person unique may not be appreciated (Goldsmith, 1996).

The concept of personhood also contributed towards dementia research and practice with Bartlett and O'Connor (2010) noting this in three specific ways. First, it has moved the perception of dementia from one of a disease or illness into a holistic understanding of the condition (Bartlett and O'Connor, 2010). Kitwood's (1997a) work and subsequent development of the VIPS model (Brooker, 2007) suggested a consideration of the whole person, appreciating their uniqueness and also their social needs as well as psychological and physical. Secondly, personhood offers a link between the experience of dementia and a person's life experiences and highlights the importance of an individual's personal biography that contributes towards their unique experience of living with dementia and their care (Bartlett and O'Connor, 2010). The third contribution is about the language and discourse that is used when discussing the condition and people living with it. Use of the words 'demented' and 'sufferer' implied that the person living with dementia was a victim with no recourse to articulate their own thoughts of living with the condition (Bartlett and O’Connor, 2010). Although these words can still be heard today, organisations such as The Dementia Engagement and Empowerment Project (DEEP) and Alzheimer’s Society have developed documents specifically aimed at the media, organisations and also the general public to provide guidance on the use of language with people living with dementia to ensure it is person-centred (Alzheimer’s Society, 2018; DEEP, 2014).

The lens of personhood is arguably one of the most influential concepts for dementia practice and research (Brooker, 2004). However, both Bartlett and O'Connor (2010) and Cahill (2018) have suggested that the concept of personhood can be limited. Cahill (2018) claims that despite the substantial contribution and reframing of dementia that personhood achieved, there was no call for legislative or political change to protect and enshrine the rights of people living with dementia. Cahill (2018) also argues that Kitwood adopted a reductionist approach to dementia in only considering the carer’s influence in the erosion of a person with dementia’s personhood and not considering the wider influence of society and political and environmental drivers. In contrast, Bartlett and O’Connor (2010) argue that personhood focusses too narrowly on the immediate and direct relational environment of a person living with dementia and does not consider “*responses and relationships within a broader societal context”* (p. 28). As Brannelly (2011) argues, citizenship infers responsibilities and duties to a community, due to being part of that population, and has been defined by Marshall (1992) as:

> “*A status bestowed on those who are full members of a community. All who possess the status are equal with respect to the rights and duties which the status bestow”*” (p. 18).

Bartlett and O'Connor (2007) suggest a move towards a model of social citizenship for people living with dementia. Social citizenship views people living with dementia as active and social citizens without the confinement of the medical discourse of dementia (Bartlett and O’Connor, 2010). Social citizenship challenges the traditional definition of citizenship as described by (Marshall, 1992), and allows for the consideration of citizen-driven campaigns and social movements (Bartlett and O’Connor, 2010).

Bartlett (2016) acknowledges that the use of a model of social citizenship is still in its infancy for people living with dementia but in recognising citizen-inspired social movements and the growth of dementia friendly communities, further thought and understanding can be appropriated to the idea of social citizenship for people living with dementia. An example of a citizen-driven movement that contributed to the social citizenship of people living with dementia was a letter writing campaign to members of parliament by people living with dementia (Bartlett and O'Connor, 2010). This campaign was driven by people living with dementia, in particular the Scottish Dementia Working Group, and aimed to draw attention to their rights as people living with dementia, and to have access to cognitive-enhancing drugs, no matter what stage of the disease they were in (Scottish Dementia Working Group, 2007).

At present in the UK, active groups of people living with dementia, campaign and advise on policy, raise awareness, educate the public and give power to a once significantly marginalised group in society (Bartlett, 2014; Weaks et al., 2012). EDUCATE, one of the member involvement groups in the Neighbourhoods and Dementia study, is based in Stockport in the North West of England and stands for Early Dementia Users Cooperative Aiming to Educate. Using the power of their collective voice, they aim to educate health and social care professionals, students and the general public on dementia and since their formation in 2009, members have spoken at over 200 local and national events (Perry and Chaplin, 2014).

The Scottish Dementia Working Group was co-founded in 2002 by Dr [now Professor] Heather Wilkinson, who drew on her knowledge of social action and the disability movement, and James McKillop, a person living with dementia (Weaks et al., 2012). The group is primarily a campaigning collective and aims to influence decisions that are made about people living with dementia at local, national and international levels (Scottish Dementia Working Group Research Sub-group, 2014). Whilst these groups are considered activist groups in their drive to raise awareness and facilitate change, it is important to acknowledge that peer-support groups for people living with dementia also exist. People living with dementia have provided a positive reaction to involvement in peer-support groups, where they can interact with people who are in the same position as them and develop new friendships (Clarke et al., 2013). This helps to facilitate the maintenance of personhood in people living with dementia and drive the ideal of social citizenship.

It is not just within the UK that active collectives of people living with dementia are making their voice heard. The European Working Group of People living with dementia (EWGPWD) is made-up of people living with dementia from across Europe including the UK, Germany and the Czech Republic. The EWGPWD operates independently with its own agenda of activities but aims to ensure that Alzheimer Europe as an organisation, produces projects, conducts meetings and organises activities that are relevant to people living with dementia (Alzheimer Europe, 2019). Members of EWGPWD give presentations to the European parliament, media interviews and collaborate in research ensuring their voice is heard across education, policy and research (Alzheimer Europe, 2019).

The use of a social citizenship model also has explicit effects on the field of dementia research. Bartlett and O'Connor (2010) suggest the use of the EXPECT framework to focus the citizenship focussed lens on dementia research. The EXPECT framework (Bartlett and O'Connor, 2010 p. 95) contains the following elements:

- **E**vidence-based practice reconsidered: privileging people's stories
    - asks researchers to consider the valuable contribution that people living with dementia can bring to research with their personal stories and subjective accounts of living with the condition.

- e**X**tended research agenda
    - advocates for research to adopt a broad focus beyond that of improving care, and towards understanding people's lives and Bartlett and O'Connor (2010) identify three specific areas to which this focus could be widened. These areas are stigma and discrimination; work, paid and unpaid and travel and transport. These areas are meaningful to people living with dementia and this is supported by existing research (Burgener et al., 2011; Swaffer, 2014; Bryden, 2016).

- **P**articipatory and creative methods
    - ensures that research blends with the social citizenship lens by adopting a research 'with' rather than 'on' approach (Bartlett and O'Connor, 2010) and is inclusive in very nature of the methods used (Austin, 2018). The use of creative methods such as video technology to capture the rich lived experience of people living with dementia in the arts sector (Dowlen, 2019) or walking interviews with

people living with dementia to explore their own community (Kullberg and Odazakovic, 2018); can further increase the inclusion agenda with the implementation of methods that enhance accessibility to the research but to ensure the voice of people living with dementia is recognised (Bartlett and O'Connor, 2010).

- **E**thical debates and dilemmas
  - calls for an educated inspection of ethical issues in dementia research and a consideration of how to continually assess the involvement and capacity of people living with dementia in research (Dewing, 2002; Bartlett and O'Connor, 2010). Adapting consent forms by using simple language, including the use of pictures and photographs and using a clear font and sub-headings is regularly used as a strategy for inclusions and accessibility in research (Jayes, 2013). Volkmer (2019) also advocates for including the target audience in the creation and adaption of participant information sheets and consent forms to ensure accessibility and that it makes sense to the people who will actually be using the forms. However, despite these moves towards increasing accessibility and ensuring informed consent is obtained, Bartlett and O'Connor (2010) suggest that some existing protocols for ensuring informed consent is obtained can actually be incompatible with the lens of citizenship. Ethics boards have been viewed to adopt an overprotective and paternalistic approach to research with people living with dementia despite the Mental Capacity Act (Department of Health, 2005) stating that people should be assumed to have capacity unless proven otherwise. A specific example of this is of a research study, that in order to meet ethics board requirements, mandated GP approval for a person living with dementia to take part even though initial consent was given by self-referral.

- **C**ritical lens
  - highlights the importance of the subjective experiences of people living with dementia, however, argues that focussing on only these experiences is too narrow and that researchers should consider methods that allow for an

    exploration of subjective experience alongside socio-political and cultural contexts (Bartlett and O’Connor, 2010). In exploring lived experience, there are always multiple factors that influence the experience, not just a person’s own narrative but opposing stories from others, institutional and system rules and power dynamics (Czarniawska, 2004; Bartlett and O’Connor; 2010).

- **T**ranslation of research into practice
    - Phinney (2008) proposes three key elements that should be considered when adapting knowledge into practice for people living with dementia: adaption, dialogue and advocacy. Adaption highlights the cognitive difficulties that can be experienced by people living with dementia and advocates for different methods to be used in presenting research findings such as photograph displays, videos and spoken word. Dialogue represents the acknowledgement that people learn better from two-way exchanges and conversations and the use of group discussion can be an effective way of passing on new findings and information to people living with dementia. The final component of Phinney’s (2008) framework is advocacy and recognises the power that individuals and groups of people living with dementia have in disseminating information and information that has particular relevance to their own lives.

The EXPECT framework (Bartlett and O’Connor, 2010) aimed to address a view that dementia research had a very narrow lens and required a more considerate and creative approach. The framework calls for a more imaginative yet sensitive method to identifying and selecting research methods and that researchers should adopt participatory approaches to research to ensure a more citizenship focused approach to research (Bartlett and O’Connor, 2010).

There has clearly been a rise in dementia activism in recent years, both from individuals and groups of people living with dementia (Williamson, 2012). The voice of people living with dementia is becoming more prominent and with the movement towards models of citizenship, people living with dementia will continue to be empowered to contribute towards research, policy and practice, as will be demonstrated in this thesis.

1.4 Dementia, Human Rights and Activism

Traditionally, the rights, needs and wants of people living with dementia have been a low priority on a national and global scale (Cahill, 2018). It is recognised throughout the world that people living with dementia are repeatedly denied their human rights and are often restrained, both physically and chemically, without consideration of these rights (World Health Organisation, 2015). People living with dementia retain the same rights as anyone else in society, but the nature of their illness means that they often have great difficulty in protecting their own rights (The Scottish Government, 2013). In 2015, at the first Ministerial Conference on Global Action against Dementia held in Geneva, Rosa Kornfield-Matte, the United Nations Independent Expert on the Enjoyment of All Human Rights by Older People, called on all members states to adopt a human rights-based approach to dementia and acknowledge the condition as a human rights issue as well as a public health challenge (Kornfield-Matte, 2015). There are numerous definitions of human rights (Cahill, 2018), but the UK's Equality and Human Rights Commission (EHRC) states that:

> *"Human rights are a set of basic rights and freedoms that everyone is entitled to , regardless of who they are. They are about how the State must treat you. They recognise that everyone is of equal value, has the right to make their own decisions and should be treated with fairness, dignity and respect. Human rights have been written down in international agreements such as the Universal Declaration of Human Rights (1948) and the European Convention on Human Rights (1950)"* (EHRC, 2010, p. 6).

All people in the world are entitled to human rights (World Health Organisation, 2015). Human rights encompass both legal rights and ordinary rights. From a legal perspective, rights refer to any kind of entitlement enshrined in the law whilst in ordinary or philosophical rights, these rights are associated with being a citizen or human being (Marks, 2014). Human rights are also defined as being either negative or positive. Negative rights include the right to privacy and freedom of expression and require protection from misuse and exploitation (Cahill, 2018). Negative rights tend to be at the forefront of the understanding of human rights whilst positive rights include rights such as the right to education and the right to healthcare (Cahill, 2018). Positive rights put a pressure or claim on others for assistance in the rights being acknowledged (Velasquez et al., 2014).

Despite the call to action in 2015 by Rosa Kornfield-Matte, a human rights-based approach to dementia has not been embedded in the majority of countries' policies although there are a few exceptions (Cahill, 2018). Dementia has not typically been recognised as a disability, although this perception has changed in recent years. People living with dementia have historically not been at the forefront of human rights debates in the way other marginalised groups are (Mental Health Foundation, 2015). However, it is suggested that the word 'disability' should not be considered negative or stigmatising, but a means to an end to ensure that people living with dementia secure the same human rights as other stigmatised groups (Cahill, 2018; Mental Health Foundation, 2015):

> *"Disability and illness narratives can provide us with the opportunity to circumvent a reliance on a description of the physical impairment and expose attitudes and practices imposed upon a person which may diminish opportunities to live well in the face of an illness such as dementia."* (Angus and Bowen-Osborne, 2014, p. 149).

People living with dementia do not tend to recognise themselves as being disabled and there is often a focus on dementia as a health condition as opposed to a disability (Mittler, 2016; Shakespeare et al., 2019). Dementia is a disability under the Equality Act (2010), which defines disability as a mental or physical impairment that has a lasting and significant negative effect on a person's ability to carry out normal day to day activities. Reframing dementia as a disability benefits people living with dementia as their rights are then enshrined in national and international legislation, offering a level of protection but also the ability to challenge policies and practices that discriminate (Cahill, 2018). The World Health Organisation (2015) advocates for people living with dementia to be empowered to recognise and demand their human rights are recognised rather than wait for legislation, policies and services to catch-up. Shakespeare et al. (2017) propose a relational disability model of dementia which considers both the medical model of investigation into deficits and treatments alongside one of action to address stigma and discrimination in individual, social and system contexts. This relational model of dementia would consider how dementia as a health condition and the social constructs of it, create and inform dementia as a disability (Shakespeare, 2006; Shakespeare et al., 2017). One way that people living with dementia are campaigning to have their voices heard and rights acknowledged is through activism and campaigns.

A growing number of people are actively campaigning for social change, for their human rights to be acknowledged and for the opportunity to grow as a collective (Bartlett, 2015). Groups such as the Scottish Dementia Working Group have helped to establish the creation of a UK-wide network of groups committed to advocating for the rights of people living with dementia (Thomas and Milligan, 2018). DEEP, the UK Network of Dementia voices, originally began as a one-year scoping project in 2011 with 17 member groups and by the end of 2015, had over 50 member groups involved (DEEP, 2019). DEEP now over consists of over 100 groups of people living with dementia and is an active promotor and advocate of human rights for people living with dementia (Hare, 2016). DEEP also provides support to individuals hoping to start a group and groups who are aiming to develop their influence and activism in dementia policy and services (Innovations in Dementia and ECRED, 2016).

On an international platform, the Dementia Alliance International (DAI) was established in 2014 with a commitment to eradicating stigma and discrimination and furthering the human rights agenda (Thomas and Milligan, 2017). The DAI began with the aim to establish one collective voice of advocacy to argue for rights of individuals living with dementia (Brooke, 2019). In 2016, the DAI published a report which advocated for the human rights of people living with dementia on a global scale. The report offers advice to individuals and organisations on how they can support and advocate for the human rights of people living with dementia and lobby governments to enshrine these rights in law (DAI, 2016). Through campaigning as a collective, people living with dementia are beginning to have their voices heard and their human rights acknowledged.

There is growing recognition for people living with dementia to be actively involved in the development of policies that affect them. The World Health Organisation (WHO) presented an action plan in 2017 to address and recognise dementia as a priority on a global scale, presenting seven strategic areas that governments should tackle to improve the lives of people living with dementia (WHO, 2017). The first area of action is to consider ‘Dementia as a public health priority’ and aims for ‘75% of countries to have developed or updated national policies, strategies, plans or frameworks for dementia… by 2025’ (Alzheimer’s Disease International, 2018, p. 7). In the past, dementia policy would sit either within older adult policy, mental health policy or both. However, more recently, dementia policy is now recognised as standing on its own merit (Cahill, 2018).

As people living with dementia are demonstrably impacted by dementia policy, their involvement in the development of said policy is critical (Cahill, 2018). People living with dementia should be recognised as the experts in their own care and should be actively invited to contribute to the development of policy as equal partners (Eley, 2016). People living with dementia can make meaningful contributions to policy at both regional (McCabe and Bradley, 2012) and international scales (Alzheimer's Disease International, 2017).

1.5 The rise of user involvement in research

Research has historically been considered to be something of a specialised role, where the task of research is to explain and report upon the work and stories of others (Munn-Giddings and Winter, 2013). For many years, user involvement in research meant that government departments, commissioners, funders and other key investors would be involved in the research process (Beresford, 2007). This perspective has now shifted to the idea that user involvement includes members of the public and the populations that the research is focussed upon. User involvement in research requires the idea of research being a 'specialist' task to be relaxed, with Munn-Giddings and Winter (2013) suggesting that research needs to consider something from numerous different points of view. This more flexible view of research contrasts with the rigid, traditional definition of research offered by Polit and Beck (2012, p. 3):

> "*systematic inquiry that uses disciplined methods to answer questions or solve problems… to develop, refine and expand knowledge.*"

Munn-Giddings and Winter (2013) also suggest that the focus on research being systematic could lead to rigidity in research that does not allow for flexibility, and that responsiveness should be adopted, along with the notion of research being systematic, in order to allow the research process to develop.

The methods in which people are involved in research, covers a wide scale of engagement (Cook, 2012). INVOLVE is a part of the National Institute for Health Research (NIHR) and was established in 1996 to actively support user involvement in health and social care research (INVOLVE, 2013). INVOLVE describes the involvement of the public in research 'as research being carried out ‘**with**’ or ‘**by**’ members of the public rather than ‘**to**’, ‘**about**’ or ‘**for**’ them’ (INVOLVE, 2012, p. 6).

INVOLVE (2012) describes three different approaches to public involvement in research

- Consultation – is when members of the public are asked for their views and opinions which in turn inform decision making.
- Collaboration – is when there is an on-going partnership between researchers and the members of the public and involves shared decision-making.
- User controlled research – is where research is organised, directed and controlled by service users and their respective organisations.

User involvement in research has been considered and implemented for decades, particularly within the disability activism movement (Cameron et al., 2019). Shaping Our Lives, a national user-led organisation for service users and people with disabilities, advocates that whilst user involvement is quite rightly a shared goal across practice, policy and research, there are often many barriers that exist to their full participation (Beresford, 2013). User involvement should always be mutually beneficial to all parties involved (Meakin et al., 2017; Cameron et al., 2019). However, organisations occasionally have stigmatising attitudes. When service users are treated with more respect during user involvement activities than when accessing the services for support, this can lead to service users feeling undervalued (Beresford, 2013; Meakin et al., 2017; Cameron et al., 2019). This highlights that despite the many benefits and contributions of user involvement in research and policy, there remains barriers to full and equal engagement.

‘Public and Patient Involvement’ (PPI) and ‘user involvement’ have become synonymous as terms in the UK to cover all types of user involvement (Cook, 2012). Although INVOLVE gives a fairly straightforward presentation of what user involvement is defined as, it has been highlighted that within different research networks, the notion and understanding of PPI varies greatly (Staley, 2009; Cook, 2012). PPI is the involvement of members of the public in research in advisory or consultative roles where they may not have any personal experience of the experience or phenomena being explored. In contrast, participatory research involves a deeper understanding or partnership between those whose lives are being explored and those researching (Cook, 2012).

Participatory research is a methodological approach to research that is synonymous with user involvement in research yet is argued by Cook (2012) to be distinctively different. The idea of participatory research can be traced back to Lewin's (1946) seminal work which focussed on action research and issues with minorities groups in North America and was strongly focussed on the notion of intergroup relations. Participatory research came to prominence in the late 1970s and 1980s (McIntyre, 2008) and was advocated to address power and resource imbalances between dominant researchers and marginalised groups of people (de Koning and Martin, 1996). Whilst traditional research may be driven by a sole investigator, participatory research looks to engage with participants and communities to develop a collaborative approach to the research being perused (Higginbottom and Liamputtong, 2015; MacDonald, 2012).

Whilst the principles of participatory research could be broadly accepted, the field is varied in terms of application and design (Higginbottom and Liamputtong, 2015). Participatory research is a broad methodology that engages the people whose 'life-world and meaningful actions are under study' in the research process (Bergold and Thomas, 2012, p. 192). The actual definition of participatory research is open to interpretation with Cook (2012, p. 4) arguing that "*participatory research does not merely ask patients/the public to comment on what 'is', but challenges people to work together to design what 'could be'.*"

Participatory research provides opportunities for individuals and groups, who are not professional researchers, to engage and actively take part in the research process (Higginbottom and Liamputtong, 2015). The emphasis is on generating knowledge from the perspective of those being researched along with those carrying out the research (de Koning and Martin, 1996). Participatory research can be described as an umbrella term that embraces a number of different methodological approaches such as participatory action research and appreciative inquiry (Higginbottom and Liamputtong, 2015).

Participatory research is interpreted differently depending on how the researchers interpret the methodology. For example, participatory research can take place when researchers and participants design the research collaboratively, or the design is carried out a by a sole researcher, but data collection is carried out in partnership with the research community (de

Koning and Martin, 1996). Higginbottom and Liamputtong (2015 p. 9) offer a clear description of four different modes of participation as described below.

- Collegial – Equality in roles and responsibilities. Mutually beneficial.
- Collaborative – Researcher retains some authority with representation of community.
- Consultative – Community engagement or advisory groups informing the study design by researchers.
- Contractual – Researcher has full control with token participation from community (often with employment contracts).

The modes of participation as described by Higginbottom and Liamputtong (2015) bear a similarity to the approaches proposed by INVOLVE (2012) in the introduction to this doctoral study. This reinforces the different levels of participation that can be introduced in participatory research. Although this doctoral project attempted to adopt a collegial approach to research, the research would ultimately be viewed as collaborative due to the balance of power within the project. This will be discussed in further detail in Chapter Six.

de Koning and Martin (1996) explore several different meanings of participatory research, from joint design of the research, to researcher design and user collection, to the research being led by the members of the population being studied. These descriptions are fairly similar to the different approaches described earlier from INVOLVE (2012). An interesting point argued by Cornwall and Jewkes (1995) is that the key component of participatory research is not in the methods used but in the how the research is conceptualised and conducted, which is determined by the attitudes of researchers. My understanding is that it is the balance of power that is being examined here and that the more power handed to the participants, the more participatory the research will become. Implementing this balance of power can be facilitated by the use of co-researching. Co-researching can be defined as "*a participatory method of research that situates participants as joint contributors and investigators to the findings of a research project". (*Given, 2008). Co-researching is a method that aims to involve groups of people in research with the goals of reducing inequalities in health and promoting human rights and citizenship (Tee et al., 2007). Moreover, co-researching has been employed successfully in other health related fields such as learning disability (Redmond, 2005; Tuffrey-Wijne and Butler, 2010; Flood et al., 2012) and mental health (Tee et al., 2007; Wallcraft and Nettle, 2009).

1.6 The involvement of people living with dementia in research

The move from the biomedical view of dementia to one of personhood and subsequently citizenship, called for the experiences and perspectives of people living with dementia to be recognised in research (Hubbard et al., 2003). Historically, people living with dementia were studied in research as opposed to being participants, partly due to a lack of understanding of dementia and the ability of people living with dementia to give consent (Brooke, 2019). From the beginning of the 21st century, people living with dementia were calling for researchers to consider them as ‘active participants in this work, not merely ‘subjects’’ (Friedell and Bryden, 2002). It is important for people living with dementia to be offered the opportunity to take part in research to ensure their voice is heard, as the European Working Group of People living with dementia (2013) highlight ‘Nothing about us, without us’.

Wilkinson (2002) highlighted that the involvement of people living with dementia in research is important for two distinct reasons. The first reason being around the idea of shifting power. Wilkinson (2002) addresses the traditional power imbalances that existed between people living with dementia and others and how the involvement of people living with dementia in research could help to address this, by reducing stigma and challenging misconceptions such as nobody with dementia has capacity. The second main reason for involving people living with dementia is to further develop understanding. Engaging with the voice of people living with dementia adopts a more person-centred approach to research and acknowledges the subjective experiences that only people living with dementia can articulate (Wilkinson, 2002). There is a concern that there is a potential negative impact of people living with dementia being involved in research, particularly if they are having a negative experience of living with the condition, but research suggests that people living with dementia who have been involved in research found the experience positive and meaningful (Brooke, 2019).

With regards to dementia, people living with the condition should be given the opportunity to be involved in research (Alzheimer Europe, 2012) yet often, it is a result of ethical concerns that this population is excluded (Sherratt et al., 2007; Higgins, 2012; Holland and Kydd, 2015). The adoption of the process consent model as advocated by (Dewing, 2007) allows for the continuous assessment of capacity but also gives power to the person living with dementia in that it allows for the individuals to leave the process at any time. There is also the argument that excluding people living with dementia from taking part in research due to a reduction in capacity is an act of disempowerment and denies them the right to be part of something which may be of fundamental importance to them (Sherratt et al., 2007).

The advantages of involving people living with dementia in research are emphasised by Law et al., (2011) who highlight potential benefits such as getting the approach and language right, having high quality data, reaching a broader audience and having a focus for the research. However, people living with dementia make a valuable contribution to research, not simply as participants but as active collaborators involved in the selection, design and recruitment of studies (Alzheimer Europe, 2012). The impact of people living with dementia who actively collaborate in research has been found to be overwhelmingly positive, with a sense of empowerment and guidance towards future work (Gregory et al., 2018).

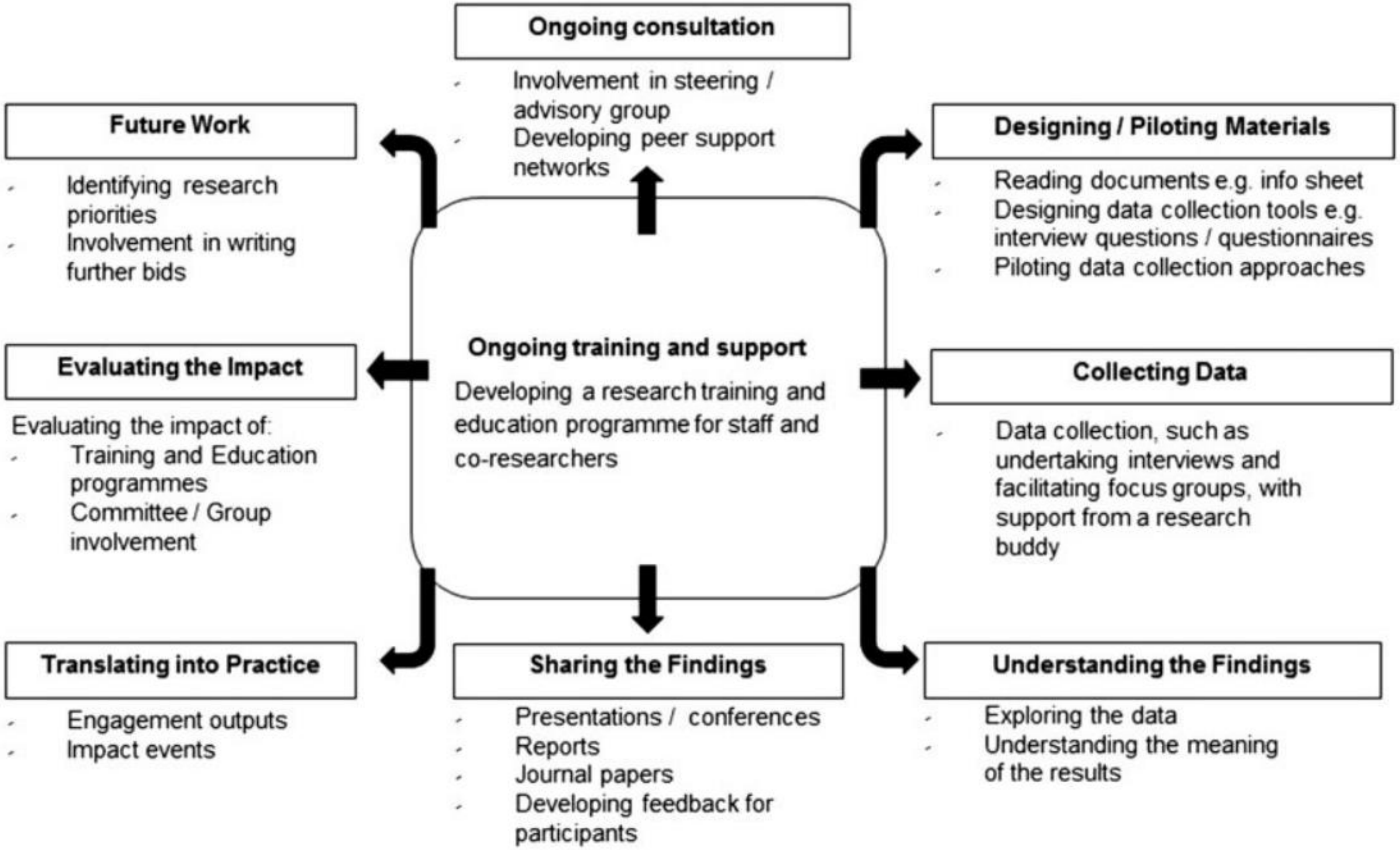
The move towards not just involving people living with dementia but ensuring a collaborative approach in research is advocated by organisations such as DEEP and also individual researchers (Bartlett, 2014; Swarbrick, 2015). Swarbrick et al. (2019) developed the 'CO-researcher Involvement and Engagement in Dementia' Model or COINED Model for short, collaboratively with people living with dementia (See Figure 1). The project involved the input of the three dementia working groups involved in the Neighbourhoods and Dementia study, Open Doors, EDUCATE and the Scottish Dementia Working Group. The COINED model was developed during the initial application stage of the Neighbourhoods and Dementia study and was embedded within work programme one which was concerned with member involvement (Swarbrick et al., 2019). The three dementia working groups met independently of each other with Caroline Swarbrick functioning as a three-way channel for the exchange of ideas and considerations in the development of the model. The key aim of this project was to explore ways in which people living with dementia would like to be involved as co-researchers throughout the research process and how could this be facilitated. Some of the key features of the COINED model include training and support, impact, accessibility and a recommendation to use creative methods in the research process (Swarbrick et al., 2019).

With this drive towards user involvement in research, the potential benefits of research with people living with dementia and the rights of people living with dementia to be involved in these processes, it can be now explored as to what extent people living with dementia are involved in research beyond that of being participants and how co-research is facilitated in this emerging sphere. There is a clear call for people living with dementia to have their voices heard, their rights respected and to be empowered to take ownership of decisions made in both their care and in research that concerns people living with dementia. Dementia research needs to embrace and recognise these rights by placing people living with dementia at the centre of the research process.

1.7 Summary

This chapter has explored dementia and the different discourses associated with the perception of dementia. This was followed by a discussion around the growing call for the human rights of people living with dementia to be recognised in policy and service provision. The concepts of participatory research and PPI were then presented followed by an examination of the developing field of participatory research in the dementia care field. The following chapter will explore the current literature that involves people living with dementia, beyond that of being participants.

Figure 1: The Co-researcher Involvement and Engagement in Dementia (COINED) Model (Swarbrick et al., 2019).



Chapter Two: Research with people living with dementia – A review of the literature

2.1 Introduction

This chapter reviews the literature on the involvement of people living with dementia in research, beyond that of being a participant. A thematic synthesis of the literature is adopted in order to gather a holistic summary of existing research. The aims and the objectives of the review will be presented followed by an outline of the key terms and the review question. The search strategy used to identify current knowledge in this area will then be described followed by a discussion around the quality assessment of the involvement of people living with dementia in research and the methods for quality appraisal that were developed. The chapter will then go on to outline the thematic approach to the literature which will be addressed under three main headings; theme 1: co-researching conditions; theme 2: being involved; and theme 3: influences and impressions. Finally, drawing on the findings of the thematic synthesis, evidence gaps in the literature will be outlined to provide the rationale for the research question and study design that follows in chapter three.

2.2 Aims and Objectives

The aim of this thematic synthesis of the literature is to explore the involvement of people living with dementia in research beyond the role of research subjects or participants.

The objectives are to explore:

- To what extent and how people living with dementia are involved in research beyond that of being participants.
- How research with people living with dementia is facilitated or challenged.
- The subjective experiences of people living with dementia involved in research.

2.3 Methods of review

2.3.1 Terminology

As discussed in the first chapter, the terminology employed in participatory research can vary in definition from researcher to researcher and each description is open to interpretation. In describing user involvement, INVOLVE (2012) outline the three approaches of consultation, collaboration and user-led research; a hierarchy of increasing participation. However, the misuse and overemployment of 'user involvement' has led to the term being described as a symbol of 'tokenism' (Swarbrick, 2015, p. 714). Therefore, for this literature review, studies of a collaborative nature where research takes place alongside and led by people living with dementia will be examined to evaluate the contribution and extent of user involvement.

The links between the terms as outlined in Table 2 can be acknowledged but should also be distinguished. For example, the use of 'co-researchers' is accepted as a form of participatory research; however, not all members of the public involved in research are taking part as 'co-researchers'. The term 'co-researchers' is used to define the collaborative, co-operative and community-based nature of this study and is used to describe members of the public and experts by their own lived experience actively working in equal partnership with 'academic researchers' in all - or parts - of the research process (Swarbrick et al., 2019). The use of the term 'co-researchers' is less common in dementia research literature than in other similar fields such as aging and learning disability research (Bindels et al., 2014; Littlechild et al., 2015). This may be down to the fact that this type of participatory research is relatively new in the dementia field. As discussed in Chapter One, user involvement in the learning disability field has been prevalent for decades (Cameron et al., 2019) and the use of the term 'co-researchers' is widely held and acknowledged (Tuffrey-Wijne and Butler, 2010; St John et al., 2018). This review aims to consider the literature where people living with dementia are involved in research beyond that of being simply participants. This includes studies where people living with dementia are not explicitly described as being actively involved in the research process. even though they are clearly involved in the research beyond that of being participants.

Table 2: Working definitions of participatory research utilised in this review.

User involvement and PPI (INVOLVE, 2012)	An approach of consultation, collaboration or user-controlled facilitation to research where the public are involved in research beyond that of just being participants
Participatory research (Cook, 2012)	An umbrella term that describes research where participants work alongside researchers at all or parts of the research process.
Co-Researchers (Given, 2008; Swarbrick, 2015)	Used to describe members of the public and experts by their own lived experience actively working in partnership with 'academic researchers' in all - or parts - of the research process.

2.3.2 Inclusion/Exclusion Criteria

Inclusion Criteria:

- Articles in English from any country.
- Studies where a person(s) living with dementia are taking part in the research process beyond that of solely being a participant.
- Studies that use a participatory methodology and involve a person(s) with dementia in the research process.
- Studies from any year.
- Studies that focus on primary research or are reflective summaries of such research.

Exclusion Criteria:

- Studies where the person(s) living with dementia are solely participants in the research.
- Studies where the carers of people living with dementia are the main focus of the participatory element of the research.
- Studies that are neurologically, biologically or medically focused.
- Studies which include other groups of people other than those living with dementia and where the groups cannot be distinguished from one another.

2.3.3 Search strategy

A comprehensive and detailed search of current and past literature is essential in order to answer the proposed review question (Parahoo, 2014). An electronic search of online databases to identify relevant articles was conducted in May 2016 and subsequently updated in June 2018 and February 2019. As no single database could retain every relevant health and/or social science journal included within it (Bettany-Saltikov, 2012; Tait and Slater, 1999), multiple online databases were searched. The OVID (multiple database search) was used which searched Medline, AMED, PsycINFO, Social Policy & Practice, EMBASE, and HMIC concurrently. Searches of CINAHL, Web of Science and ASSIA were also carried out. The on-line electronic databases AMED, CINAHL, MEDLINE and PsycINFO are all regarded as key resources in the comprehensive search for published research studies within healthcare (Lefebvre et al., 2009). The OpenGrey database was also searched for material that may have been relevant but reported outside the domain of traditional academic publishing. Further searches were carried out using the reference lists of included articles. A hand search of back catalogues of journals can produce further results as not all journal articles are indexed under the appropriate keywords (Bettany-Saltikov, 2012) and delays can occur in indexing online databases.

The PICO (Population, Intervention, Comparison, Outcome) framework is a popular tool utilised for developing research questions and developing search strategies (Polit and Beck, 2012), however it is criticised for lending itself to the search for quantitative studies over qualitative studies (Cooke et al., 2012). The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research Type) tool was developed to advance the rationale beyond that of PICO in relation to searching for qualitative and mixed method studies (Cooke et al., 2012). It was from using the

SPIDER tool that the search terms for this review were initially developed, although it soon became apparent that the searches required for this review were not straightforward.

The terminology used in the searches required careful consideration. From the review question it was apparent that the words ‘co-research’ and ‘co-production’, with suitable truncation and wild card symbols, would be appropriate (See Table 3). An initial scoping search was carried out using these keywords. However, it quickly became evident that these words were not adequate to be used autonomously for this review. Only one article that met the inclusion criteria, Tanner (2012), was returned from this initial search. To expand the search, further keywords were considered. The keywords ‘involvement OR engagement OR consultation OR participate’ replaced ‘co-research’ and ‘co-production’. This broader search strategy resulted in a huge return of results with the OVID databases search returning 23,717 and Web of Science returning over 43,000 articles. Even with limitations applied, including qualitative articles and English language only, OVID still had a search result of over 8000 articles. Whilst these numbers are not unreasonable, the majority of articles were irrelevant to the aims and objectives of this review, therefore further consideration needed to be applied to the search terms. Co-researching is considered to be a form of participatory research (Kara, 2015). As a result of this, the search term ‘participatory’ was added to the search strategy as a mandatory filter (See Table 3).

Table 3: Search terms used to identify relevant research articles for review.

	Search phase 1	**Search phase 2**	**Search phase 3**
Search Terms	**Dementia OR Alzheimer*** **AND** **Co?research* OR Co?Product***	**Dementia OR Alzheimer* AND involvement OR engagement OR consultation OR participate**	**Dementia OR Alzheimer* AND participatory**

A hand search of the journal: *Dementia: the international journal of social research and practice* (February 2002 - June 2016) was carried out to enhance the search process and was updated in June 2018 and February 2019. This journal was chosen due to its objective: '*to provide a major international forum for social-behavioural research and practice that has direct relevance on improving the quality of life and quality of care for people living with dementia and their families'* (Keady and Harris, 2002, p. 5). Moreover, the Editors of this particular journal also highlighted the importance of having people living with dementia and their families further involved in the research process (Harris and Keady, 2011). After each search was completed on the relevant database, I screened the results using keywords, titles and abstracts.

2.3.4 Limitations of the Search Strategy

Despite the systematic approach taken with this search strategy due to certain features it fits within the criteria of a narrative review as opposed to a systematic review. As Greenhalgh et al. (2018) highlight, a systematic review aims to address narrow, focused questions whilst a narrative review aims to deepen understanding. The search strategy adopted in this review aimed to explore the involvement of people living with dementia in research, beyond that of being participants or the subject of the research and therefore fits with the goals of a narrative review. In this way, this review provided a strong foundation upon which several key concepts were developed within this thesis.

However, as previously described in section 2.3.3, there was an initial systematic approach taken to this search strategy. Keywords were identified and a rigorous approach to database searching was adopted to provide a framework for the narrative review. Although ten electronic databases were searched, these were primarily health related databases. The social sciences were considered in the search strategy by inclusion of the Social Policy & Practice and ASSIA databases, however, the inclusion of further social sciences databases may have resulted in further appropriate papers being identified and included in the review. It is also important to appreciate that relevant papers may not be included on-line databases at all and therefore may have been missed from this review. For example, a paper that explored the use of co-operative inquiry in developing arts media with people living with dementia (Anderson et al., 2006) was published in a book and therefore did not meet the inclusion criteria for this review.

Keyword selection also provided some limitations. As described earlier in the review, the initial scoping search produced too few results. The second search used much broader words such as ‘involvement’ and ‘participation’ but in return produced far too many results for a single reviewer. The final search adopted the keyword ‘participatory’ and returned a reasonable amount of results with some success in identifying papers from the review. However, it is important to consider that this keyword itself produced limitations. Not all of the papers identified as suitable for the literature review classified or identified themselves as being ‘participatory’. Therefore, with the inclusion of this keyword, articles that met the inclusion criteria but did not explicitly identify as being participatory research, may not have been identified in the final electronic search. The difficulties in the use of terminology in this developing field are evident throughout this thesis and on reflection, further consideration needs to be given towards a universal adoption of appropriate language in this developing sphere of research.

2.3.5 Quality Assessment

Quality assessment, or critical appraisal, is the process of assessing the methods and findings of each study to determine wherever the study answers the proposed research question and wherever any level of bias needs to be considered when presenting the results (Petticrew and Roberts, 2006). Within the qualitative paradigm, it is agreed that qualitative research should be of a high standard, yet what this constitutes is greatly debated (Polit and Beck, 2012). It is argued that without rigour, research is of no value (Morse et al., 2002). However, the established models of attaining rigour - reliability and validity - have previously been dismissed in qualitative research with the argument that they are only applicable to the numbers and values of quantitative research (Altheide and Johnson, 1998).

Guba and Lincoln (1989) developed the concepts of trustworthiness and authenticity as substitutions to reliability and validity in qualitative research and signalled a move to a more evaluative process for assessing quality in this type of study. The establishment of trustworthiness in a research study involves the identification of credibility: where there is confidence in the findings; transferability: showing that the findings have suitability in other settings; dependability: the findings are reliable and can be repeated and that the findings have confirmability: researcher bias and interest is at a minimum (Lincoln and Guba, 1985). The authenticity of a research study is assessed on a further five criteria. Fairness is concerned with different viewpoints; catalytic authenticity involves the concept of ideas which bring about change; ontological authenticity is concerned with changes to the public's social environment; educative authenticity involves the development of knowledge amongst those involved in the research; and tactical authenticity considers wherever participants in the research are empowered to action (Lincoln and Guba, 1985). Even with these developments, it is maintained that a study may only produce significant impact in one of these criteria and therefore each qualitative study should be viewed with its own distinct value (Finlay, 2007).

Assessing the quality of research studies, particularly when carrying out a review, can be complemented by the use of a critical appraisal tool. There is no 'gold standard' critical appraisal tool that can be applied across different types of study (Katrak et al., 2004). The Critical Appraisal Skills Programme toolkit (CASP) is a popular tool for quality assessment (Krainovich-Miller et al., 2009) due to the user-friendly interface and appropriate level of detail that ensures the tool's suitability for assessing different types of evidence (Nadelson and Nadelson, 2014). As the aim of this literature review is to document the involvement of people living with dementia in research, using a tool such as CASP that critiques study design and findings would not be appropriate. Instead, a tool that explores user involvement in research was suitable for this review.

User involvement is now considered to be good research practice (INVOLVE, 2012) and with this role being developed, it is necessary to have guidelines for their effective participation (Boote et al., 2006; Staniszewska et al., 2011; Wright et al., 2010;). Wright et al, (2010) developed a set of critical appraisal guidelines based on available literature and expert experience. Wright et al., (2010) were informed by the CASP Framework and developed a set of nine criteria to assess the quality and effectiveness of user impact. Boote et al. (2006) had previously developed criteria for successful user involvement in health research, through the identification of eight principles for successful consumer involvement in National Health Service (NHS) research. However, Boote et al (2006) did not consider ethical considerations, recruitment strategy, methodological impact or rationale for user involvement in their standards (Wright et al., 2010). It was with these considerations that the guidelines established by Wright et al. (2010) were developed. As the tool by Wright et al. (2010) (see Appendix 1) was developed to specifically consider user impact and involvement, I used it to assess the quality of articles in this literature review by the authors.

To strengthen the quality assessment, the GRIPP2 (Guidance for Reporting Involvement of Patients and Public) (Staniszewska et al., 2017) checklist for assessing the quality and impact of user involvement was also applied to the review. Assessing the quality and impact of user involvement in research relies on high quality and transparent reporting, therefore the GRIPP checklist (Staniszewska et al., 2011) was also originally applied to the studies in the review (see Appendix 2). The GRIPP checklist was developed from two systematic reviews to enhance the quality of PPI reporting and thus strengthen the evidence base for user involvement (Staniszewska et al., 2011). GRIPP 2 has recently been published and produced two different checklists, one being for articles concentrating on PPI activity and the other for articles concentrating on the reporting of PPI (Andrews et al., 2015).

GRIPP2 (Staniszewska et al., 2017) was developed on the basis that the original checklist had originated from systematic review evidence and without input from the international PPI community. GRIPP2 acknowledged this deficit and was developed in consensus with the broader PPI community (Staniszewska et al., 2017). GRIPP2 has produced a 'long-form' and a 'short-form' with the former being for publications that are primarily concerned with PPI whilst the latter is for publications where PPI is a secondary concern (Staniszewska et al., 2017). Therefore, to enhance the quality appraisal further, the GRIPP2 long-form (see Appendix 3 for an example) was applied to the included articles.

The critical appraisal guidelines (Wright et al., 2010) and GRIPP2 long-form checklist (Staniszewska et al., 2017) were used together to evaluate the level to which people living with dementia were involved in the research beyond that of being subjects or participants. As Brett et al. (2017) highlight, the reporting of user involvement in health and social care research is inconsistent and the use of tools such as GRIPP2 can increase the quality of reporting. Although these tools were not specially designed for use in a literature review, GRIPP2 has been successfully used in a scoping review to summarise how user involvement is implemented in dementia research (Miah et al., 2019). Both tools were appropriate for assessing the involvement of people living with dementia in research and therefore aligned themselves with the aims of this review and in assessing quality.

2.4 Findings

2.4.1 Search Results

As detailed in the flow diagram in Figure 2, duplicates were removed, and 22 articles were retained for full-text assessment. Seven of these articles were later excluded after an in-depth examination of their content and it was found that they met the exclusion criteria. An example of this process is a paper by Rabeharisoa et al. (2014) which looked at evidence-based activism. Although the review included studies where people living with dementia have contributed to the study along with other groups of people, such as carers and family members, in the Rabeharisoa et al. (2014) paper, it was not possible to differentiate these groups in the research process and the data collected. Consequently, the voice of people living with dementia was lost. This was also the case with Littlechild et al. (2015) who carried out a study with co-researchers from different populations including people living with dementia and older people.

The manual search through the journal *Dementia: the international journal of social research and practice* produced a further four papers for the review and three other papers suggested by the supervisory team were also included, resulting in 22 papers to be examined in the review (See Table 4). It is likely that these additional papers were not picked up in the electronic search as they did not specifically state that they are participatory studies; however, they do include people living with dementia in the research process beyond that of being a participant and therefore meet the review inclusion criteria. Finding these additional papers highlights the issue with conflicting and non-standardised terminology in this field, an issue I will return to later in this chapter as well as in the discussion chapter of this thesis.

Figure 2: Overview of the literature search, retrieval search, and retrieval process.

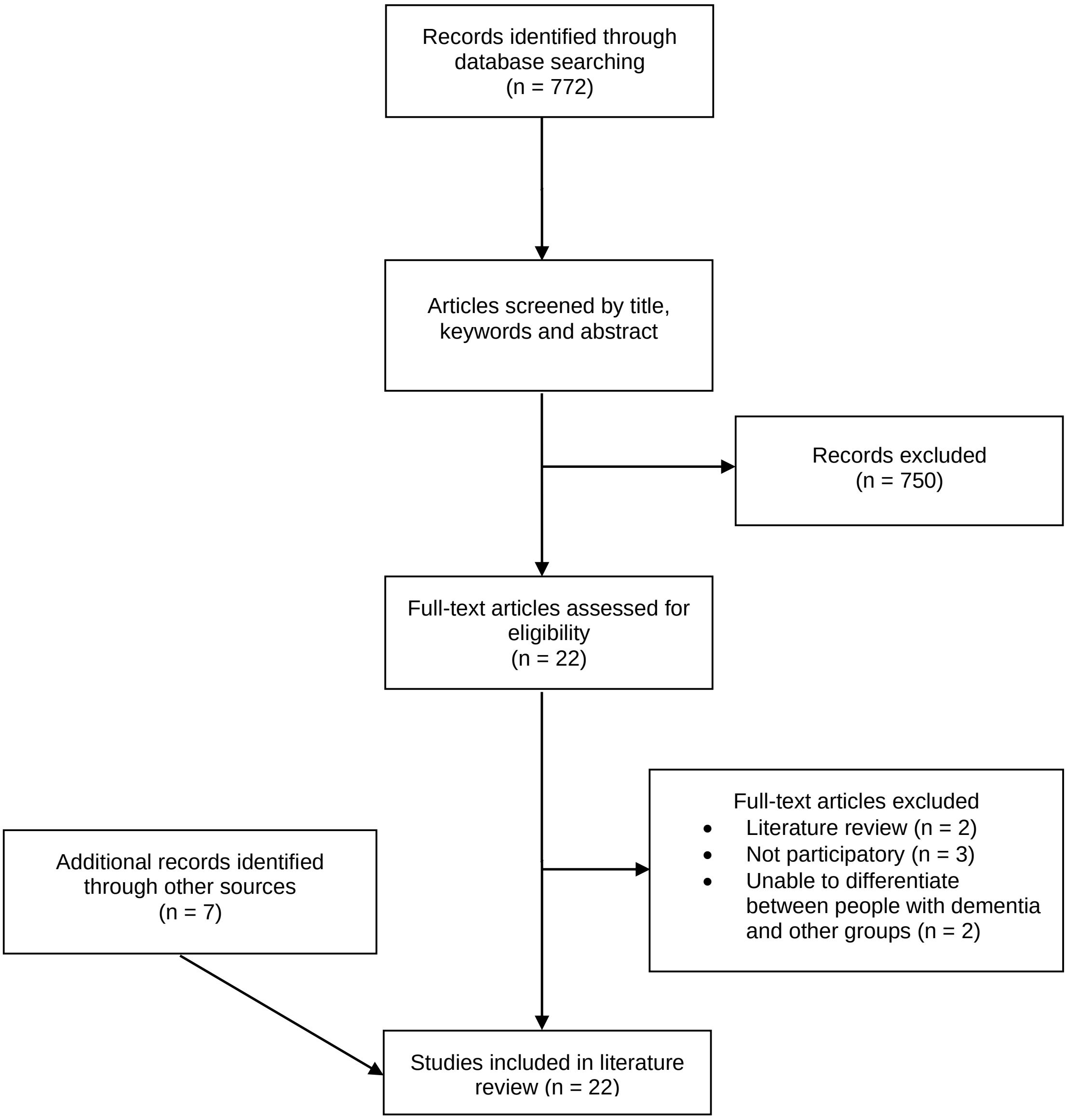


Table 4: Summary of articles included in the review.

No.	Author (Year)	Country	Focus of study	No. of people living with dementia involved in research process	Consent Process	Level of involvement	Data Collection Methods	Data Analysis Methods
1	Bartlett (2012)	UK	Modifying Diary Method as a data collection method	16	Process consent	Data Collection	Prediary individual Interviews and one focus group. Written, photo and audio diaries	Content and Thematic Analysis Techniques
2	Bartlett et al. (2015)	UK	A model of reference for involving people living with dementia in research and knowledge production with a focus on place	7	Written consent	Collaborators on Journal Article (3) and participants in residencies	Art based methods during residencies	Not Reported
3	Caine (2014)	UK	Using Participatory Action Research on the use of music to increase wellness within the home	5	n/r	Design, Data Collection	Discussion groups, semi-structured interviews, feedback forms	Grounded Theory and Thematic Analysis. Narrative Approach for diaries

4	Capstick (2011)	UK	Explores the adaptions made for a participatory video project for people living with dementia in a day care setting	2	Process consent, Consent by editing	Data Collection	Participatory Video	Not Reported
5	Capstick and Ludwin (2015)	UK	Participatory film carried out in long-term social care with people living with dementia to explore the concept of place	10	Process consent, editorial consent	Data Collection and narratives	Participatory Video and photo elicitation	Phenomenological frame of reference
6	Clare et al. (2008)	UK	Developing a shared social identity	4	Informed Consent	Data Analysis	Semi-structured interviews	Interpretative Phenomenological Analysis
7	Clarke et al. (2018)	UK	Data analysis with people living with dementia	34 (including care partners)	Written consent at each workshop	Data Analysis	Qualitative interviews	Theoretical Frameworks of 'risk and resilience' and 'ethic of care'
8	Crichton and Koch (2007)	Australia	Curating self-identity	1	Verbal and written consent	Data Collection	Narratives and Story-Telling	Not reported
9	Dupuis et al. (2012)	Canada	Authentic partnerships in understanding leisure	Unable to determine	n/r	Advisory, Data Collection and Analysis	Focus Groups, Individual interviews	Thematic analysis

10	Hanson et al. (2007)	Sweden	Participatory research with people living with dementia to develop technology-based education and support service	7 in initial production stage. 19 in verification stage.	Process Consent	Design, Data Collection, Service production, including data verification	Discussion groups, video and photographic material, in depth interviews and focus groups.	Not Reported
11	Mann and Hung (2018)	Canada	Appreciative Inquiry (Action research) in acute care	7	Written consent	Data collection, development of a framework for collaboration with people living with dementia	Environmental assessment, interviews, focus groups, reflexive group meetings, individual research activities	Not reported although states people living with dementia were involved in the analysis
12	Ludwin and Capstick (2015)	UK	Participatory film carried out in long-term social care with people living with dementia. This article explores the relationships between researcher and participant	1	Consent from personal nominee	Data Collection and Narratives	Participatory Video and photo elicitation, Ethnographic field notes	Not explicitly stated but follows a form of Content Analysis
13	O'Sullivan et al. (2014)	New Zealand	To explore the support needs of people living with dementia using action research	11	Written consent	Data Collection and Analysis	Field observations, individual interviews and focus groups	Hermeneutic data analysis

14	Pipon-Young et al. (2011)	UK	Exploring the experiences of younger people living with dementia using action research	Phase one: 8 Phase two: 5 Phase three: 4	Process consent	Data collection, analysis and co-production of a leaflet	Individual interviews, action research group	Thematic analysis
15	Robinson et al. (2008)	UK	The development of assistive technologies with people living with dementia to promote independence	Phase one: 10 Phase two: 22 Phase three: 2	Not reported	Scoping, Participatory Design	Focus Groups and Workshops	Constant Comparative Analysis
16	Stevenson and Taylor (2017)	UK	Risk communication in dementia care	4	Not reported	Data Analysis	Interviews with people living with dementia	Grounded Theory
17	Swarbrick et al. (2019)	UK	Development of a model for involvement and engagement in research for people living with dementia	Exact numbers not reported but multiple groups were involved	Not Reported	Development of a model, identification of themes	Group discussion	Not explicitly stated but discussion of themes was stated
18	Tanner (2012)	UK	Co-researching with people living with dementia	3	Process Consent	Preparation sessions, data collection, data analysis	Interviews conducted by people living with dementia	Not explicitly stated but discussion of themes was stated

19	Ward et al (2011)	UK	Explores friendships with people living with dementia	2 case examples	Not reported for individual case study but university ethics approval for evaluation	Data collection including narrative	Personal account and evaluation of a group	Not explicitly stated but includes narrative.
20	Wiersma (2011)	Canada	Using photovoice as a methodology with people living with dementia	4	Informed Consent	Data collection	Photovoice (Cameras used by the participants to collect their own data)	Not reported
21	Williams and Keady (2011)	UK	Single case study of a couple and their adjustment to a diagnosis of dementia and the impact it has on them	1	Process consent	Data Collection and Co-production of data	Interviewing	Centre-stage Diagramming
22	Wolverson et al. (2010)	UK	Subjective experience of hope	4	Written consent	Data Analysis	Semi-structured interviews	Interpretative Phenomenological Analysis

2.4.2 Quality of Included Studies

Not all of the studies that were critiqued using the guidelines by Wright et al. (2010) were primary studies that actively reported user involvement in their research design; two were primary studies that did not specifically report user involvement (Clare et al., 2008; Wolverson et al., 2010) and a further two of the papers were reflective summaries (Bartlett et al., 2015; Wiersma, 2011). These papers were included as they reflected on the participatory methodology that the review aims to explore. This highlighted one of the main difficulties in the quality appraisal of research studies in this review. Whilst these particular studies did not 'tick many of the boxes', they contributed valuable data to the review with their discussion of experience and user involvement, despite not using that specific terminology.

Sandelowski and Barroso (2003) advocate the idea of inclusiveness in the use of tools to assess quality and that ultimately no study should be excluded due to perceived poor quality as the findings may still be significant. None of the 22 studies identified from the literature search were excluded based on the quality appraisal as the appraisal tools were assessing level of involvement and therefore any articles shown to have a poor level of involvement would still contribute to the findings.

2.5 Thematic Synthesis

To present the review findings, I utilised a thematic synthesis approach. Thematic synthesis is an approach to synthesising qualitative data (Price and Baker, 2012; Noyes et al., 2019) that developed out of a requirement to conduct literature reviews that consider and explore questions with regards to need, appropriateness, acceptability and effectiveness (Barnett-Page and Thomas, 2009). Other qualitative synthesis approaches such as framework synthesis and meta-ethnography were considered, however the accessibility and transparency of thematic synthesis (Noyes et al., 2019) made it a more appropriate choice for a literature review of this nature. The use of thematic synthesis fits well with the aim to explore the involvement of people living with dementia in research beyond that of being a participant or research subject. Thematic synthesis draws from the methods used in primary thematic analysis to formally identify and develop themes (Thomas and Harden, 2008). Thematic synthesis is an inductive approach which involves three stages (Nicholson et al., 2016). Similar to thematic analysis, the first stage involves line-by-line coding followed by the development of descriptive themes. The final stage involves the generation of analytical themes that go beyond the primary research contained within the articles being reviewed (Thomas and Harden, 2008; Nicholson et al., 2016).

For this literature review, the themes were drawn from the literature by the reading and re-reading of the papers and grey literature and the manual coding of data using highlighters and printouts of the articles. These codes were then transferred to an electronic document to allow for ease of grouping into descriptive themes. Appendix 4 provides an example of the coding utilised in the review. An inductive approach was taken to the analysis and the themes were derived from what was actually in the data as opposed to applying concepts and ideas to the data in a deductive approach (Nowell et al., 2017). The themes were initially formulated by myself and refined with the members of my supervisory team. Three main themes emerged (‘Co-researching Conditions, Being Involved, and Influences and Impressions’) from the analysis, including associated sub-themes.

Theme 1, co-researching conditions, considers the practicalities of the involvement of people living with dementia in participatory research. This includes the concepts of time and place, available support, and ethical considerations. Theme 2, being involved, explores the various layers of involvement and the relationships and connections built between researchers and co-researchers and the barriers and challenges that can be encountered. Theme 3, influences and impressions explores the person(s) living with dementia and their self-identity along with the sense of purpose that may be gained from being involved in research. The components of power and control are also present in this theme. The three themes follow a linear pattern that outlines a trajectory of involvement for people living with dementia in the research process. There is some overlap between the three themes which will be developed later in the chapter.

2.5.1 Theme 1: Co-Researching Conditions

The considerations of practicalities for co-researching are evident throughout the literature. By practicalities, I mean to consider what needs to be in place for co-researching to occur. Although the majority of papers in this review did not use the word ‘co-researching’, this theme heading has been selected to give visibility to the conditions that should be considered in order for people living with dementia to be meaningfully involved in the research process.

Time and Place

The notion of time is a key consideration in co-researching conditions and the practicalities involved with collaborative research. Time must be respected, in making sure there is time to carry out the research, arranging mutually convenient times for all those involved and also being aware of time limits to carry out the research and disseminate findings. The Scottish Dementia Working Group developed guidelines in the form of core principles for involving people living with dementia in research and introduced an alternative philosophy of time, 'dementia time' (Scottish Dementia Working Group Research Subgroup, 2014). This idea of 'dementia time' is particularly relevant to the identified population, but also to other groups where cognitive impairment may impact their contribution to the process. The core principles acknowledge that people living with dementia may not present memories in a chronological fashion, that regular breaks are necessary and that sometimes they may need time out from the research process (Scottish Dementia Working Group Research Sub-group, 2014). Ensuring breaks and rest periods for the people involved in the research was suggested in some of the papers (Bartlett et al., 2012; Bartlett et al., 2015; Caine, 2014; Hanson et al., 2007) with time for support also a consideration for participatory research involving people living with dementia. Time and on-going support are described by Hanson et al. (2007, p. 411) as an 'essential' prerequisite for carrying out participatory research, a notion also advocated by Pratt (2002) who described her experiences as a researcher when working with people living with dementia:

> *"One particular lesson I learned whilst interviewing people living with dementia was the importance of time… people living with dementia have good days and bad days, they may experience changes over time and they may take time to open up to you"* (p. 176).

Bartlett (2012) acknowledged that in supporting people living with dementia to keep diaries, every individual required different amounts of time, from weekly support to very little contact time at all. This highlights how time should be considered on an individual basis when involving people living with dementia in participatory research. Time spent prior to actually carrying out research, in building rapport and relationships, is also noted to be of significant value in participatory research (Bartlett et al., 2015; Capstick and Ludwin, 2015; Tanner, 2012).

The discussion of time as a theoretical notion in its application to participatory research is evident as a theme in the literature; however, the practicalities of time are also applicable. The time taken to recruit to these studies varied from several months (Hanson et al., 2007; Wolverson et al., 2010) to two years in one study (O'Sullivan et al., 2014) and is, evidently, something that must be taken into consideration in planning a research project of this nature.

The subject of place, where involvement actually happens, is the main focus of the paper by Bartlett et al. (2015, p. 788): 'We found that by privileging place a more equitable, productive, healthier, and respectful way of involving people living with dementia as collaborators could be realised'. Bartlett et al. (2015) highlighted the need to create productive spaces as opposed to somewhere where people met and worked. Some of the studies took place within a day centre or community space (Capstick, 2011; Hanson et al., 2007; Robinson et al., 2009) which Robinson et al. (2009, p. 495) suggest brings a '*sense of continuity and familiarity for the participants*.' Other studies took place within the home (Bartlett, 2012; O'Sullivan et al., 2014a; Pipon-Young et al., 2011; Williams and Keady, 2012). One study took place wherever was most convenient for the people involved, which resulted in a mixture of place settings between the home and a healthcare setting (Wolverson et al., 2010), and demonstrated a degree of flexibility by the research team. Mann and Hung (2018) met in the preferred place of the co-researchers. The limitations of individual spaces are also explored, for example, Capstick (2011) highlighted the confined space within a day centre as a barrier along with potentially intrusive background noise. It is suffice to say that due consideration should be given to the concept of place when considering practicalities:

> *"Give sufficient attention to the location… ensure that it is a congenial environment, has disabled access, is close to amenities such as toilets, cafeteria (serving high quality food and drinks) and public transport, car parking and is in a central well-known location which is readily accessible."* (Hanson et al., 2007, p. 427)

Place, from a theoretical viewpoint, is also relevant from the perspective of creating a safe space. Dupuis et al, (2016) discuss their work in Canada and their goal to change the culture of working with people living with dementia into one of collaboration and working differently to be more inclusive with a key factor of this being the creation of a safe space:

> *"…where all partners feel a sense of emotional and physical comfort and there is a common feeling of trust. A safe space is one in which partners feel comfortable expressing their views openly without fear of being judged or dismissed."'* (p. 94).

Appropriate Support

Ensuring appropriate support was in place for people living with dementia to take part in the research process varied from study to study. Some researchers offered a variety of different ways of supporting those involved, such as by telephone or email (Bartlett, 2012). Crossing over from the previous sub-theme of place, where the research actually occurs can contribute to support for participants:

> *"A residency whereby researchers and participants share food and home together for a short period of time, to 'extend the space' for research and provide a supported space for participants to share their experiences with researchers…"* (Bartlett et al., 2015, p. 790).

The majority of the papers identified for this review also looked at practical support in the form of healthcare staff, carers and family members. For example, Caine et al. (2014, p. 95) stated that 'carers and people living with dementia should be equal partners in the process of deliver and design'. This explicit inclusion was not advocated in every study and Clarke et al. (2018) acknowledge that there is regular discussion within academic circles about the ability of people living with dementia to take part in research as co-researchers. Hanson et al. (2007) utilised volunteers and healthcare staff to provide support to the people involved, both during the design stage and after. Although the inclusion of formal support in helping with interpreting needs could be seen as proactive, the risk is that the people doing the supporting impose their own thoughts and beliefs on to the process and thus the voice of people living with dementia is lost. Swarbrick at al. (2017) was the only paper to discuss the use of academic support; something that was demanded by the co-researchers in their development of a model of involvement and engagement for researching with people living with dementia:

> *"Group members were insistent that support should be provided from an academic standpoint in parallel to peer support, either through formal agencies or informal peer support network."* (p. 4)

Away from the formal methods of support, O'Sullivan et al. (2014) noted that each individual taking part in their research had informal support from at least one family member. They highlighted the substantial impact that family support can have on the person living with dementia but also recognised that the voice of people without family support may therefore not be represented.

Support can also be viewed away from a psychological perspective but in a more practical viewpoint. The importance of ensuring appropriate financial support is in place to ensure appropriate transport, venues and resources can be put in place to support the research activity. It is recommended that this should be written into the application for research funding from the beginning (Gove et al., 2018).

Ethical Considerations

Involving people living with dementia in research can be considered challenging due to the impact of cognitive impairment and potential ethical considerations (Holland and Kydd, 2015) and there is also no established framework for co-researching (Swarbrick et al., 2016). Clarke et al. (2018) faced a particular dilemma with their study as they desired to include people living with dementia as 'co-workers' as opposed to research participants, but they faced obstacles in this goal:

> *"On the advice of National Health Service (NHS) Research Ethics Committees in both England and Scotland, the latter position* (research participants) *took precedence, forcing those we aspired to position as co-analysts who lived with dementia to be described as 'research participants' and to demonstrate their 'informed consent' to participation."* (p. 2*).*

Ethical considerations varied from study to study depending on the nature of design and methodology, however it was noted that not all studies reported their methods of gaining consent (Robinson et al, 2008; Caine, 2014; Stevenson and Taylor, 2017). Although two of these studies were concerned with co-design, they still involved potentially vulnerable groups of people and safeguards are assumed to have been in place to protect those involved. Process consent was the most utilised form of gaining consent in the literature (Bartlett, 2012; Capstick, 2011; Capstick and Ludwin, 2015; Pipon-Young et al., 2011; Tanner, 2012; Williams and Keady, 2012) and this continuing cycle of gaining informed consent that runs throughout the whole research process, can help to make involvement more meaningful and strengthen the process of assent (Dewing, 2007).

Process consent considers informed consent as a continual cycle throughout the research process (Dewing, 2007) and allows participants to collaborate with researchers in the decision-making process regarding continued involvement (Polit and Beck, 2012). Seven of the studies adopted this process of consent (Bartlett, 2012; Capstick, 2011; Dupuis et al., 2012; Hanson et al., 2007; Pipon-Young et al., 2011; Tanner, 2012; Williams and Keady, 2012) which is of particular relevance when considering the progressive and degenerative nature of dementia. Dewing (2007, p. 15) outlines the process consent method as having five key features:

- Background and preparation
- Establishing the basis for capacity
- Initial consent
- On-going consent monitoring
- Feedback and support

Dewing (2007) describes these features as being non-linear and fluid depending on research context. This method of process consent allows for capacity to be continually assessed and for the researcher to critically self-reflect if the question of whether the person has capacity is not straightforward.

It is recommended by Sheratt et al. (2007) that researchers gain carer assent and consent from a legal representative before engaging with people who lack capacity. Ludwin and Capstick (2015) involved a person without capacity in their research and were the only paper to consider this option:

> *"Florence was assessed not to have capacity to consent to taking part in the study for herself, and her son was appointed as her personal nominee under the U.K. Mental Capacity Act (Department of Constitutional Affairs, 2005). Florence's son agreed that she would have wished to take part in the study at a time when she did have capacity to consent, meaning that it was possible for us to recruit her to the study."* (p. 34)

Balancing the rights of people living with dementia to take part in research and recognising their contribution to society, whilst also protecting them as a vulnerable group, can be particularly difficult (Sherratt et al., 2007). One of the studies emphasised that they only worked with people with mild to moderate dementia for 'pragmatic and ethical reasons such as, their ability to participate over time was uncertain' (O'Sullivan et al., 2014, p. 23). Despite two of the studies not reporting on ethics, it can be seen from the literature that ethical considerations can be a thought-provoking subject. Ethical consent must be gained to safeguard the rights of those involved (Higgins, 2012), but it can be obtained in different ways. People living with dementia should be afforded the choice to be involved in research (Holland and Kydd, 2015), although, as this review has demonstrated, limitations to their involvement may be applied due to ethical considerations.

Another ethical consideration that was evident in the literature was the difference in ethical improvement given by different countries, even within certain countries, such as the UK. Clarke et al. (2018) were able to gain consent to include people with and without capacity in England, however, in Scotland only those with the capacity to consent were allowed to be included in their study. The Adults with Incapacity Act in Scotland only allows research to be conducted with adults lacking capacity if the research cannot be conducted with adults who do retain capacity. Although this was highlighted in Clarke et al.'s (2018) paper, no discussion was offered of the difference this made, if any, to their study. It is apparent that there is a lack of studies that include people with dementia who lack capacity. As discussed in Chapter One, particularly within the UK, there are legal frameworks that exist to protect people who may lack capacity, but these frameworks may also hinder the involvement and participation of underrepresented groups.

Mann and Hung (2018) gave a significant amount of consideration to ethics and highlighted the importance of not just preventing harm but promoting social justice. In their study, they actively described their presentation to the ethics board in their respective country of Canada. Mann and Hung (2018) also highlighted the importance of considering 'everyday' ethics as well as institutional ethics and gave due consideration to 'mutual respect, trust and sharing power' (p. 10). Supporting this view of trust and respect, Stevenson and Taylor (2017) emphasise the importance of communicating the nature of their role to people living with dementia and view it as 'imperative for ethical practice' (p. 8). It is highlighted that the distinction between the role of the participant in producing new data and being involved as a partner in the research process should be frequently reiterated so people living with dementia are clear about their role in the research (Stevenson and Taylor, 2017).

2.5.2 Theme 2: Being Involved

The second theme to emerge from the literature was that of being involved. After the practicalities of participatory research with people living with dementia have been considered, the next step in the process is to consider how to actually involve people living with dementia as co-researchers. The first sub-theme looks at the different layers of involvement that have emerged from the literature and in what ways people living with dementia have previously been involved in research. The next sub-theme contemplates the relationships that should be considered and developed throughout the research process and the final sub-theme considers the challenges and barriers that were encountered in these studies.

Layers of involvement

Only two of the 22 studies failed to provide a rationale for user involvement (Wolverson et al., 2010; Clare et al., 2008) and neither of these studies claimed to have any participatory element to their design. Both studies were identified through the manual search of the journal *Dementia: the international journal of social research and practice* and were included in the review due to their use of interpretive phenomenological analysis (IPA) and, more specifically, their inclusion of people living with dementia in the data analysis stage, thus meeting an inclusion criterion for the review.

The layers of involvement vary greatly from paper to paper, from participation in data collection (Bartlett, 2012; Capstick, 2011; Crichton and Koch, 2007) to involvement in data analysis (Clare et al., 2008; O'Sullivan et al., 2014; Pipon-Young et al., 201; Wolverson et al., 2010) and dissemination of findings (Bartlett et al, 2015). Only one article (Mann and Hung, 2018) was identified where a person or people living with dementia was fully involved in all stages of the research process, from design to dissemination. In this instance, Jim Mann (a person living with dementia) worked collaboratively with a clinician, Lillian Hung, to co-research and co-develop knowledge for change. In exploring the level of user involvement, only three of the studies actually used the term co-researchers (Stevenson and Taylor, 2017; Swarbrick et al., 2016; Tanner, 2012) and even with the use of such terminology, the co-researchers were not always fully involved in the research process.

However, Swarbrick et al (2016, p. 3) went a step further in acknowledging the contribution by people living with dementia by defining co-researching 'whereby 'co-' incorporates collaboration, cooperation and community – to further consolidate that partnership.' Interestingly, Mann and Hung (2018) refer to the person living with dementia as an 'advisor' despite their involvement from the beginning in the design of the research and Mann being the lead author on their paper. Clarke et al. (2018) pointedly discuss the positioning of people living with dementia in their paper, and how their desire to place people living with dementia as equals in the research was thwarted by NHS ethics committees who advised that they were viewed as research participants. The rest of the studies, except for the two IPA papers mentioned previously, involved some kind of participatory element to their design, or discussion, and did recruit and involve users in line with the aims of their study, although perhaps not to the extent that the guidelines would dictate.

Tanner (2012) discussed the use of people living with dementia as co-researchers and explored the anticipated benefits of this approach:

> *"Our co-research approach was premised on the belief that the shared identity of being someone with dementia would facilitate relationships between researchers and participants, thus enhancing the experience of the interview process for both parties, as well as enriching the data obtained."* (p. 299).

Despite the use of the word 'co-researcher' it was difficult to determine whether the people living with dementia taking part in this study were actually doing so collaboratively. It was apparent from Tanner's (2012) study that the people living with dementia were involved in data collection and analysis, in that the people living with dementia interviewed participants in the research and that meetings were held to discuss principal themes that were emerging from the data. However, this was all reported by an 'academic researcher', the co-researchers did not appear to be involved in the dissemination, therefore, the material presented could be considered the subjective view of the academic researcher. There is also no description of the co-researchers being involved in the design process or having any input on choice of data collection method. As discussed in the introductory chapter to this thesis, for this review, co-research is defined as involving the individual in a collaborative partnership; therefore, although Tanner (2012) certainly appears to use participatory methods, it cannot be determined whether it is co-research. However, the author does later mention the term '*co-interviewers*' (p. 302.) which could be considered more appropriate terminology.

Wiersma (2011) used the term co-researchers in describing how her methods allowed participants to be involved in the process and '*to be in control of the representations of the research*' (p. 213). Swarbrick et al. (2019) and Stevenson and Taylor (2017) also used the word 'co-researcher' in their description of the involvement of people living with dementia. Stevenson and Taylor (2017) specifically involved people living with dementia in the analysis of their findings, similar to the methods employed by Clarke et al. (2018). Although people living with dementia were not involved beyond the analysis stage, it was described by the authors that the overall quality of the findings were enhanced by the provision of 'new insights to be explored in further interviews' (Stevenson and Taylor, 2017, p. 6).

Bartlett et al. (2015) were keen to work as collaboratively as possible '*to develop common themes as co-workers in the same endeavour*' (p. 795). That said, a study where a person living with dementia is involved in every stage of the research process has not yet been located in the search process. I was aware of research being carried out within the Neighbourhoods and Dementia study that aims to work collaboratively with people living with dementia as co-researchers, however, this work remained on-going at the time of data collection that informed this PhD study and was not yet published and available on search databases. Ward et al. (2012) did include the actual narrative of a person living with dementia and the individual was also included as a co-author on the paper. The paper also highlighted that the person had full control over content, editing and design of the piece. The production of a narrative would be considered co-researching under the terminology defined for the paper and this method does allow for the opinion of an expert in the lived experience of living with dementia. This expert opinion contributes to the emerging voice of people living dementia and thus acknowledges the human rights of the person living with dementia (Mental Health Foundation, 2015).

Building connections

The relationship between researchers and participants is of particular significance in any kind of participatory research:

> *"In terms of our learning about research processes, the relationship between the researcher(s) and the individual co-researchers, and between the co-researchers themselves, was crucial. Considerable effort had to be devoted to nurturing and sustaining these relationships throughout the project."* (Tanner, 2012, p. 301).

Bartlett (2012) describes her data collection method as a way for people living with dementia to engage *'as equal partners in the data-gathering process*' (p. 1724) and ensures the visibility of the whole person. The Scottish Dementia Working Group Research Sub-group (2014, p. 682) highlight that the *'setting of research agendas should happen in a mutual relationship between people living with dementia and researchers'*. Caine (2014) discussed how their chosen methods helped build connections and placed *'a strong emphasis on trust and relationship building'* (p. 94). Hanson et al. (2007) explained how partnership working helped develop a bond of recognition of each other's knowledge and mutual respect. Whilst these papers considered the benefits of the relationships developed in the participatory research process, Crichton and Koch (2007) explored the impact these relationships have on the data that is generated and how they contributed to the process:

> *"This is a mode of participatory research in which we have, ipso facto, recounted and elicited stories of Laura along with members of her social network. We have spoken for, about and with her and in doing so have played a part in curating her identity."* (p. 378).

Crossing over from the first theme of 'co-researching conditions', Bartlett et al. (2015) explained how the sharing of a neutral space can produce more equal working relationships in research and help to reduce any power imbalance between participants and researchers. The move towards participatory research hopes to address some of this imbalance. However, not all of the papers included in the review considered the researcher/participant relationship, particularly those which did not claim to be participatory (Clare et al., 2008; Robinson et al., 2009; Wolverson et al., 2010).

Barriers and Challenges

Even with ideal conditions presented for carrying out co-research, there will always be challenges presented in the involvement of people living with dementia. For example, Bartlett (2012) looked to present a modified diary method for people living with dementia that handed an element of control to the user in what data was collected. She did highlight a particular challenge with regards to this method and population in that the keeping of diaries can remind '*people what they have lost*' (Bartlett, 2012, p. 1723) and that the potentially negative impacts of this method should always be highlighted by the researcher. Capstick (2011) had to be creative in her involvement of people living with dementia in a participatory video to ensure she could still involve people who were unable or less keen to go out to capture film. Caine (2014) also highlighted creativity as a method of overcoming challenges with particular reference to the use of creative methods with language and word-finding difficulties. This was also an obstacle encountered by O'Sullivan et al (2014).

One study in particular acknowledged that participants required training in order to be considered as 'equal researchers' yet decided that that due to cognitive difficulties they would not train individuals in the data analysis process and thus acknowledged this could be considered 'artificial collaboration' (Pipon-Young et al., 2011, p. 611). The authors did not present any potential solutions to overcome this challenge yet Gove et al. (2017) from Alzheimer Europe highlight the importance and challenges of training in their paper on the involvement of people living with dementia in research:

> *"Relevant and appropriate training should be offered to people living with dementia if and when required. When organising such training, attention should be paid to the capacities and skills of the people living with dementia who have volunteered, the complexity of language used and how this can be moderated, the time and frequency of the training and the possible need to refresh the training at some point."'* (p. 5).

As Tanner (2012) worked alongside people living with dementia to conduct interviews with participants in their study and actively highlighted these individuals as co-researchers, that they gave in depth consideration to challenges and barriers within the research. One difficulty that was encountered was that the co-researcher and participant had "*little in common*' (p. 304). This had particular effect due to the emotional link and rapport between co-researchers and participants that was determined to be an essential tool. However, little was offered as a solution apart from the suggestion of attempting to match parties together, which, in turn, could introduce an element of bias.

Dupuis et al. (2012) engaged in using participatory action research in their study and during their second cycle, concerns were raised that their research team was '*top heavy'* with academic researchers and healthcare professionals (p. 244). In order to challenge this power differential, the team engaged with a group of people living with dementia to ensure more collaborative action. Although Dupuis et al., (2012) had the flexibility and time in their research to address this imbalance, practically, it may not always be an option for people carrying out co-research due to time constraints and levels of support. This highlights another cross-over between this second theme of being involved and the first theme of co-researching conditions.

2.5.3 Theme 3: Influences and Impressions

This final theme explores what being involved in research means to the person living with dementia. The argument has been provided in the introduction for the involvement of people living with dementia in participatory research, however, it needs to be considered how this impacts the person and explore wherever it is possible to derive meaning from their involvement in research.

Self-Identity

> *We are NOT going to be tick boxes* (Bartlett, 2012, p. 1722)

The above quote is taken from the data collected from Bartlett's (2012) study but shows the strength of feeling that now exists within people living with dementia as a population. The use of participatory methods suggests an increasing sense of value on the experiences and perceptions of those living with dementia, thus empowering the individual and reinforcing their sense of identity.

The papers that included people living with dementia in co-design (Hanson et al., 2007; Robinson et al., 2008) suggested that user involvement helped to empower the individuals and thus give them a sense of purpose in their contributions to the research. This resonates with the Scottish Dementia Working Group Research Sub-group's (2014, p. 681) principles for involving people living with dementia in research: 'we want to be valued, and to be kept involved and informed'.

Several of the identified studies discuss the notion of self-identity and how their methods of being involved in their study helped to develop this concept for people living dementia (Bartlett, 2012; Bartlett, et al., 2015; Caine, 2014; Clare et al., 2008; Crichton and Koch, 2007; Ludwin and Capstick, 2015; Pipon-Young et al., 2011; Tanner, 2012; Wiersma, 2011). For example, Bartlett (2012) discusses the use of diary methods to aid individuals in discovering or rediscovering their sense of identity. Crichton and Koch (2007) used participatory methods to weave the life story of one individual living with dementia through interviews with the lady herself and family members. Their focus was on using this method to 'curate her self-identity' (Crichton and Koch, 2007, p. 365). The analysis of the narrative was carried out by the researchers and authors of the paper and therefore was open to interpretation. Without the actual voice of the person living with dementia it is difficult to determine if this story-telling approach did indeed help curate her self-identity.

Interestingly, only one study actually reported through a direct quote the sense of self that was identified by the person living with dementia: "*Houston says 'I think this approach is more respectful of me as a person'*" (Bartlett et al., 2015, p. 795). In acknowledging how the approach affected her as a person, the co-author of Bartlett et al.'s (2015) paper described some idea of a self-identity. It is from very limited evidence from which it is possible to gain an idea how self-identity is developed in involvement in research, as the majority of the studies report from the subjective viewpoint of the 'academic researcher'.

Power and Control

Power and control are intrinsically linked. With more control, a person holds more power (Bachmann, 2001). Caine (2014) described how within any kind of integrated working '*the power must be equal*' (pp 92.) and that it is well accepted that power is usually on the side of the researcher. Caine (2014) advocates for their particular participatory methodology as being a suitable framework for reversing '*the traditional power differentials inherent in research and practice development involving people living with dementia"* (Capstick, 2011, p. 146).

Three of the papers (Bartlett, 2012; Bartlett et al., 2015; Pipon-Young et al., 2011) describe methods that allow for participants to have control over how they are represented thus take responsibility for themselves and help challenge any traditional power imbalance. For example, Bartlett (2012) describes "*hoping that participants would feel more in control of the process and in a better position to utilise their strengths in keeping their diaries"* (p. 1719). Clarke et al. (2018) attempted to position people living with dementia as co-workers in order to address the imbalance of power that traditionally exists between researchers and participants, although were advised against this by ethics boards in both England and Scotland. Despite this, they 'regarded all of these *'participants' to be co-analysts…-each person bringing their own knowledge to analysis and to creating an understanding of the data'* (Clarke at al., 2018, p. 2).

Four of the studies included users in the dissemination of the findings, thus attempting to shift some of the balance of power. Bartlett et al. (2015), Ward et al. (2012) and Mann and Hung (2018) included people living with dementia as co-authors on their respective papers, although with Bartlett et al.'s (2015) paper it is difficult to determine the people living with dementia's contribution. In Ward et al's (2012) paper, a person living with dementia was a co-author and contributed their own personal narrative to the article which was clearly and purposely described. In Mann and Hung's (2018) paper, there was a section written by the person living with dementia in first person, however it was unclear throughout the rest of the paper what their contribution was. Whilst Swarbrick et al.'s (2016) paper does not individually name people living with dementia as co-authors, the working groups that they are part of are acknowledged. In the film produced as a result of the respective study, Capstick (2011) made an attempt at including users in the dissemination of findings by giving narrator credits to the user. Wiersma (2011) discussed and reflected upon a participatory method of data collection and production, and although did not specify the inclusion of people living with dementia in the dissemination process, she did discuss wanting to involve participants in the dissemination and how this may transpire.

A main objective within participatory research and co-researching is to address the power imbalance (de Koning and Martin, 1996) and by utilising such methods researchers can empower people living with dementia. It may be argued that there is never a true sharing of power due to the knowledge and expertise in research methods that the academic researcher may possess, as opposed to the expertise in lived experience that the person with dementia holds. In spite of this, striving for an equal partnership has its benefits as discussed in chapter one.

2.6 Summary

The three major themes that developed from this review were 1) co-researching conditions; 2) being involved; and 3) influences and impressions. The three themes linearly meet the objectives of the review. However, it is apparent that due consideration must be given to the environment in which the research takes place in order for people living with dementia to become involved in a meaningful way. Time, place, support and ethics are dominant sub-themes in the literature and should be considered when commencing the research process.

The actual involvement of people living with dementia varies considerably from paper to paper and the three studies that report people living with dementia as co-researchers, do not involve the individuals in every stage of the research process. The relationship between researchers and participants was also explored and highlights the benefits of this in participatory research. Barriers and challenges in this type of research were discussed and suggestions from the literature of how to overcome these obstacles were also noted. Finally, the impact on the person, specifically the person living with dementia, was discussed and it was noted how the majority of data for this theme came from academic researchers therefore may be considered subjective. The emerging voice of people living with dementia in the research is highlighted and thus considered a subject to be explored further.

There have been two literature reviews (Di Lorito et al., 2017; Rivett, 2017) published recently on the involvement of people living with dementia in research, however neither have identified papers where people living with dementia were involved in the research beyond that of that of being participants but were not referred to as co-researchers. Rivett's (2017) review primarily discussed Tanner's (2012) paper but failed to highlight any other work in this developing field. Consequently, the review of Rivett (2017) appears to be more of a discussion paper, with less detailed review. Di Lorito et al's (2017) review was more comprehensive and systematic in its approach but only included seven papers in the entire review, three of which included people living with dementia. The papers involving people living with dementia (Littlechild et al., 2015; Scottish Dementia Working Group Research Subgroup, 2014; Tanner, 2012) have all been identified in this literature review. The three articles highlight the need for further research in this area but fail to acknowledge where researchers *have* included people living with dementia in participatory research but have not referred to them as co-researchers. Di Lorito et al (2017) refer to 'peer' research but this again highlights the difficulties in terminology in the co-researching field and the need to expand reviews in this area to include a wide variety of search methods.

Guidelines have been developed by people living with dementia (Scottish Dementia Working Group Research Sub-group, 2014, Swarbrick et al., 2019) and recognised organisations such as Alzheimer Europe (Gove et al, 2018) to facilitate the involvement of people living with dementia but it remains a developing field of research. Despite the increase in participatory research involving people living with dementia, the existing literature fails to explore how individuals living with dementia can be involved in research that is meaningful to them. Minimal discussion on the impact on the person involved in research exists in this literature and when it does, it is difficult to determine if it is actually the voice of a person living with dementia or what the researcher interprets from their own perspective. Furthermore, research where people living with dementia are involved in all aspects of the research process is scant. This demonstrates a clear gap in the knowledge base for the involvement of people living with dementia as co-researchers. For this reason, I have conducted a co-operative inquiry with people living with dementia to strengthen the knowledge base regarding the involvement of people living with dementia in research and explore how this was facilitated. The theoretical background to this methodology and the subsequent design will be discussed in the following chapter.

This chapter presented a thematic synthesis of the current literature that involves people living with dementia beyond that of being a participant. The review highlighted that limited research has involved working *with* people living with dementia in research and generally studies involve people living with dementia as participants only. The literature review also highlighted that even when people living with dementia are involved in the research, their voice is often lost, and it is difficult to determine if the findings that are presented are congruent with the lived experience of people living with dementia or are the subjective view of the researcher. This study will seek to address these concerns by fully involving people living with dementia across the entire research process and will discuss the facilitators and challenges that were encountered during this process.

Chapter Three: Co-operative inquiry and initiating the inquiry group

3.1 Introduction

This chapter will start with a brief rationale for the use of co-operative inquiry and an introduction to human inquiry. This will be followed by the philosophical underpinnings of co-operative inquiry, a methodology that falls within both the participatory and action research paradigms. Next, this chapter will introduce the initiating phases of a co-operative inquiry that was conducted with a group of people living with dementia and care partners in the city of Salford. An overall context for the study will be presented before a brief examination of the existing use of co-operative inquiry in the dementia research field. The process of initiating the co-operative inquiry will be discussed before an in-depth discussion of the development of establishing the inquiry. Within this chapter, I have used Heron's (1996) scheme to describe the development of the inquiry: Initiating; Establishing; Contracting; Devising a Research Plan; Roles; Ground Rules; and Writing. Due consideration will also be given to ethical issues throughout the co-operative inquiry and in my reflective writings.

It is important to note that I have not used pseudonyms in this thesis to describe the working groups or the co-researchers involved in this study. The working groups that are mentioned are identifiable in the public realm via the Neighbourhoods and Dementia post-study website and the co-researchers made the choice and consented to be identified by their real names. This will be discussed in greater detail further on in the chapter.

3.2 Theoretical Rationale for Co-operative Inquiry

As highlighted in Chapter One, there is growing recognition that people living with dementia and their care partners should be involved as active participants in all stages of the research process (Moriarty, 2019) as this contributes towards their rights to be heard and acknowledged (Bartlett and O'Connor, 2010; Cahill, 2018). The thematic analysis of the literature in Chapter Two identified that although participatory research is beginning to be utilised within the field of dementia care, the voice of people living with dementia is often lost or not recognised. In response, the 'CO-researcher INvolvement and Engagement in Dementia' (COINED) model was developed and co-produced with people living with dementia (Swarbrick et al., 2019) and as described in the first chapter. This study has embraced the COINED model by working with people living with dementia as partners in research, or ‘co-researchers’ (as is utilised by Heron (1996) in the language of co-operative inquiry) to identify, design and implement a co-operative inquiry. The term co-researchers is also used to define the collaborative, co-operative and community-based nature of this study and to describe members of the public and experts by their own lived experience, actively working in partnership with ‘academic researchers’ in all - or parts - of the research process (Swarbrick et al., 2019, p. 3167).

Co-operative inquiry is an inclusive framework where are all participants are not only co-researchers but also co-subjects (Heron, 1996; Heron and Reason, 2006) and being the creators and narrators of their own actions and stories (Reason, 1998). Co-operative inquiry supports and enables individuals to ensure their voice is heard and recognised in research and involves undertaking research that is meaningful to them (Heron and Reason, 2006). Therefore, it is a natural fit for this research study. I will explore the theoretical and practical application of co-operative inquiry in detail later in this chapter.

3.3 The Nature of Human Inquiry

Human inquiry is considered to be participative, holistic and egalitarian in its principles (Moggridge and Reason, 1996) and is entrenched within the anti-positivist and interpretivism movement towards recognising that not everything can be empirically measured. It is used to encompass all approaches to development and learning, *with* and *for* the people at the heart of the inquiry (Moggridge and Reason, 1996). Human inquiry is a move away from the traditional social research approach of simply contributing to knowledge and seeks to create ‘living knowledge’ (Reason, 1996, p. 15) which is valid and integrated into the lives of the people involved in the study.

As an approach, human inquiry does not have a forthright purpose in that there is a straightforward outcome, but, instead, is understood to be an expression and actualisation of human capability (Reason, 1996). Therefore, the purpose of human inquiry is suggested to be:

> “*The enhancement of human flourishing – the flourishing of persons as self-directing and sense-making agents located in democratic communities and organisations*” (Reason, 1998, p. 418).

It involves the direct participation of groups of people for reciprocally beneficial real-world purposes rather than the singular goals of an individual researcher (Moggridge, 2001). Human inquiry gives involved individuals an emancipatory perspective to the creation and ownership of their own knowledge, learning through experience and then applying this new knowledge to their own lives. It also helps individuals gain a more detailed understanding of themselves in relation to their social spheres (Moggridge and Reason, 1995). Human inquiry is regarded to be empowering as participants can broaden and advance their ways of understanding, interpreting and acting (Moggridge and Reason, 1995).

There are several approaches to human inquiry that have been significantly developed in theory and demonstrated in practice including action research, co-operative inquiry and participatory action research. These approaches have all developed in different contexts and although they retain the principles of human inquiry at their core, each approach places a different emphasis on certain aspects of the process (Moggridge, 2001).

The concepts of ‘participatory research’ and ‘action research’ merge frequently (Bergold and Thomas, 2012). For example, Lykes and Mallona (2008) discuss participatory research and action research as one approach:

> “*Participatory and action research was conceived within the majority world in the 1970s and 1980s to systematize and amplify local knowledge, transforming it into social activist movements that contested the power of elites and struggled for greater socio-economic justice…*” (p. 109).

However, these two different methods of human inquiry arguably reflect varied levels of obligation and commitment in the research process and the impact of those being studied (Bell et al, 2004). It is argued that action research and participatory research are managed independently and are distinctly different, with participatory research having less of a focus on action and change and more on collaborative working and partnerships (Bergold and Thomas, 2012).

Participatory research is a source of considerable debate with some viewing the approach unreliable, biased and impressionistic, whilst others advocate for its use to address the power imbalances that exist in conventional research methods (Cornwall and Jewkes, 1995). Traditional research aims to be as objective as possible to reduce bias and any possible influence on the findings (Breda, 2015) and with the involvement of members of the public or co-researchers, it is argued participatory research lacks objectivity (Morello-Frosch et al., 2013). However, participatory research draws from a different philosophy where researchers are not so concerned with objectivity, but with breaking down the barriers between researchers and 'subjects' that are evident in traditional research, giving a voice to all those who participate (Breda, 2015). A further critique of participatory research is that experienced, qualified researchers collect data with less bias than co-researchers without a research background, however, it can also be argued that co-researchers may gather more honest responses and increase engagement in the research (Krieger et al., 2013).

A practical consideration of participatory research is that with the inclusion of the public, co-researchers may not be able to maintain commitment to the project (MacDonald, 2012). This was something I was critically aware of in working with people living with dementia and a discussion around commitment with regards to capacity and expectations is presented later in this chapter and in Chapter Four.

Reason and Bradbury (2008) describe action research as "*a family of approaches"* (p. 7) and argue that there is never a 'correct' or 'true' way of approaching such research. There are many practices that fall under the 'action research' label including participatory action research (Swantz, 2013), feminist participatory research (Reid and Frisby, 2013), action learning (Pedler and Burgoyme, 2013) and also, co-operative inquiry (Heron and Reason, 2013). Co-operative inquiry therefore appears to fall under both the action research and participatory research labels with it being featured heavily in Reason and Bradbury's (2008) 'The Sage Handbook of Action Research: Participative Inquiry and Practice'. However, Heron (1996) argues that although co-operative inquiry has similarities to action research "*its source, range of application and epistemology… are quite distinct, and take it on to a different place"* (p. 1). This is particularly interesting, as Peter Reason, who co-edited the 'The Sage Handbook of Action Research: Participative Inquiry and

Practice' was one of the developers of co-operative inquiry along with John Heron. An issue I will now go on to explore.

3.4 Co-operative Inquiry: Research 'with' rather than 'on' people

Co-operative inquiry is an approach to participatory research and human inquiry that involves cycles of action and reflection through clearly defined phases and is defined as a "*a way of working with other people who have similar concerns and interests to yourself"* (Heron and Reason, 2006, p. 144). The idea of co-operative inquiry was first suggested by John Heron (1971), although at that time was known as experiential research, and was further developed into a framework for research by Heron and Reason (1988; 1995). Heron began to develop the idea of co-operative inquiry in 1968-1969 when he reflected on the idea of mutual gazing in interpersonal encounters. He proposed that it was impossible for a researcher to truly understand the lived experience of a person by observation or other research methods and that these observations needed to come from within (Heron, 1996).

In 1970, the Human Potential Research Project was created to explore the potential of person-centred research, where the experience of the individual was at the heart of the findings and the method that would become known as co-operative inquiry, was applied in workshops throughout the 1970s (Heron, 1996). Peter Reason (1976) had identified that it is difficult to conduct inquiry into human relationships as an outsider and together with Heron continued to build on the theory of co-operative inquiry through the 1980s to develop the concept that is recognisable today (Heron, 1996).

In co-operative inquiry, there is a clear emphasis on participation and a belief in the involvement of 'ordinary' people without a research background (Heron and Reason, 2006). Therefore, in a co-operative inquiry, all inquiry group members are involved in its initiation, development and management and become intrinsically involved in the inquiry itself. Through its formation, inquiry group members, acting as co-researchers, can influence all stages of the inquiry process and the direction of subsequent actions (Heron and Reason 2006). Accordingly, co-operative inquiry honours the right of individuals to have their say in decision-making that affects them (Reason and Heron, 1995; Heron, 1996). The person is placed at the heart of the research and the research topic is defined and fluctuates depending upon its meaning to the individual and the group and how it is interpreted from a personal perspective (Heron, 1996). Heron and Reason (2006) suggest that groups of six to 12 people work well in a cooperative inquiry, below six being too small and above 12 being hard to facilitate.

There are different forms of co-operative inquiry and groups can be assembled by one or two initiating researchers, familiar with the method, who decide on an inquiry topic and invite others to join the inquiry (Heron and Reason, 2006). This was the case with this research study. As the initiating researcher, I approached a group of people living with dementia and their care partners to join the inquiry group. I was awarded a studentship to conduct participatory research with people living with dementia and from this initial step, progressed to the formation and completion of a co-operative inquiry. The way in which I approached this, how the inquiry was initiated, and the challenges encountered in this part of the process will be discussed in detail in Chapter Four.

Table 5: Kinds and degrees of participation (Heron, 1996, p. 22)

		Researcher	***Subject***
Political participation	A	Full	Full
Involvement in research	B	Full	Partial
Thinking and decision-making	C	Full	Nil
Epistemic participation	D	Full	Full
Involvement in experience	E	Partial	Full
Action being researched	F	Nil	Full

In a co-operative inquiry, there are two kinds of participation, epistemic and political. The types of participation can be distinct or intertwined with each other. Epistemic participation is concerned with the co-researchers as ‘knowers’ who become involved in areas of inquiry that are to be ‘known’. Epistemic participation involves members of the inquiry becoming grounded in their own experience and considering a deeper kind of ‘knowing’ with the action being researched (Heron, 1996). The different types of knowing are discussed later in the chapter in section 3.4.1. Political participation considers the relationship between the co-researchers and the decisions that are made in the inquiry. As well as providing data to the inquiry, members of the group are also involved in the decision-making and thinking throughout the whole inquiry process (Heron, 1996). The different ways that co-researchers can participate in an inquiry has been mapped out by Heron (1996) as documented in Table 5.

By referring to Table 5, it can be explained how a co-operative inquiry can be full-form, partial-form or a supported action inquiry (Heron, 1996). A full-form co-operative inquiry would exist when every member of the inquiry alternates between co-researcher and co-subject, a combination of rows A and D. Partial-form inquiry combines rows A and E, where everyone is involved as co-researcher but not everyone is a co-subject. This would be the case where an initiating researcher such as myself approaches a group of people and introduces co-operative inquiry to them but is not a full co-subject and does not have the lived experience of the other co-researchers. Supported action inquiry is a more limiting form of inquiry than full-form and partial-form. Supported action inquiry is more likely to develop when an initiating researcher approaches potential inquiry group members and educates them on the use of co-operative inquiry. However, once the inquiry group members have an understanding of inquiry methods, the initiating researcher backs off and adopts a supportive position with no position as co-subject at all (Heron, 1996). Examples of supported action inquiry could include a lecturer supporting students to facilitate their own independent learning and a mental health professional supporting a service user to adopt self-help technique in managing their mental health. As Heron (1996, p. 25) highlights, supported action inquiry “*is tangential to co-operative inquiry”* so the majority of co-operative inquiries will take either a full or partial form to participation.

A further differential within co-operative inquiry extends to wherever the phases or steps in the research process occur within an inside or an outside inquiry. Inside inquiries take place within the whole group and their experience working together in the same place. An outside inquiry is about what goes on in group members’ working and/or personal lives, outside the group meetings (Heron and Reason, 2006). For example, an inside inquiry was conducted by Heron (1996) in exploring the phenomenon of group energy where the inquiry took place over three days of group meetings. Baldwin (2001) conducted an outside inquiry with a group of social workers where the group collaboratively decided what parts of their practice to explore and then carried this out in their daily routines before coming together as a group to discuss what they found. Co-operative inquiries can also be differentiated as having either open or closed boundaries. Closed boundary groups are only concerned with what is going on within the group, between the co-researchers. Open boundary groups will consider interaction amongst the group but also with others outside the inquiry group in the wider world (Heron and Reason, 2001).

An effective co-operative inquiry will have elements of both Apollonian and Dionysian inquiry cultures although they may lean predominately towards one or the other (Heron and Reason, 2006). An Apollonian inquiry takes a more straightforward, systematic, linear, methodical and controlling approach to the reflection and action process whilst a Dionysian inquiry adopts a more imaginative, drawn-out, implicit and expressive approach (Heron, 1996). As the use of co-operative inquiry in dementia research is only now emerging, this project leaned towards a Dionysian inquiry culture as it allowed for an informal and creative environment to mature.

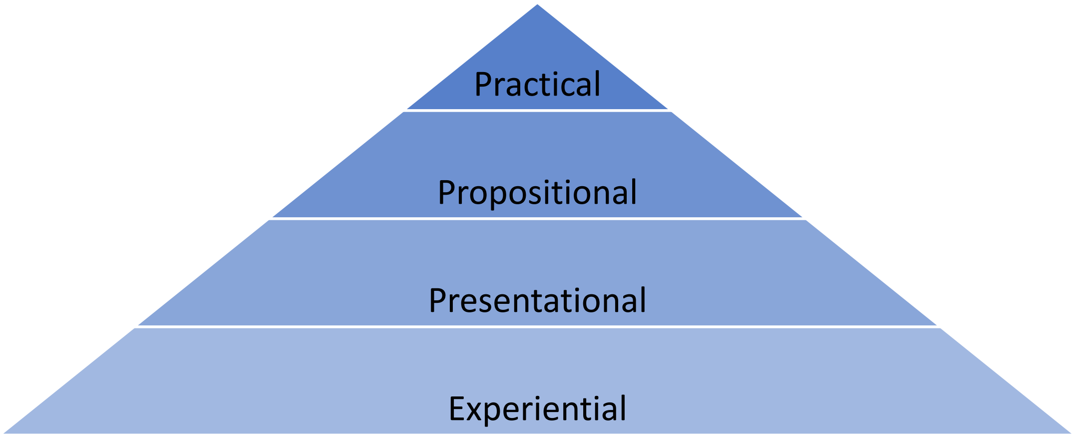
A final distinction between inquiry types is whether the inquiry is informative or transformative. Heron (1996, p. 48) states that this is "*a fundamental distinction"* between inquiry types and feeds into what the outcomes of the inquiry will be. An inquiry that is mainly descriptive and informative will have outcomes that are suggestions about the nature of the domain that has been explored. In a practical and transformative inquiry, the primary outcomes will include the development of skills and situational changes (Heron, 1996). This project had both informative and transformative aspects to it which will be explored and identified in Chapter Five.

3.4.1 Four ways of knowing

Among the central features of a co-operative inquiry are the four ways of knowing. Heron (1996) argues that any kind of knowledge is validated by its own internal criteria but also by its congruence and interdependence with all the other types of knowledge. In his early work, Heron (1996) referred to four different inquiry outcomes, which included practical skills, propositional reports, presentations of insight and transformations of person being. These concepts were later developed into the four different types of knowledge. Figure 3 illustrates the four different types of knowledge, and their relationship to each other.

Experiential knowing is what we know from our own perceptions and experiences through encounters with people, places or things. Emerging from this experiential knowing is *presentational* knowing, a form of expression that involves different forms of imagery through creative means such as drawing, movement, sculpting and so on. *Propositional* knowing is our understanding of theories and ideas in spoken or written form. *Practical* knowing is essentially knowing how to do something, expressed through competence or skill (Heron and Reason, 2008).

Figure 3: Relationship between the four ways of knowing (Heron, 1996).

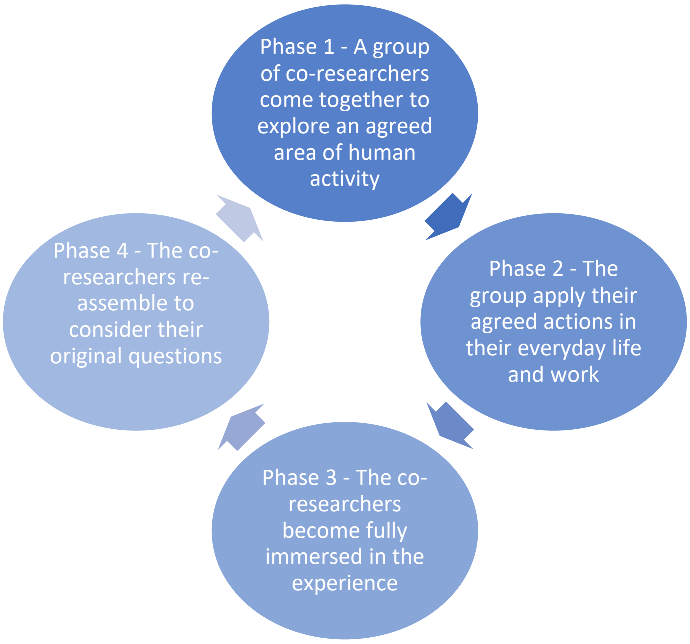


In a co-operative inquiry, our knowing has its foundations in our experiences, which is then communicated through: stories, images, and other creative means; understood through ideas and theories which make sense to us; and expressed in meaningful ways or actions in our lives (Heron and Reason, 2006). A co-operative inquiry can also create what is described as an "*extended epistemology"* – epistemology meaning a theory of how you know and extended because it reaches beyond the primarily theoretical knowledge of academia (Heron and Reason, 2006). Heron and Reason (2006) highlight that traditional research includes exclusive roles for researcher and participant yet within co-operative inquiry, those traditional roles are replaced by a partnership that fosters a creative, practical collaboration that aims to address the concerns of the population being researched.

3.4.2 The stages of a co-operative inquiry

Co-operative inquiry advocates for all co-researchers to be fully involved in the research process and suggests a systematic approach to the inquiry. This is approached through four phases that can be repeated as many times as necessary, although with a Dionysian inquiry culture, there may be more fluidity in the approach. The four phases of action and reflection in a co-operative inquiry are illustrated in Figure 4 below. The cycle is repeated several times depending on what is being explored. The repeated cycling enhances the validity of the findings (Heron and Reason, 2006). However; other validity measures are also used within a co-operative inquiry which will be discussed further in Chapter Five.

Figure 4: Cycles of action and reflection in the co-operative inquiry process



3.4.3 Critical subjectivity and Reflexivity

In order for both theory and practice to develop within the co-operative inquiry, a state of consciousness called *critical subjectivity* must be developed by the researchers (Reason and Heron, 1995). It could be argued that working so closely with an inquiry group and generating knowledge collaboratively could mean that the findings are inherently biased. Critical subjectivity means acknowledging our own personal beliefs and experiences and building on these instead of disregarding them in the search for objectivity (Heron and Reason, 2006). Heron and Reason (2006) recognise that as human beings, people can and do fool themselves about their experiences but that they can also turn their attention inwards in a critical manner. In acknowledging that as humans we have self-defence processes that can automatically deny, distort and manipulate reality at an unconscious level (McLeod, 2009), it is important to adopt a critical sense of this consciousness and articulate this in our communications. Consequently, it is possible to recognise the restrictive bias but authentic value of this perspective (Reason and

Heron, 1995). Heron and Reason (2006) developed a number of inquiry skills and validity practices to enhance the critical subjectivity of researchers or "*quality of knowing"* (p. 15). These skills and procedures are:

- **Being present and open:** This involves being open to the meaning that we give to, view, and discover in our world. Being mindful and acting with empathy in our participation with others.

- **Bracketing and reframing:** This involves suspending our pre-imposed constructs on our perceptions, so we can be more open in our exploration. This skill also involves applying alternative premises and theories to the constructions of narrative accounts of the world experienced by us or reframing our perceptions and assumptions.

- **Radical practice and congruence:** This is about enhanced awareness during actions in an inquiry. Being aware of strategic aspects, fundamental standards, motivations, defining beliefs and outcomes. This skill also involves recognising any lack of congruence that may occur in the different aspects of action and making modifications as necessary.

- **Non-attachment and meta-intentionality:** This skill involves remaining dedicated and immersed in an action but at the same time, not investing your personal identity and emotional well-being in it. It also involves considering alternative behaviours and their potential application to specific situations.

- **Emotional competence:** This skill is about recognising and handling emotional states in different ways. Part of this skill includes ensuring action is uninhibited by bias that can be driven by our own conditioning.

- **Research cycling:** As mentioned earlier, co-operative inquiry involves phases that cycle through action and reflection, considering the experience or practice from different angles, trying different ways of working and experiencing, developing new and alternate ideas. As the inquiry is taken through several cycles, then the different types of knowing will become more refined through both negative and positive feedback.

- **Divergence and convergence:** The cycling inquiry can be convergent or divergent. The former being when the active participants look at the same issue or problem several times, perhaps in more detail each time. Whilst the latter involves the participants looking at different issues or problems in consecutive cycles. Numerous variations of divergence and convergence can occur during a single inquiry and it falls to the individual groups to determine the balance within their own inquiry.

- **Authentic collaboration:** It is crucial that the members of the inquiry create an authentic form of collaboration. One facet of this is that members of the inquiry construct their own inquiry method internally so that a democratic relationship is developed with the initiating researchers. The other characteristic of authentic collaboration is that each co-researcher is wholly and authentically engaged in each phase of action and reflection and that each member of the group is heard and influential in the decision-making process. If one or two individuals dominate the discussion and the overall inquiry, then it is not truly co-operative.

- **Challenging consensus collusion:** This procedure involves a member of the group formally adopting the role of 'devil's advocate' to question whether there is any complicity present. Collusion can include not discussing or noticing limitations in programmes of action, fixation or false expectations in the generation of ideas, projections that misrepresent the inquiry process and a lack of rigour and objectivity in the methods of inquiry and in applying validity procedures such as this one. Failure to challenge consensus collusion could imply consensus collusion.

- **Managing distress:** The inquiry group should adopt a policy of regularly considering if any distress has arisen amongst group members and if recognised, managing that distress appropriately. The nature of human inquiry may invoke stress or anxiety and can result in a preoccupation of this in the mind, thus the inquiry can be adversely affected. Depending on the nature of the inquiry, looking in depth at their lives and experiences could uncover aspects or feelings that a co-researcher may feel uncomfortable with. Therefore, the inquiry group members must be willing to explore and tackle distress openly when or if it arrives, allowing members to heal and process their reactions.

- **Reflection and action:** Finding a balance between action and reflection is important to the inquiry process. Too much reflection on too much action is simply activism, whilst too much reflection on too little action is ‘armchair theorising’, that doesn’t involve the collection of new information. It is up to the individual inquiry group to find their own equilibrium between action and reflection and will mainly depend on the subject being explored.

- **Chaos and order:** Like with reflection and action, a group needs to balance the chaos and order that might occur during an inquiry. The inquiry group should develop an attitude of toleration during inquiry phases that may be messy or chaotic. With time and space, these phases tend to become more ordered. Applying boundaries to these messy phases early can lead to false and inauthentic knowledge. Chaos may not feature in a group’s inquiry, but the members should be ready for it, tolerate it, and wait for a collective resolution (Heron and Reason, 2006).

Critical subjectivity is used within co-operative inquiry to explore the validity of the research and in turn enhances the soundness of the research process (Heron, 1996). Critical subjectivity involves awareness of our knowing and not supressing our immediate experiences of what we know but embracing them and acknowledging any bias that occurs within it (Reason, 1994). Critical subjectivity has strong parallels with the concept of reflexivity:

> *“Reflexivity can be defined as thoughtful, conscious self-awareness. Reflexive analysis in research encompasses continual evaluation of subjective responses, intersubjective dynamics, and the research process itself”* (Finlay, 2003, p. 532).

Reflexivity is a running theme throughout the co-operative inquiry process (Heron and Reason, 2006) and therefore was an integral part of this research project. Even at the earlier stages in this project, before I had recruited co-researchers to work with me, I considered the impact of my own contributions to the co-operative inquiry process, with particular attention being paid to the desire for a collaborative partnership but with the awareness that this was my own individual doctoral study. I aimed to use the skills I had developed from reflection in my mental health nursing practice in order to facilitate the concept of reflexivity in the research, as the concepts of reflection and reflexivity are noted to be closely related (Kara, 2015).

Although reflexivity can contribute to the credibility of a study (Finlay, 2003), it is also the subjective opinion of the researcher, where the parallels with critical subjectivity can be seen. Collaborative reflexivity can help to reduce the subjectivity by introducing the group to the concerns and views of the author and asking for reflective feedback (Away, 2003). As co-operative inquiry is a cyclical process, reflexivity should be considered on a regular basis.

Critical subjectivity and reflexivity are an inherent part of the co-operative inquiry process and it is something I am decisively aware of. As I do not live with dementia and am not the care-partner of a person living with dementia, it could be argued that I am not a 'full co-subject' (Heron and Reason, 2006, p. 186) and the co-operative inquiry that was formed would be termed what Heron (1996) refers to as *partial form co-operative inquiry.* In a partial form co-operative inquiry, everyone is involved as co-researchers, however, I, as a co-subject, have an external perception and view of the topic being investigated. I will discuss this in depth and reflect on my own part in the process in detail in Chapter Six.

3.5 Co-operative Inquiry in Action

Co-operative inquiry has been utilised as a methodology since the 1970s (Heron, 1996). It has been used in a variety of fields, from international development (Godden, 2018) to education (Bellefeuille et al., 2006) to human resource management (Csillag, 2013). It has also been used widely in healthcare research, but sparingly, with diverse groups. For example, Trollvik et al. (2013) worked alongside children and their families in an inside inquiry, to develop an education programme for children living with asthma and showed that children could be active collaborators in research that was of interest to them. Nkomazana et al. (2016) utilised co-operative inquiry in their work with healthcare managers to explore and develop best practice for the supervision of primary healthcare workers and Manley et al. (2008) conducted a transformative inquiry with consultant nurses for older people over six months to explore their leadership role in practice.

Co-operative inquiry has also been used broadly within the mental health field. Hostick and Mcclelland (2002) explored the nurse-service user relationship in an inside inquiry which involved two nurses and two service-users meeting with the two initiating researchers over four monthly-held meetings. Although, the group was small in terms of sample size with six members in the inquiry group, the use of co-operative inquiry ensured that "*the description of the nurse-client* *relationship and the influences on it is extremely rich and potentially useful with implications for clinical and managerial practice"* (Hostick and Mccelland, 2002, p. 111). Another example of the use of co-operative inquiry that included staff and service users is the work of Berring et al. (2016) who explored de-escalation techniques in mental health settings in an outside, transformative inquiry where the co-researchers became learners and implementers of the techniques, they acquired during the inquiry meetings.

As mentioned earlier in this chapter, co-operative inquiries can take place over weeks, months or years. Hummelvoll and Severinsson (2005) conducted a four-year co-operative inquiry in a mental health setting. The inquiry group consisted of the researchers, acute healthcare staff and mental health students and utilised research methods such as focus groups, interviews and observations within the inquiry. The researchers found that co-operative inquiry was a useful methodology in the bridging the gap between theory and practice. Not all of the mental health related co-operative inquiries are concerned with practice in mental health settings. Van Lith (2014) explored mental health recovery and art-making through the lens of co-operative inquiry and in her findings brought about further understanding of the place of the initiating researcher and the role of art-making and its relation to the values of recovery in mental health. Co-operative inquiry has also been implemented as a methodology in mental health education when a group of general practitioners came together in an informative inquiry. The inquiry group adapted mental health materials from the World Health Organisation (WHO) to their home healthcare system and interestingly found how their own analytic medical training negatively influenced their ability to be open and present in the inquiry (Mash and Meulenberg-Buskens, 2002).

Although co-operative inquiry is widely applied in a variety of research fields, it is not without critique. The issue of ensuring authentic collaboration is an unavoidable challenge when conducting a co-operative inquiry (Oates, 2002). It can be particularly problematic when there is an external researcher initiating the research with their own goals and objectives, such was the case with this doctoral study. Adopting the inquiry skills and validity practices, as detailed in section 3.4.3 on critical subjectivity, can aid the drive for authentic collaboration, but the goal of equal power sharing is not always realistic (Godden, 2017). It is important that the initiating researcher(s) are aware and consider this throughout the inquiry process.

The ethics of conducting a co-operative inquiry, particularly with vulnerable people, can be complex and time consuming (Tee and Lathlean, 2004) and may lead researchers to avoid using participatory methods. A one-off assessment is not adequate for the involvement of vulnerable people in a co-operative inquiry (Tee and Lathlean, 2004) and researchers should ensure they have the time and resources available for continuous assessment. The continuous assessment of capacity used during this doctoral study, ‘process consent’, is discussed later in this chapter.

A further critique of co-operative inquiry is the use of terminology. In Heron’s (1996) seminal work on co-operative inquiry, there is little time or discussion given to the involvement of vulnerable people who may lack capacity and the terminology used is often not accessible to those without formal research training. Despite the production of ‘A layperson’s guide to Co-operative Inquiry’ (Reason and Heron, 1999), language such as ‘extended epistemology’ and ‘authentic collaboration’ is still embedded within this text which could be daunting to the general public. This could result in a reluctance to engage in the research despite the overall goal of co-operative inquiry being to research ‘with’ people rather than ‘on’ them. It is a further skill required by the initiating researcher(s) to ensure that the co-researchers are unconcerned by the academic language of co-operative inquiry but fully understand the process of it and what is entailed.

The rest of this chapter will explore the aims and objectives of the PhD study and the initiating of the co-operative inquiry that took place. The initial phases of the inquiry including the recruitment strategy, the development and adaption of a co-operative inquiry and a discussion of the ethical challenges will be reviewed.

3.6 Aims and Objectives of the Study

The research aim of this study is to form, develop and conduct a co-operative inquiry with a group of people living with dementia and their care partners.

The supporting objectives are:

- To explore the creation of a co-operative inquiry with a group of people living with dementia and how this is subsequently facilitated.
- To develop an action output that had meaning and resonance for the formed group.

- To examine the facilitators and barriers in working collaboratively with people living with dementia in research.
- To evaluate the position of researcher reflexivity during the different stages of the co-operative inquiry.

As the research was participatory, it was also vital that due consideration was given to researcher reflexivity as awareness around power and the shifting balance of power is an important concept in operationalising co-operative inquiry and this will be discussed in detail in the following chapter.

3.7 Context for the study

As this study was nested in work programme one of the ESRC/NIHR Neighbourhoods and Dementia study (May 1st 2014-October 31st 2019) as described in the background at the start of this thesis, it made sense to work with one of the established research groups attached to the study, these being Salford INSPIRE, EDUCATE (Stockport, Greater Manchester), The Scottish Dementia Working Group and Open Doors (Salford, Greater Manchester). As I was based in the city of Manchester, it would not have been geographically practical to include the Scottish Dementia Working Group, although I did meet with them on 6th June 2016 to discuss aspects of the study. Their work on including people living with dementia in research (Scottish Dementia Working Group Research Sub-Group, 2014), as noted in Chapter Two, is pertinent to this research in the identification of core principles that all researchers should acknowledge when working with people living with dementia such as the use of clear, non-scientific language and ensuring proper breaks and refreshments.

Of the groups situated locally to me in the city of Salford, the Open Doors Research Group was the largest and most active group. Dr Caroline Swarbrick, one of my PhD supervisors, was instrumental in setting up the Open Doors Research Group which worked closely with work programme one of the Neighbourhoods and Dementia study. Therefore, after several consultation visits to their post diagnostic group meetings and dementia cafes between October 2016 and January 2017, it felt like a natural fit for the project.

Open Doors aims to support the delivery, development and innovation of dementia services in Salford and is funded and supported by Greater Manchester Mental Health NHS Foundation Trust (GMMH) as described in its supporting literature:

> *The Open Doors Service is based upon the promotion of living well with dementia and aims to literally 'open doors' for people living with dementia, whose goals are to support the delivery, development and innovation of dementia services within Salford.* (Greater Manchester Mental Health NHS Foundation Trust, 2018).

Open Doors, as part of Greater Manchester Mental Health NHS Foundation Trust (GMMH) was the first NHS trust in the UK to employ a person living with dementia in their services to truly ensure a voice is given to people living with dementia. The people living with dementia employed by GMMH are active in the Open Doors project as facilitators and help to support the people living with dementia and their care partners in Salford. Among the services developed by Open Doors are a dementia café, two support groups, a book club and a dining club. The project also takes an active part in research both within GMMH and with local universities (Greater Manchester Mental Health NHS Foundation Trust, 2018). As part of the Open Doors Research Group, they were involved in the development of the COINED model (Swarbrick et al, 2019) which is explored in greater detail in Chapter One but prior to this, members of the Open Doors Project had been at the forefront of innovative ways of ensuring the voice of people living with dementia was heard and recognised. The Open Doors Service was one of the first NHS services to employ a person living with dementia to support the facilitation of their service. Mike Howorth, was a person living with Alzheimer's disease and was employed by Greater Manchester West Mental Health NHS Foundation Trust in 2010 who in his role developed networks across the city of Salford and took on duties such as role modelling, leading the dementia café and taking part in research and educational opportunities (Howorth et al., 2012).

I visited the Open Doors service several times before initiating the co-operative inquiry to meet some of their members and learn about the research they were currently involved in, as well as previous research participation. The service manager of Open Doors was supportive and enthusiastic of the proposed research in these initial meetings which also supported the decision work with Open Doors. From a resource perspective, there were various suitable locations available for group work in the Salford area which were accessible for people living with dementia.

3.7.1 Building upon what has been done before

A co-operative inquiry was utilised in the development of the COINED (CO-research Involvement and Engagement in Dementia) model with the Neighbourhoods and dementia study (Swarbrick and Open Doors, 2017; Swarbrick et al, 2019). This previous study involved the three working groups from the Neighbourhoods and Dementia study working collaboratively to build and develop the COINED model as described in Chapter One. The inquiry group met eight times but due to the groups being situated in different parts of the country, they met independently but with the same facilitator (Swarbrick and Open Doors, 2017). It was important to consider how this doctoral project could build upon this innovative work with people living with dementia. The research carried out by Swarbrick and Open Doors (2017) showed that co-operative inquiry could be successfully applied to dementia research, but it was not without its challenges.

The knowledge generated from the co-operative inquiry undertaken as part of this doctoral study will contribute to the four ways of knowing; experiential, presentational, propositional and practical (Heron and Reason, 2006). It builds upon the foundation developed by Swarbrick and Open Doors (2017) that the use of a co-operative inquiry produces knowledge that supports the involvement of people living with dementia as co-researchers in a congruent fashion and adds to the existing body of dementia research.

3.8 Initiating the co-operative inquiry

I had to consider three fundamental but closely interdependent issues in initiating the inquiry:

> i. The initiation of group members into the methodology of the inquiry so that they can make it their own;
>
> ii. The emergence of participative decision-making and authentic collaboration so that the inquiry becomes truly co-operative;
>
> iii. The creation of a climate in which emotional states can be identified, so that distress and tension aroused by the inquiry can be openly accepted and processed, and joy and delight in it and with each other can be freely expressed.
>
> (Heron and Reason, 2006, p. 20)

Arguably, the issues above are all concerned with empowerment. The first issue is concerned with methodological and cognitive empowerment, the second issue with political empowerment and the final issue with interpersonal and emotional empowerment (Heron and Reason, 2006).

Heron (1996) highlights that the initiating researcher should have skills in all three of these areas; this will be discussed in greater detail in Chapter Six when discussing my own critical subjectivity and reflexivity. The creation of a co-operative inquiry can occur in one of two ways. It can begin with one or two initiating researchers who have an idea and then recruit appropriate co-researchers, or it can commence as a result of an already formed group who begin the process together as a whole (Heron and Reason, 2006). For this doctoral project, it was the former approach that occurred. As a post-graduate researcher, I had an idea, informed by my studentship to recruit people living with dementia and their care partners, to create a co-operative inquiry to explore a subject that was meaningful to them. After visiting and meeting members of Open Doors, and with the support of the service manager, the initiating phase of the co-operative inquiry began.

3.8.1 Time, Space and Criteria

As highlighted in the literature review provided in the preceding chapter, the notion of time is a key consideration in co-researching conditions and the practicalities involved with collaborative research and co-operative inquiry. Time must have prevalence and be appreciated, in making sure there is time to carry out the research, arranging mutually convenient times for all those involved and also being aware of time limits to carry out the research and disseminate findings. The Scottish Dementia Working Group developed guidelines in the form of core principles for involving people living with dementia in research and introduced an alternative philosophy of time, ‘dementia time’ (Scottish Dementia Working Group Research Sub-group p, 2014). This idea of ‘dementia time’ is particularly relevant to this inquiry, but also to other groups where cognitive impairment may impact their contribution to the process. The core principles acknowledge that people living with dementia may not present memories in a chronological fashion, that regular breaks are necessary and that sometimes they may need time out from the research process (Scottish Dementia Working Group Research Sub-group, 2014).

Furthermore, time and on-going support is described by Hanson et al. (2007, p. 411) as an ‘*essential*’ prerequisite for carrying out participatory research, a notion also advocated by Pratt (2002) who described her experiences as a researcher when working with people living with dementia:

> *‘One particular lesson I learned whilst interviewing people living with dementia was the importance of time… people living with dementia have good days and bad days, they may experience changes over time and they may take time to open up to you’* (p. 176).

The time needed to build relationships in participatory research can be significant and impact on the length of the study (Higginbottom and Liamputtong, 2015). I began trying to recruit a group of people for this co-operative inquiry at the end of 2016, the inquiry did not receive ethical approval to begin the research until September 2017, and the inquiry ended in June 2018. Time is perhaps something that was underestimated in undertaking this project. As previously discussed, being part of the Neighbourhoods and Dementia study, I had access to active populations of people living with dementia and planned to recruit from these working groups. Recruiting from the Open Doors service involved adopting a convenience sampling strategy (Polit and Beck, 2012), as these individuals were in close proximity to me geographically but were also accessible due to the support of the service manager (gatekeeper).

Space is of particular importance when conducting research with people living with dementia both in a physical and in a metaphorical sense. The initial and consultative meetings were all held within the Humphrey Booth Resource Centre which was chosen due to it being familiar to members of the Open Doors. The Humphrey Booth resource centre is run by a community interest company in the Swinton area of Salford which provides day care services to older people from the local area. There are meeting rooms available for hire alongside a café that is open during the day for hot and cold meals and snacks. The Humphrey Booth Resource Centre also provided tea and cakes at meetings (for a fee, met by my research budget), was accessible and had free car parking available, meeting some of the recommendations suggested by Hanson et al. (2007):

> *Give sufficient attention to the location… ensure that it is a congenial environment, has disabled access, is close to amenities such as toilets, cafeteria (serving high quality food and drinks) and public transport, car parking and is in a central well-known location which is readily accessible.* (p. 427)

Moving forward with the plan to recruit from the Open Doors Service, inclusion and exclusion criteria for the members of the inquiry group were then established. With reference to the ESRC studentship, I developed the inclusion/exclusion criteria that would also ensure the aims of the study were met. The studentship stipulated that the research should be participatory and with people living with dementia but after completing my literature review and meeting with individuals living with dementia, I felt strongly that the research should go beyond that of being participatory and adopt the goals of work programme One of the Neighbourhoods and dementia study by adopting a partnership between academics and people living with dementia. The vision of work programme One was '*To feel enabled and empowered to develop and facilitate our own research agenda*' (https://sites.manchester.ac.uk/neighbourhoods-and-dementia/work-programme-1/).

It was therefore important that the people involved in the study had experience of living with dementia, whether that was living with a diagnosis or caring for someone with a diagnosis.

Inclusion criteria

- Individuals will have a diagnosis of dementia or be a care partner of an individual with a diagnosis of dementia.
- Individuals will live in the community.
- Individuals who have capacity to understand and provide informed consent to participation in the study at the beginning of the study.
- Individuals will be a member of the Open Doors service.

Exclusion criteria

- Individuals who live in institutional care, including nursing or care homes and hospitals.
- Individuals who do not have capacity to consent to take part at the beginning of the study.
- Individuals who do not speak English.
- Individuals who are not members of the Open Doors service.

It can be noted from the developed inclusion and exclusion criteria, that I could only recruit people who had capacity to give consent to the inquiry group. However, that was not my original intention or design. I had originally planned to include people living with dementia who may not have capacity to consent, but I was unable to gain ethical approval for this requirement. I will return to this position later in the chapter.

In late 2016 and early 2017 (see Figure 5 for a timeline of events), I attended four meetings run by the Open Doors service to gather interest and explain what I hoped to do. This included attending the dementia café at Roe Green Cricket Club in Worsley, Greater Manchester twice and peer support group at Humphrey Booth Resource Centre twice. On all four occasions, I presented my study to the group and handed out leaflets (see Appendix 5) that included by contact details and the date of initials meetings. I explained to those present, that I would like to work collaboratively and co-research with a group of people living with dementia to identify a research subject that was meaningful to them. Although members of the group were receptive to the research, there was some confusion when I said that there was no clear research plan but that we would research what they were interested in as opposed to what I had decided. It was evident from this reaction that being asked to design their own research was not something members of the group were familiar with.

3.8.2 Establishing

After receiving interest in the research, I coordinated six consultation meetings with interested members of the Open Doors group over a period of five months (see Figure 5). The number of attendees varied during these consultation meetings from zero to eight. On the one occasion when no-one attended the consultation meeting, I had to reflect on why that happened. Speaking with the service manager and members of Open Doors Service at a different meeting, I discovered that the day and time I had scheduled the meeting for (a Tuesday afternoon) was a particularly busy day for those who had shown interest. Naively, I had underestimated how full the diaries of members of the group were on a day to day basis.

Once our inquiry group was established, we mutually agreed on convenient days and times to meet which were mainly Thursday afternoons. As I have mentioned earlier in the chapter, Heron and Reason (2006) suggest that groups of six to 12 people work well in a co-operative inquiry, below six being too small and above 12 being hard to facilitate. The final number for the co-operative inquiry was six people (including myself) which fitted with Heron and Reason's (2006) suggested numbers. These individuals met the inclusion criteria for the research and therefore ethical approval was sought once a research plan was in place. It was natural part of the process for me to take the role of facilitator in this inquiry. The co-operative inquiry had an integral part to play in my doctoral project and I was the initiating researcher. Further discussion around the role of the facilitator is explored in Chapter Five.

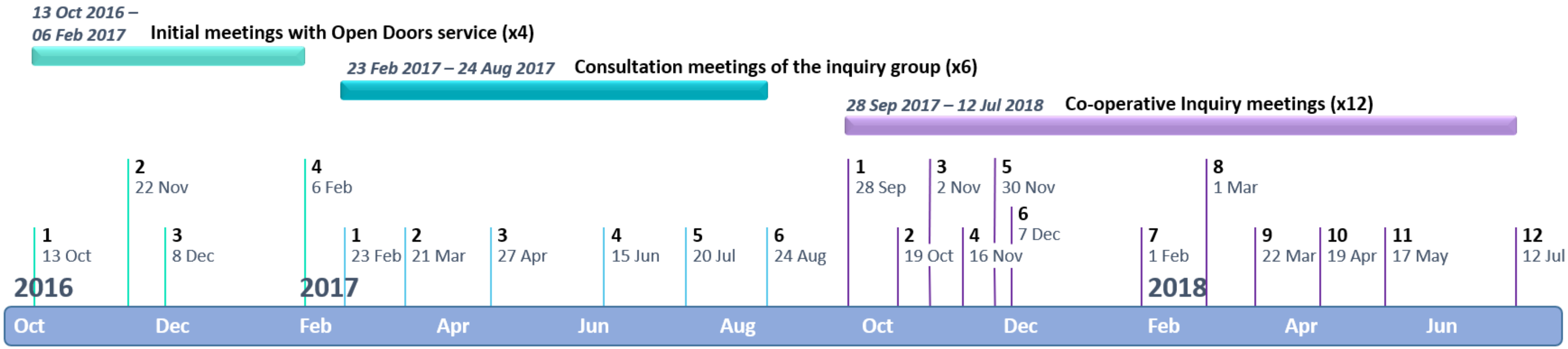
As this research was being carried out with members of the Open Doors group who are funded by Greater Manchester Mental Health NHS Foundation Trust, NHS ethical approval was required in order for the research to proceed. The group was formed prior to gaining ethical approval in order to fully immerse the group members in the research design. No data was collected during these consultation meetings, but a research goal began to be formed.

3.8.3 Contracting

This phase of the creation of a co-operative inquiry is highlighted by Reason and Heron (1996) to be one of the most important phases. Contracting is when the inquiry group has the opportunity to begin defining their research plan and establishing group process. This is also the opportunity to discuss practical aspects of the research such as when and where we would meet and how often this would occur.

Hanson et al. (2007) suggest that significant consideration should be given to the location of where the involvement in research takes place. As highlighted by the Scottish Dementia Working Group Research Sub-group (2014), research should take place in a place that is appropriate and accessible. As the members of the Open Doors service all live in Salford or the surrounding area, a convenient place in this locality was sought. It was highlighted in the initial meetings and consultation phase by people living with dementia, that the Humphrey Booth Resource Centre would be preferable, and this is where the majority of our meetings took place. This location was known to those who were interested in the project as it is where the majority of the Open Doors meetings take place. The Humphrey Booth Resource Centre is run by a not-for-profit community interest group and is also free to hire, which was helpful in managing the costs relating to the research. Although, I attempted to book rooms in advance for consistency, two of our later co-operative inquiry meetings had to be held elsewhere. When searching for another location, I consulted with the co-researchers prior to booking, to ensure that a location that they were familiar

Figure 5: Timeline of the co-operative inquiry.



with could be sourced. On these two occasions, when the Humphrey Booth Resource Centre was unavailable, we met at Pendleton Gateway which is centrally located in Salford, Greater Manchester and easy for the co-researchers to get to. Pendleton Gateway is managed by the local council and NHS and again offered free committee rooms for members of the local community.

In recognition of the time, skills and expertise that the members brought to the group, it was appropriate to offer the co-researchers a financial incentive for their participation (INVOLVE, 2013). In discussion with the main funder of this PhD study (ESRC), it was agreed that each member of the group would receive a £10 gift for each month they are involved with the study, up to a maximum of £100 in total**.** This was arranged to be paid in cash to recognise their contributions as co-researchers.

3.8.4 Devising a plan

A co-operative inquiry involves arranging meetings at appropriate intervals to allow sufficient time for action and reflection (Heron and Reason, 2006). Studies implementing a co-operative inquiry approach have carried out their inquiries over various time-scales, from just a few months (Hostick and McClelland, 2002; Traeger and Norgate, 2015) to four years (Hummelvoll and Severinsson, 2005). After three consultation meetings, we had our final co-operative inquiry group in place. During the final three consultation meetings we discussed and devised a research plan.

During these meetings, we discussed what topic we would like to explore. One subject that was considered and suggested by myself, was exploring what taking part in research meant to people living with dementia, but it was hard to formulate an action plan around this area as members of the group had varying experiences of being participants in research. It also did not appear to have much significant meaning to the group although they did highlight that dementia research was important. The experience of taking part in research may have been a topic that was too abstract to develop a co-operative enquiry around.

During this initial phase, it was difficult to identify a topic as it appeared that the co-researcher's previous experiences of taking part in research involved being approached with a plan already in place. The concept of a researcher stating that they wanted to explore what was meaningful to them as people living with dementia appeared to be new to the inquiry group. This does not appear to be a commonly reported issue in the literature. In co-operative inquiries conducted within the mental health field, most researchers report approaching groups with an idea for a topic to explore (Berring et al., 2016; Van Lith, 2014) or report that the inquiry group actively participated in the identification of themes for inquiry, seemingly without difficulty (Hummelvoll and Severinsson, 2005). Hostick and Mcclelland (2002) did report the desire to ensure the methods were being developed from the inquiry group and thus, it was difficult to provide the level of detail typically required to gain ethical approval. Unfortunately, it was not reported how this challenge was overcome.

When discussing a potential topic to explore within my regular supervision meetings, the topic of stigma was suggested, as my main supervisor had returned from Canada where stigma was considered an important topic for people living with dementia. Indeed, within the consultation meetings of the inquiry group, the area of stigma and the representation of dementia in our society were often discussed and as an initiating researcher, I suggested to the group that we explore stigma as a research topic. Stigma was unanimously agreed as a topic to explore as it was evident through the consultation meetings that it evoked a passionate and emotive response and social action was possible within the study timescale. The discussion of stigma evidently had meaning to the co-researchers and initial conversations showed a rich amount of data that would contribute to our inquiry. For example, despite local, national, and international programmes to address stigma (Pinfold et al, 2005), it remains an experience that people living with dementia continue to encounter on an everyday basis and in different ways (Swaffer, 2014).

With the broad subject area of stigma agreed, the group then had to decide how they wanted to research and explore this topic. Various suggestions were made both from within the inquiry group and from my own supervisory team including:

- Exploring the portrayal of people living with dementia in the media including television and film.
- Exploring how people living dementia are represented in news media with a focus on language.
- Exploring how dementia is viewed in society and working alongside local groups, nurses or journalists.

It was during a consultation meeting in April 2017, that one of the co-researchers, Lesley, suggested the idea of developing the group's own experiences of living with dementia and stigma into a script. Further discussion on this idea ended in a group agreement that the members of the inquiry with dementia or their care partners would collate their experiences of living with dementia and I would combine these experiences into a script that we would then work on together. In discussing our initial ideas around stigma, it became evident that although there were negative experiences that the co-researchers had experienced in living with dementia, there were also positive experiences and it was agreed that the members of the inquiry group would collate both. At this preliminary stage, various ideas of what we would do with the script were expressed including making it into a video or putting on a live performance, but no firm decision was made on this until after ethical approval was gained and the research had officially begun.

3.8.5 Roles

Roles within a co-operative inquiry must be considered early on in the process. Leadership can be rotated, or one or two people can take a facilitator role (Reason and Heron, 1996). Within this co-operative inquiry, I naturally took the role of facilitator as the initiator of the inquiry. The fact that I had an additional goal beyond that of being part of the inquiry, but to also produce a doctoral thesis, was also a consideration in my role as facilitator. In this role, I arranged by mutual agreement the time and date of the meetings. I booked the rooms and arranged refreshments and sent reminder emails to all members of the inquiry. Collating the groups' experiences of living with dementia into one document was also a task in my role. Within the remaining members of the inquiry, no additional supportive roles were taken on although they remained full co-researchers and participated in generating ideas, sharing experiences and knowledge generation. An additional role that was introduced towards the end of the inquiry was that of an external provider, in the shape of the animator who supported us with the production of an animation. A semi-structured interview was conducted with the animator, at the end of the animation process to gather their perceptions and experiences of being part of the inquiry which is discussed within the findings chapter. The introduction of this external influencer and their contributions to the inquiry will be explored in the next chapter.

3.8.6 Ground Rules

Ground rules are helpful within an inquiry group, particularly to identify and protect any confidences (Reason and Heron, 1999). Having ground rules in place can help achieve beneficence and non-maleficence within an inquiry group (Tee and Lathlean, 2004). Ground rules also contribute towards the production of a safe space where individuals can feel free to talk openly without judgement (Kisfalvi and Oliver, 2015). This is particularly relevant considering our chosen subject of stigma, which can produce an emotive reaction when being discussed. The ground rules were identified and developed by the group as a whole in the consultation stage of the inquiry and consisted of the following:

- Listen when others are talking.
- Give everyone a chance to speak.
- Take a break whenever you need one.
- Keep an open mind.
- Be constructive in feedback.
- Have fun!

Although these ground rules appear very straightforward, it was important to ensure these were in place at the beginning, so all members of the inquiry group felt safe and comfortable. It was interesting that the last rule was 'Have fun!' which I feel really captured the ethos of the inquiry group throughout the research process.

3.8.7 Writing

Reason and Heron (1996) advocate for deciding early on in the process who will be writing about the work and in what format. All members of the inquiry group were encouraged to write about their experiences and the amount of writing that contributed to our script varied from individual to individual. The co-researchers had the option to keep either written or audio diaries to record their experiences of living with dementia and their reflections on the research process. Written diaries were chosen by the co-researchers to record their experiences of living with dementia, both positive and negative. The use of diaries to collect data is not new to dementia research and Bartlett (2012) describes the diary method as a way for people living with dementia to engage "*as equal partners in the data-gathering process*" (p. 1724) and ensures the visibility of the whole person. As the facilitator of the group, I found myself being the one who collected and collated the data and presented the data back to the group for analysis and further action cycles. The co-researchers retained their diaries so that they were able to share only the stories and experiences they were comfortable with. During our inquiry meetings, I had a password-protected laptop with me and would type the experiences that were shared into a word document. The co-researchers all had access to email accounts and also had the option to email me directly with the experiences that they wanted to share, and some chose to do this between the inquiry group meetings. I would frequently share the updated word document with the inquiry group via email between meetings to allow the co-researchers to reflect on the experiences that had been gathered. I would also print hard copies and bring them to our research meetings to ensure everyone had access to the data.

I plan to publish some of this work in peer-reviewed journals and have obtained consent for the members of the group to be identified as co-authors in this work in line with the recommendations from Reason and Heron (1996):

> *'We have found it helpful to adopt the rule that anyone can write whatever they like about the group, so long as they state clearly who was the author and whether other group members have seen and approved the text'* (p. 8).

The planning, development and writing of this thesis is a key component of this doctoral study but not necessarily an integral part of the co-operative inquiry. Therefore, the other members of the inquiry group have not contributed directly to the writing of this thesis, although their thoughts and contributions to the co-operative inquiry are a key feature and I have aimed to acknowledge this within my own writing.

3.9 Ethics

As this was an empirical research study that involved human participants, it was essential that ethical consideration was exercised to protect their rights (Polit and Beck, 2012). This section of the thesis will look at the ethical approval process and consider key components such as privacy and consent and will also describe the challenges faced in carrying out this kind of research. As this co-operative inquiry formed the basis of a doctoral project at the University of Manchester, approval was first sought from the University as the study sponsor. After this was gained, an application via the Integrated Research Application System (IRAS) was submitted for ethical approval from an NHS Research Ethics Committee (REC). NHS ethical permission had to be sought as Open Doors is funded by Greater Manchester Mental Health NHS Foundation Trust and therefore the co-researchers are positioned as users of NHS services.

3.9.1 Privacy and autonomy

Research with people living with dementia can sometimes involve people living with dementia who are not aware of their diagnosis (Alzheimer Europe, 2012). The people living with dementia, who were all recruited from Open Doors for this study, had an awareness of their diagnosis and were comfortable discussing issues around their condition. I ensured privacy for all who took part and, ensured that the group members were all aware that should they wish to be anonymised for any part of the process or choose not to take part in any stage, that was their choice. To further facilitate a ‘safe’ space, I ensured that my fellow co-researchers were aware that they could speak with me privately if they had any concerns or worries about group activities so that I could address them as facilitator. As the co-researchers were part of the Neighbourhoods and Dementia study, they also had access to a clinical psychologist as part of work programme 8 (see https://sites.manchester.ac.uk/neighbourhoods-and-dementia/work-programme-8/ for more information). The role of the clinical psychologist in this setting was to provide emotional and psychological support to all researchers, co-researchers and participants in the Neighbourhoods and Dementia study and self-referral was available to ensure privacy and confidentiality. This service was built into the information sheets and consent forms as part the NHS research ethics study design/permissions.

3.9.2 Capacity and Consent

Informed consent is when an individual has enough information about research and is able to understand that information, in order to make a voluntary choice to decline or consent to participation in the research (Higgins, 2012). The Mental Capacity Act (2005) states that it should be assumed that a person has capacity unless there is evidence that they do not. This evidence can include being unable to retain information or being unable to communicate their decision. Being unable to understand, retain or communicate information is a potential ethical issue when working with people living with dementia due to the neurodegenerative nature of the condition

(Higgins, 2012). If the individual is not capable of giving consent, then it may be sought from a legally authorised representative (Sherratt et al., 2007).

It is recognised that gaining informed consent from a person living with dementia or gaining consent by proxy *only* at the start of a research study, is not an ethical way of conducting research with people living with dementia (Hubbard et al., 2003). People living with dementia may have capacity to give informed consent at the beginning of the research but may not retain this capacity through the length of the study. The process consent method requires researchers to establish the basis of informed consent and gain initial consent, but also continually reassess the capacity of people living with dementia throughout the research process (Dewing, 2007). Process consent considers informed consent as a continual cycle throughout the research process (Dewing, 2007) and allows participants to collaborate with researchers in the decision-making process regarding continued involvement (Polit and Beck, 2012). The process consent method is described as having five key features:

i. Background and preparation
ii. Establishing the basis for capacity
iii. Initial consent
iv. On-going consent monitoring
v. Feedback and support
(Dewing, 2007, p. 15).

Dewing (2007) describes these elements as being non-linear and fluid depending on research context. This method of process consent allows for capacity to be continually assessed and for the researcher to critically self-reflect if the question of whether the person has capacity is not straightforward.

The process consent approach was adopted for this study and I used this model to continually assess the capacity of my fellow co-researchers to take part in the process. Consent to take part in this inquiry was formally taken for each co-researcher living with dementia in the first meeting after ethic approval was granted and capacity at this time was formally assessed using the British Psychological Society's structured capacity assessment form (see Appendix 6). Capacity was then assessed, and consent obtained in later meetings in a much more informal capacity.

Formally assessing capacity and gaining consent at each individual meeting would have been an intrusive process for those co-researchers living with dementia and would also have significantly impacted the time we had together as an inquiry group. Therefore, when following the process consent model, I adopted a much more informal questioning approach to assess capacity and gain consent. I would question their understanding of the project with regards to what we had already achieved and what we hoped to achieve in the future, whilst ensuring they wished to remain a part of the co-operative inquiry and had no concerns about their continued involvement. This was then detailed in my field notes.

3.9.3 Research Governance

This study was not a clinical trial or intervention and did not aim to place any burden or discomfort on the people participating in the research. There is a risk that the people taking part in the study could have become distressed in discussing their experiences. If this had occurred, then I planned to liaise with either a relevant key worker or next of kin to ensure the person living with dementia was supported appropriately. The next of kin or keyworker, such as a support worker or registered nurse was identified during the recruitment stage by liaising with the person with dementia and the service manager for the Open Doors Services, when necessary. The distress protocol was in place to ensure appropriate support was given and whether their continuation in the study would be appropriate.

Safeguarding is the responsibility of everyone; therefore, if anyone disclosed anything that caused concern, I would follow local policy in Salford for safeguarding adults by reporting to the appropriate authorities. I ensured that the co-researchers were aware that confidentiality may have been broken and information may have been shared if there was a risk of harm. I also planned to liaise with the supervisory team for further support and guidance should any incident have occurred which may have caused harm or distress. As this study is part of the Neighbourhoods and Dementia study, the co-researchers and participants also had access to a clinical psychologist for support via work programme eight, which ran as a well-being service.

The research took place in public spaces such as the Humphrey Booth Resource Centre and the University of Manchester lone-working policy for postgraduate students was followed. Furthermore, there was the issue of support, which was also identified in the themes from the literature in Chapter Two. I ensured that the individuals recruited to the inquiry group were aware that they could bring personal support to any of the meetings.

Research with people living with dementia can sometimes involve people living with dementia who are not aware of their diagnosis (Alzheimer Europe, 2012). The people living with dementia, who were recruited as co-researchers to the study were all aware of their diagnosis and were comfortable discussing issues around their condition. However, I ensured privacy was an option for anybody taking part and, should they have decided to be anonymised for any part of the process or choose not to take part in any stage of the inquiry, then the co-researchers could make that choice at any time. No information about a co-researcher was revealed by the chief investigator to any third party (other than for the purpose of data collection and analysis, or risk of harm) without their written permission.

I was the primary custodian of the data. The data could also be accessed by members of the academic supervision team and by individuals from the University of Manchester, the NHS and regulatory authorities for the purpose of monitoring and auditing.

All confidential material including consent forms, reflective notes, transcripts, and audio material was locked away securely within the University of Manchester or stored on password protected computers. As I travelled to a site outside of the University for the purpose of this study, any written or audio-recorded data was stored on a password-protected portable hard-drive, encrypted by the University of Manchester.

3.9.4 Challenges in the ethics process

Gaining ethical approval for this study was not a straightforward process. Having gained sponsorship approval for the study from the University of Manchester, I proceeded to apply for the study to be reviewed at an NHS Research Ethics Committee (REC) meeting in London. As the research could have potentially included adults lacking capacity and the methodology was strongly placed within the qualitative paradigm, I ensured to select a REC that had knowledge of these fields.

Despite this, the submission and protocol were initially rejected by the REC based in London (see Appendix 7). Unfortunately, little evidence was given as to why the application was rejected, but it may have been because I had originally wanted to include people who may lack capacity at the beginning of the research. I had also included a section on patient and public involvement (PPI) in the research protocol which may have confused the committee as this was not PPI but co-research. On the 21st July 2017, I attended this initial ethics meeting with a member of my supervisory team and found it a particularly difficult experience. Despite this initial REC being categorised as having qualitative research expertise, the committee had a difficult time understanding the methodology and the important part the co-researchers had to play even though some of the co-researchers were living with a diagnosis of dementia.

Together with my supervisory team, I had a strong belief that the research the inquiry group wanted to conduct was valuable and ethically designed. I also felt a compelling sense of responsibility for the established group who were ready to start data collecting. With some minor adjustments to the research protocol, I submitted my protocol again but to a different committee in Wales, which had the same specialisms of qualitative research and adults lacking capacity. As the people living with dementia in the inquiry group had capacity, I removed the request to include people lacking capacity. I attended the research ethics committee meeting in Wales on 6th September, again accompanied by a member of my supervisory team. Despite removing my request to include people who may lack capacity, I successfully argued that should those people living with dementia in the group lose capacity during the process of the inquiry, they should be able to remain in the study. I felt this was an important part of the ethical approval process as their contributions would still be valuable and it would be both unfair and unethical if one of the co-researchers still showed an interest in being part of the inquiry yet had lost capacity to consent. Therefore, approval was given for anyone who no longer had capacity to consent to remain in the inquiry providing they still showed an interest in taking part, a consultee could consent for them, and that they showed no signs of distress. Ethical permission was therefore now in place to conduct the co-operative inquiry reported in this study and to use the real names of people living with dementia and their care partners should this be desired, and, in this case, all co-researchers wanted to be known by their real names. The ethics committee letter providing approval to conduct the study is provided in Appendix 8.

3.10 Data Collection

3.10.1 Observations and Field Notes

Within this co-operative inquiry, I used field notes and observations to record the inquiry and research process. Observational research is a type of non-experimental research that entails the examination and analysis of an individual's behaviour (Cuttler, 2017). Observational research can be conducted without intervention (naturalistic observation) or with some sort of intervention (Zechmeister and Zechmeister, 2009). Participant observation occurs when the researchers become active members of the group they are studying (Cuttler, 2017) which was the case in this study but was also the intent. Participant observation can be disguised or undisguised, disguised being when the researchers conceal their identity and purpose in joining the group and undisguised in where they reveal their intentions. In this study, the observation was undisguised as not only is it a part of the co-operative inquiry to be a fully integrated member of the group, but it would be unethical to observe people in this context without their consent. Although it can be argued that disguised participant observation is less susceptible to reactivity than undisguised observation (Cuttler, 2017), it involves a form of deception which would not be in keeping with co-operative inquiry framework.

A main benefit of participant observation is that the researcher is situated in a way to understand and explore the experiences of the individuals and the research process, although it should also be highlighted that when people know they are being observed, this in turn can alter their behaviour (Cuttler, 2017). In this study, the co-researchers were all aware that I would be observing them as part of the co-operative inquiry in order to report our findings and but also to report how the group was facilitated. I took notes openly and from my perspective it did not appear to affect the operations and behaviours of the group. I could postulate that this was because each of the co-researchers had been involved in research before where they were observed, but I also feel that a safe space was created and that the relationships between myself and the co-researchers was one of honesty and openness.

The field notes were recorded in my own written diary and included relevant observations from our inquiry meetings such as quotes from the co-researchers and observations from the meetings. These observations included: how the inquiry group reacted to changes of setting such as when we couldn't hold our meetings in our regular spaces; if there was any noticeable friction in the group; and how the group reacted to new people attending our meetings such as the animator. I would also record relevant observations of the behaviour of the group such as their use of humour. These field notes were often recorded during the inquiry meetings, however I would also take time after each meeting to reflect on my role as the facilitator and what worked well along with what I would change in the future. Recording these field notes was an important reflective tool and helped to develop my critical subjectivity as part of the co-operative inquiry process.

3.10.2 Semi-structured Interviewing

To support my own observations from the co-operative inquiry and to facilitate the inclusion of external partners, I interviewed the animator who developed the final action output of the inquiry group. Interviews can be time consuming, challenging and laborious, however, they enable the researchers to collect detailed information on perceptions and views of a person’s experience (Addo, 2014). The interview took place via the telephone as the animator was based in another city and there was no financial recompense for taking part in this activity, therefore it made sense for logistical and resource reasons. The interview comprised of four open questions that allowed the participant to talk freely and tell their story in their own words. Prompts were also used as necessary (see Appendix 9). This allowed me, as the interviewer, to gain all potential data and the participants the freedom to express themselves in whatever way they feel is right (Polit and Beck, 2012). The interview was recorded on a Dictaphone, with permission from the participant.

After the data was recorded it was transcribed, by myself to maintain confidentiality. In the transcription, the participant was given a pseudonym of ‘the animator.’ This allowed the transcription to retain that human characteristic, yet protected confidentiality and allowed the participant to remain anonymous. The data from the interview was used to support and evaluate the findings in Chapter Five.

3.11 Data Analysis

Thematic analysis was considered for this doctoral project as it fits well with the qualitative nature of the research and exploration of human experience. Thematic analysis is the search for themes in human experience (Luborsky, 1994) and can be conducted in a number of different ways (Braun and Clarke, 2012). The flexibility in the approach of this method was particularly useful in working with people living with dementia as there is not a rigid, prescribed method to follow. The use of thematic analysis has also been utilised in other projects that involved a co-operative inquiry (Hostick and McClelland, 2002; Tee et al., 2007).

As this research was not being carried out with co-researchers trained in analytic techniques, the group could not adopt a rigorous analysis method such as Braun and Clarke's (2006) six phases of thematic analysis. However, as we moved through the inquiry process, it became evident that the group were identifying broad themes using an inductive approach and the themes were derived from what was actually in the data as opposed to applying concepts and ideas to the data in a deductive approach (Braun and Clarke, 2012).

The data that I collated on the word document was shared with the group at regular intervals during the inquiry process and the group was encouraged to reflect on and analyse these experiences between meetings and then bring their findings to the rest of the inquiry group. Avoiding the use of technical jargon and complex research skills such as coding, we would discuss overall concepts and ideas that were appearing in the data that was collected. Further discussion of the identified themes is presented in Chapter Four in the context of the timeline when the themes were identified.

3.12 Summary

This chapter has discussed the methodological approaches taken in this study and explored some of the key features of participatory research and co-operative inquiry. Whilst it has a long-established history, co-operative inquiry is an emerging methodology in the field of dementia research. The flexibility of co-operative inquiry allows for it to be adapted to suit the goals of the group and is an appropriate choice of methodology for this research. As the key feature of co-operative inquiry is research 'with' rather than 'on' people, it will assist in the goal to ensure the voice of people living with dementia is heard in a transparent and humanistic manner and will also allow for an exploration of how this inquiry was facilitated.

Following the presentation of the theoretical framework of co-operative inquiry, this chapter described the initiating and establishing of a co-operative inquiry with a group of people living with dementia. A brief discussion explored the decisions made during the consultation meetings before consideration of the ethical issues and challenges that were encountered in approaching this co-operative inquiry. Chapter Four will now explore the inquiry processes that took place during the 12 co-operative inquiry meetings that occurred after ethical approval was granted.

Chapter Four: Inquiry processes

4.1 Introduction

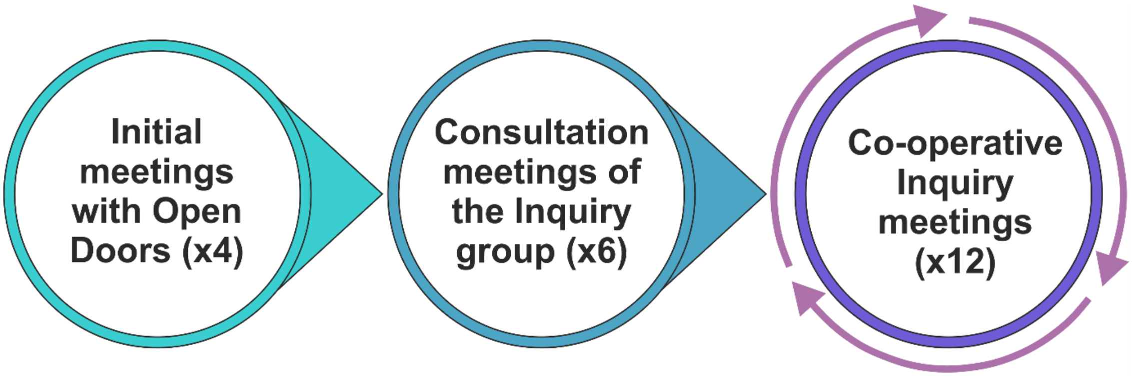
Co-operative inquiry involves cycles of action and reflection (Heron, 1996; Heron and Reason, 2006) over four distinct phases. These phases will now by explored with consideration of the co-operative inquiry that took place. This chapter is a discussion of 'what the group did' following ethical approval with 'how the group did it' to follow in the next chapter. The co-researchers will be introduced followed by a discussion of the twelve research meetings. The discussion of the individual research meetings will include my own reflections on the research process in line with the co-operative inquiry concept of 'critical subjectivity' and will consider the four ways of knowing that are an integral part of the co-operative inquiry process. In a co-operative inquiry, our knowing has its foundations in our experiences, which is then communicated through stories, images, and other creative means; understood through ideas and theories which make sense to us and expressed in meaningful ways or actions in our lives (Heron and Reason, 2001, 2008). The inquiry skills and validity procedures of co-operative inquiry will also be referred to throughout this discussion In agreement with the co-researchers, I arranged for six meetings to be held on a fortnightly basis until the end of 2017, with a further six meetings to be held on a monthly basis in 2018. The chapter will conclude a critical analysis of the data collection method that was used.

4.2 Moving into the inquiry process

In the establishing phase, we had created an inside inquiry, where the nature of our research would take place within our inquiry meetings when we met as a group. The inquiry group decidedly adopted a Dionysian approach to allow for creativity to flow and as we moved through the cycles of inquiry it became apparent that we had both transformative and informative elements to our research. As I was now immersed as co-subject in the inquiry, the inquiry was what Heron (1996) calls a partial-form inquiry.

As it took some time for the inquiry group to be formed and a co-research plan put in place, it was agreed that the group would meet every two weeks over a six-month period (July 2017-December 2017). Unfortunately, due to delays in gaining ethical approval, which was discussed in the preceding chapter, the actual research did not commence until September 2017. Meetings were held fortnightly for the remaining three months of the year and then, with agreement from the inquiry group, were held monthly until the end of June 2018. In total, 12 meetings were held with the co-operative inquiry group after ethical approval was granted (see Figure 6). These meetings took place over two hours on mutually agreed days and times, with time for comfort breaks and refreshments as mirrored in the initial meetings.

Figure 6: Initiating, establishing and inquiry meetings of the co-operative inquiry.



4.3 The co-researchers

To give further depth to this inquiry, each member of the group or co-researcher is introduced and presented below with their own personally written overview. Their pictures were drawn by the animator that we worked with later in the study. These are the co-researcher's real names as agreed in the ethics protocol and with the co-researcher's consent.

4.3.1 Lesley Calvert

I was diagnosed five years ago with Alzheimer's. I had to give up my job as a district nurse but my life was not finished so I decided to do anything I could to help the general public realise that we can still live well after a diagnosis of dementia. So I will speak to anybody who will listen. I have also helped with a good life festival which was a joint enterprise with Salford University and Alzheimer's society, and help educate trained and untrained nurses understand what life is like for people living with dementia.

4.3.2 Jim Cootes

I have lived in Salford my whole life, except for a short seven year stint living in South Africa. I cared for my partner who had dementia for five years before she moved into a care home. I stay involved with Open Doors as I am keen to raise awareness of dementia.

4.3.3 Sheila Crossley

I was a carer for my husband for seven years until his death two days later before his 80th birthday in January 2017. Belonging to various dementia groups and research programmes has helped me through some difficult times and I have made friends with people I would never have met.

4.3.4 Margaret Jones

Dementia has been part of my husband Wilf and I's lives for over 10 years. When my husband was first diagnosed there was not many services available to support us but now our voices are being heard and things are changing.

4.3.5 Wilf Jones

Having had a very busy and interesting social working life at Manchester University, after retirement, it was difficult to adjust. Dementia then came into my life and another chapter began with dementia cafes and research. There are many more chapters to write. The new chapter is made by taking part and being a member of a wide and interesting group of people, both socially *and through taking part in research. These people are very sincere and committed to research and improving existing services and raising awareness.*

4.4 Phase one of the inquiry

Phase one involves planning the inquiry, what will be explored and how the group will do this (Heron and Reason, 2006). After the group had been established, the group had to decide collaboratively what topic the group would be exploring. As discussed in the previous chapter, it was evident that stigma was a topic which the group felt passionate about exploring as people living with dementia; not only as people with a diagnosis of dementia, but those who are the care partners of people with a diagnosis.

Although the group knew they wanted to explore the concept of stigma and wanted to use the group's own experiences in this inquiry, the group did not at first know what to do with this data. It was from the suggestion of a member with a diagnosis of dementia, Lesley, that the group decided to produce a play-script with the goal of putting on a performance to share what the group had discovered.

4.4.1 Week 1 – 28th September 2017

This first meeting after ethical approval was granted, was not held in our usual meeting place of the Humphrey Booth Resource Centre, due to work being completed in the building. This led to our first practical challenge in securing another venue that was familiar to all members of the inquiry group but was still free to use and provided refreshments. Lesley had suggested at one of our initiating meetings that Pendleton Gateway would be an appropriate place as it was easily accessible by car and public transport and was free to use for the local community. I was able to book a meeting room at Pendleton Gateway and the group agreed to have our research meeting there on this one occasion. Pendleton Gateway did not provide catering, so I planned in advance to bring snacks along and was able to purchase hot refreshments for the group on the day.

As I arrived in what was an unfamiliar environment for myself, I met Jim and Lesley in the reception area. Our room for this week was a simple meeting room but a perfect size for the six of us with everyone being able to sit around the table and be heard by all parties. This first week primarily consisted of considering the operational and practical side of the co-operative inquiry.

All co-researchers were present at this first meeting. I sensed an air of excitement and keenness to get on with the research after our ethical delays, but it was important to address the essential parts of the research process in assessing capacity and gaining consent. As the facilitator, time was spent with each member of the group going through the participant information sheet and consent forms (see Appendices 10 and 11) one to one in a private area away from the meeting room to ensure the co-researcher's had time and space to ask questions. The co-researchers had been sent these forms in advance to review in their own time before being asked to sign the consent forms with myself at this meeting. As the five co-researchers had been integral parts of initiating the inquiry, they were all familiar with what it was that the group hoped to achieve but this time also allowed me to ensure that all members of the group had capacity to proceed with the research. I used the British Psychological Society capacity assessment forms in this first phase as a tool for recording and assessing capacity (see Appendix 6) but moving forward using the process consent approach (Dewing, 2007) as described in Chapter Three. This was recorded in my observation notes. In keeping with the Mental Capacity Act (2005), and as described in Chapter One, each member of the inquiry group was deemed to have capacity unless suggested otherwise. As two members of the inquiry group had a diagnosis of dementia, it was good practice to assess capacity formally at this stage.

All of the co-researchers were assessed to have capacity to take part in the research and consent was given from each individual. It was interesting to note that the co-researchers with a diagnosis of dementia had no obvious concerns in having their capacity assessed ensured it was a transparent process and that I was clear about what I was doing and why. However, it was apparent that they had taken part in capacity assessment procedures before and were unphased by the process. This reminded me that the co-researchers may not have been experienced researchers, but they were experienced participants and had taken part in dementia research before. As a registered mental health nurse, I had taken part in formal capacity assessments with 'patients' or 'service-users' but never in the role as a facilitator or as part of a co-operative inquiry. I was conscious of respecting aspects of the research process that had to be addressed whilst not imposing a paternalistic approach to the actions. This could be considered as 'radical practice and congruence', one of the inquiry skills suggested by Heron and Reason (2006). In me being aware of my actions and my motives for these actions, I can address any incongruence and make adjustments if necessary. *Practical* knowing is essentially knowing how to do something, expressed through competence or skill and the process of assessing capacity with the co-researchers, in this first meeting of the co-operative inquiry, was a new form of practical knowing for me.

A further feature of phase one is deciding how the data will be collected:

> *Finally, in phase 1, they devise and agree a set of procedures for gathering and recording data from this experience: diaries, self-assessment rating scales, audio or video recordings, feedback from colleagues or clients, etc.* (Heron and Reason, 2006, p. 4).

As the co-operative inquiry included periods of reflection, the group was encouraged to use diaries to record their thoughts, feelings and concerns about taking part in the project as well as their personal experiences of stigma and living with dementia. Adopting the methods as described by Bartlett (2012), the group was able to choose a method of diary-keeping that suited each member individually. They were given a choice of a written or audio diary; however, all members of the group decided to use a written diary. As the inquiry group had decided that they would explore the experiences of living with dementia with reference to stigma, the co-researchers agreed to take their diaries home and record their experiences to share with the rest of the group at the next meeting. I ensured that each co-researcher understood that they should only share experiences they would be happy sharing with the group and ultimately members of the public with our goal of developing it into a playscript. The diary could be used as reflective tool and if the co-researchers chose to write down any experiences that they did not want to share, this was acceptable and part of the research process. I also advised that should any members of the group have any questions or concerns that they could contact me by email or telephone at the university before our next meeting. I did not use my personal telephone number or email address to maintain appropriate boundaries.

Assessing capacity and gaining consent took time, so I had anticipated that the co-researchers may have felt that not much had been achieved in this first meeting, but I ensured to explain that at our next meeting, we would move on to gathering data and beginning to reflect on their experiences. However, on reflection, I noticed that none of the co-researchers were expressing any frustration at this meeting which centred on practical actions and that there was a sense of relief in the air in that we could finally proceed with the research. I looked forward to our next meeting where the co-researchers would begin to share their experiences of living with dementia.

4.5 Phase Two of the inquiry

Phase two is where traditionally the group would apply the actions in their everyday lives (Heron, 1999; Heron and Reason, 2006). However, as this co-operative inquiry was an inside cycle, where the actions took place within the group (Heron and Reason, 2006), it did not follow the traditional co-operative inquiry format. Members of the group between the meetings recorded their experiences of living with dementia and brought this back to the group for discussion and reflection as reflected in the rest of the chapter.

4.5.1 Week 2 – 19th October 2017

Our second research meeting took place at the Humphrey Booth Resource Centre, a fortnight after our first research meeting. Our first six meetings took place fortnightly as the group were keen to proceed with the inquiry and produce some data after the previous ethical delays. At the Humphrey Booth Resource Centre, we had a large meeting room every week but as there was only six of us, we would gather at one end of the large table which sat centrally in the room. Fruit and cake was pre-ordered and were present in the room prior to arrival and tokens were available for the co-researchers to choose and make their own hot drinks at any time during the meeting. I often noticed that certain members of the inquiry group really enjoyed making their own drinks at their own leisure and I felt this kept an open and friendly air to the research process. I always ensured to arrive early to these meetings but would quite often arrive to some of the co-researchers already being present. The Humphrey Booth Resource Centre had a café which served hot and cold lunches and some members of the inquiry group would often come early for lunch before the beginning of our meeting at 1 p.m. The co-researchers always appeared relaxed and at ease in the Humphrey Booth Resource Centre which reinforced to me that it was a suitable location.

At this second meeting, we began to gather and share the lived experiences of the co-researchers. At this meeting, two co-researchers, Lesley and Sheila, shared their experiences:

> ‘*Well, four years ago I was diagnosed with Alzheimer’s. Alzheimer’s has a stigma. People forget ME. The Person. My first time of experiencing the stigma of my condition was not long after my diagnosis. I went into a big store. Knowing I had a problem with money, I made sure I had the right money but when I was I just about to pay I released I needed something else. I asked the sales lady for the item I needed. Trying to calculate the money I needed which took me a while. The sales woman tutted, said to the lady behind ‘I’m sorry* ***she*** *is keeping you waiting. This caused me more stress. So I got all worked up and dropped the money I had out, all over the floor. Which I then had to pick up before paying. My husband who was with me was furious. He said if she had a little more patience this would not have happened and the group would not have felt humiliated.’* (Lesley – diary extract)

Lesley shared her experience with real passion, and I noticed how the group shared in her emotion with nodding heads and murmurs of agreement. Lesley felt strongly that with a little time and patience from others around her, she would not feel stressed or feel stigmatised. This experience and reflecting on it, also inspired Lesley to write a poem:

Stigma

S: the Start of our dementia story
T: the Trouble the group have with our memory
I: for Incidents the group cope with daily
G: to Give us a little more time
M: the Message the group send to you
A: the bad Attitude the group have from a few

This says STIGMA, a word not very nice
A word the group have to cope with, that has come into our life
Please be patient and think of our feelings
For as you know, the group like are human beings

(Lesley – via email)

The inquiry group discussed how dementia is a condition that is not obvious, there are no physical signs or clear indications that someone is living with dementia. The co-researchers spoke passionately about how education was so vital to allow the general public to understand and have some awareness of the condition and how our playscript would hopefully do that. Sheila also shared an experience that she had with her husband, noting that she actually could not think of any negative or stigmatising experiences of living with dementia:

> '*On a warm and sunny day sitting by the lake in Southport, my husband who had Alzheimers decided he would like an ice cream. He insisted on going on his own and as the ice cream van was only two hundred yards away I did not think there would be a problem. How wrong I was!*
>
> *When I saw other people passing with ice creams I realised he was missing and as he had taken off his jacket he had no ID on him. I must have looked distressed because a couple passed and asked if I needed help.*
>
> *They took one path while I took another. After about 20 minutes they found him still holding my ice cream. I was so relieved to see him and so grateful to these strangers who stopped to help.'* (Sheila- diary extract)

What was becoming evident as the group gathered this data, was that although there were many negative experiences, there was also many positive experiences of living with dementia. It was particularly interesting that Sheila could not think of any negative experiences of living with dementia when we had decided to research the subject of stigma. This began to shape our thinking and the group's development of experiential knowing: what we know from our own perceptions and experiences through encounters with people, places or things. This can be seen as the foundation of our research project in the lived experiences of people living with dementia. These experiences were what brought the group together and developed a recognition of both positive and negative experiences of living with dementia. As the facilitator, I could see the development of the validity procedure of 'authentic collaboration' (Heron and Reason, 2006). As an inside inquiry, our actions took place within the inquiry group meetings and I could see that all members of the group were engaging collaboratively in the research process. As a facilitator, without any experience of living with dementia, I also felt I was developing a deeper form of empathy and attunement with the group is hearing their stories and seeing their agreement on the types of experiences that they all had encountered. This would be recognised in the inquiry skill of ‘being present and open’.

The inquiry group were also developing a further form of practical knowing at this stage in the keeping and recording of their experiences in their diaries. None of the co-researchers had been asked to record their experiences in this way before for research purposes. A few members of the group admitted that they had forgotten to use their diaries, but I ensured to reinforce that this was a voluntary process and that the nature of the inquiry meant the majority of the actions and reflections would take place during our group meetings. The co-researchers could contribute at any time, as little or as much of their own experiences as they felt comfortable and we had several meetings to gather our data. This explanation appeared to offer the reassurance required at this time and we agreed that for the next meeting, the members of the group would reflect on our discussions from today and gather any further experiences that they think would be useful to our inquiry.

4.5.2 Week 3 - 2nd November 2017

In our third research group meeting, the group continued to share and explore the co-researchers experiences of living with dementia. This meeting took place in our usual venue of the Humphrey Booth Resource Centre. We began the meeting by reflecting on the shared experiences from our last meeting and I personally, reflected on what a rich amount of data we were beginning to produce. Another inquiry skill highlighted by Heron and Reason (2006) is that of ‘non-attachment and meta-intentionality’ and is a skill I reflected on frequently. This skill is viewed as the ability to not invest one’s identity and emotional security in the process whilst remaining fully committed to it and I was always consciously aware that this study was being a carried out as a doctoral study where I had an end-goal and an emotional and practical investment in the research. I attempted to be as congruent as possible in my reflections to the group in that I genuinely felt the inquiry group was developing a rich and vibrant amount of data but did not want the co-researchers to think that this was a ‘creation’ for the doctoral study aspect of the research. The co-researchers were made aware that this co-operative inquiry was for postgraduate research at an early stage and I believe that whilst being critically subjective of my actions, I had built a level of trust and honesty with the inquiry group where was no perceived alternative agenda and the co-researchers were fully immersed in the process.

After reflection, we moved on to discussing further experiences that the co-researchers had gathered before this meeting. Wilf and Margaret, who are a married couple shared a story about Wilf getting lost in Bolton which produced a lot of laughter as they cheerily argued over whose fault it was:

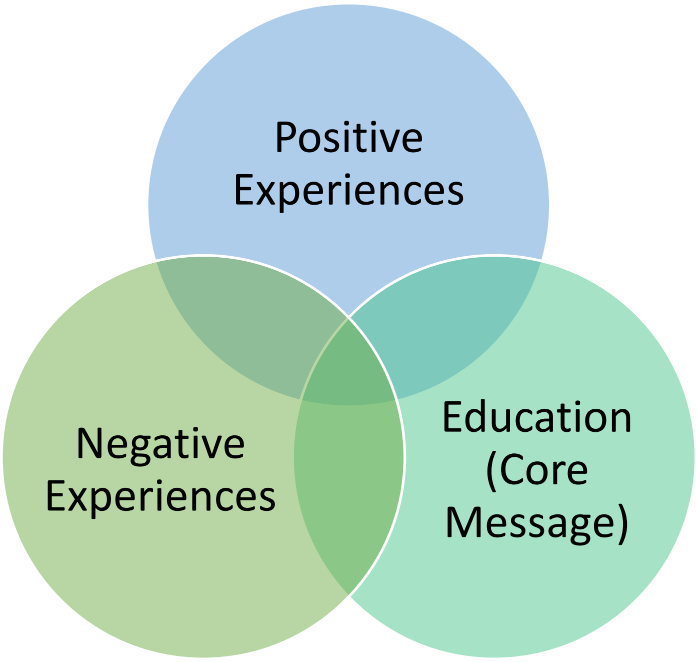
> *'The group were going to Preston to drop off our daughter to catch a train to Glasgow. It was a kind of misty night, and raining and it was winter so it was dark early. The group got to Preston after one or two variations of going round and round and every time the group went round the group kept passing Morrisons yet again. So the group got into the middle of Preston and all the traffic was congregating at it was about half five. The group were looking for the railway station and our daughter was in the back getting agitated and Wilf decided it would be better if he got out the car and looked for the train station. So he got out and he was gone! And just as he left the traffic started to move. The group then moved into the railway station and my daughter got out and took her case. I was thinking how am I going to find Wilf. I was worried about my daughter catching her train and worried about finding Wilf. I found four police cars and thought I could park there and maybe find a policeman. I went into the train station and spoke to the stall owners to get them to keep an eye out of Wilf. I left and could see through the big glass train windows Wilf walking along a platform with another man. When I eventually got there he had disappeared. He came through another door and started shouting at me! But the group found each other! In the meantime, our daughter had been texting me every minute to see if her dad had been found. By the time the group got back to the car, I had to get some petrol on the way home.'* (Margaret – diary extract)

It's something I have noted since the group formed was that people living with dementia often use humour in discussing their experiences and when I highlighted this to the group, I was quickly told that if they did not laugh, they would cry. This contributed further to our experiential knowing and in particular, my knowing as a facilitator. I had worked with people living with dementia in a professional capacity for a number of years, but this was nearly always in hospital or clinical community settings and rarely in a relaxed and informal environment, such as the one created by the inquiry group. Being a part of this inquiry, where the co-researchers were genuinely congruent and expressed themselves openly, particularly with the use of humour, instilled in me the wide variety of coping mechanisms that people living with dementia employ, without the influence of healthcare professionals and care partners.

Moving on the experience shared by Margaret and Wilf, the inquiry group had a further discussion around the proposed play script. Wilf noted that '*dementia itself is not a tragedy'* (field notes) which I felt was remarkably poignant and the group felt strongly that we should share both the negative and positive experiences in the script. The day before this meeting, I had met with a researcher with experience of creative writing, who had provided me with some helpful insights into the creative writing process. None of the inquiry group had any experience of writing a playscript before, so it was important for us to take advice and guidance from others. As the facilitator, I arranged to speak with this academic and then feed back to the co-researchers. The main advice I was given, was that our play script should have a message that we wanted to deliver to our viewers. The inquiry group needed to identify what they wanted the viewers to take away, to learn from the play. Reflecting back to the week before, the group felt that time and patience were a key message and that ultimately education was a key part of the development of this play script. The development of the script helped to develop our presentational knowing. This kind of knowing is a form of expression that involves different forms of imagery through creative means such as drawing, movement, sculpting etc. The inquiry group's presentational knowing is visible in what was produced from the research in the development of a script and the learning of new skills with regards to script-writing such as identifying a key message.

The inquiry group had naturally adopted a loose approach to data analysis that would be considered thematic analysis. From our discussions, the inquiry group collaboratively agreed on three broad themes: positive experiences of living with dementia, negative experiences of living with dementia and that the group had a core message that the group wanted to deliver to educate the general public (see Figure 7). These three themes were incorporated into the play script but in keeping with the co-operative inquiry process, we would continue to re-visit these themes throughout the research process. Revisiting these themes would also ensure that we addressed the validity procedure of 'reflection and action' which is a key part of the co-operative inquiry procedure but should be balanced (Heron and Reason, 2006). Balanced action and reflection ensures that the inquiry does not become solely a case of activism or oppositely a case of ‘armchair theorising’ (Heron and Reason, 2006, p. 18). By adopting these themes but continually revisiting them, the inquiry group aimed to keep this balance throughout the research process.

Figure 7: Core Themes of the Inquiry.



Interestingly, the original topic of stigma is not directly visible in these themes. Stigma is typically described as a loss of status and power, discrimination and includes the negative labelling of individuals or groups (Link and Phelan, 2001). The concept of stigma is well documented in the literature on dementia (Swaffer, 2014; Mittelman, 2013; Burgener et al., 2011) and is apparent in the ‘negative experiences’ theme but doesn’t retain a central position in the research.

It is argued that people living with dementia can sometimes choose to distance themselves from their negative experiences, as shame can be problematic, and can lead to negative self-perceptions such as loss of value and meaningless (Aldridge et al., 2017). However, I don’t believe this was the case in this co-operative inquiry. From my observations, the co-researchers were confident talking about their negative experiences of living with dementia but also felt that they had as many positive experiences as negative and wanted to highlight these too.

After identifying these themes, the inquiry group agreed to continue with reflection in between meetings and also gathering any further experiences. The group also decided to start considering what the core message of the script should be and bring any ideas to our next meeting for further discussion.

4.6 Phase Three of the inquiry

> *'Phase 3 is in some ways the touchstone of the inquiry method. It is a stage in which the co-subjects become full immersed in and engaged with their action and experience'* (Heron and Reason, 2006, p. 5)

This is also the stage where the co-operative inquiry may re-consider their original ideas. The group were beginning to produce a playscript with the goal of putting on a performance but as the inquiry group was a small number of six, it had to be considered if this was practically possible. In discussion with my supervisory team, I decided to suggest another way of presenting the script in an animation or video format.

4.6.1 Week 4 – 16th November 2017

We returned to the Humphrey Booth Resource Centre this week with each member of the co-operative inquiry in attendance. As the co-researchers started to bring their stories together, a rough script was developing. As facilitator, I had gathered the stories into a word document which although had no clear story or progression to it, formed the foundation of the script. I asked the inquiry group what their thoughts were with how we would deliver the script to the general public. Whilst two members of the group, Lesley and Sheila were still happy to produce and act in a play, when this was discussed further and an examination of logistics was considered, it was clear there would be difficulties. The group did not have a location or the funds to hire a venue to put on the play and none of the inquiry group had a background in theatre. I presented the idea of using a recording of our script, either with the co-researchers acting out the script themselves or using animation to tell their story.

The group spent this meeting looking at various videos and animations on YouTube. It was important here to practise the skill of 'bracketing and reframing' in trying out alternative ways of being creative in the research process (Heron and Reason, 2006). One of the animations shown was by an animator based in the North West, who had worked with the Division of Nursing, Midwifery and Social Work at The University of Manchester before and had produced animations for other groups of health populations such as people living with epilepsy and people living with mental health problems. One of my supervisors, Professor Penny Bee, had worked with the animator before and recommended his work. I felt comfortable taking the suggestions from my supervisory team to the group as this was a new process for us all and advice from outside parties was always welcome. The inquiry group really liked the animator's style of hand-drawing the animations and the sense that their story could be brought to life using animation. The group also felt that the animator's way of drawing would ensure their identity was visible throughout the animation. The co-researchers were enthusiastic in how accessible the animation would be and how it could be shown in schools, doctor's surgeries and shared publicly via social media to spread their message. The inquiry group were unanimous in their agreement that they would like to turn their script into an animation. I also employed the validity procedure of 'challenging consensus collusion' by adopting the role of being a devil's advocate and gently challenging the decision to adopt the script into an animation.

As Heron and Reason (2006) point out, the co-operative inquiry is not valid if one or two people dominate the group with suggestions and decision-making and I wanted to ensure that the decision-making here was a collaborative group effort. I understood that the co-researchers often looked to me as the facilitator in making decisions, but I reiterated that this was their work, their experiences and we should only treat and adopt their work in a way that they were all comfortable with. In keeping with the spirit with the co-operative inquiry I asked the group to take until the next meeting to think about, reflect and confirm their decision.

At our last meeting, the group had loosely identified three themes in the data they had collected so far and in keeping with this, Lesley had written a further poem about the positive experiences of living with dementia:

The Good Samaritans

When the group are struggling

And need a helping hand
There are some people out there
Who will go the extra mile
A few kind words a cheerie smile
Will make us feel much better
What this means to use
With words the group cannot explain
But knowing you are there
Will help us once again
So people who help us when the group are struggling
And people who go those extra miles
The group will call these people
The Good Samaritans
(Lesley – via email)

As a whole, the inquiry group felt that these poems should be included in our final output but were not sure how this would happen or if they would fit with the script. At this stage, the inquiry group decided to begin the script with the ‘Stigma’ poem and end it with ‘The Good Samaritans’ poem (see Appendix 12 for an early version of the script). The development of these poems further added to our presentational knowing, the creative demonstration of the inquiry group’s work. Looking forward to our research meeting, the inquiry group agreed to continue to reflect on the experiences shared and bring any further experiences they thought would apply to our identified themes. The co-researchers would also take time to reflect and think about turning the script into an animation and employing an animator who was identified earlier, to carry out this task. I agreed to make some enquiries about costs for an animation and also approach my doctoral funding body, the ESRC, for support with funding.

4.7 Phase Four of the inquiry

In this final phase, the members of the inquiry come together to explore their experiential findings and ideas which can then lead to a further cycle (Heron and Reason, 2006). In our case, the inquiry group had decided that they would produce an animation with their findings and thus a new cycle began of exploring how this would take place. I had approached the animator who had shown a keen interest in being involved and provided a provisional quote for a two-minute animation and I secured funding and approval for this from the ESRC.

4.7.1 Week 5 – 30th November 2019

This week, only two co-researchers were able join me for a research group meeting, Sheila and Jim and unfortunately, we were unable to reserve a space at the Humphrey Booth Resource Centre due to on-going building work so returned to the Pendleton Gateway for this meeting. We were in the same small but appropriately sized meeting room as before but a noticeable change this week was that the outside temperature had dropped significantly, and the room was not well heated. I had immediately addressed with the Gateway staff onsite and they had assured me the heating in the room was on but there was a significant chill in the air. As the facilitator, I apologised to the co-researchers for the cool temperature in the room, but they stated that they were happy to continue with our research meeting as there would be a steady supply of hot drinks. There may also have been a passing comment made by one of the co-researchers on the resilience of younger people in cold weather, but this was said with good humour and intentions.

Jim shared some of his own experiences of caring for his partner who was living with dementia but who was not a part of the group. Although these were incredibly powerful and emotive stories, the co-researchers felt that we could not include them in the script as his partner was not a member of the inquiry group and we did not have his partner's permission to include them so for these reasons it would not be ethically or morally right. Both Sheila and Jim had experiences of their partners living with dementia. As a group, we included Sheila's stories as they her own lived experiences of dementia and if her husband had still been alive, Sheila felt that he would have wanted to be part of the research. Jim's partner was living in a care home at the time and Jim was not a proxy for them so we felt in this case, it wouldn't be appropriate to include the stories that were in relation to a living person who would not be able to consent to their inclusion. I felt that I had to truly adopt the inquiry skill of 'being present and open' in this case, as I did not want

Jim in particular to think I was excluding his voice. I have also felt comfortable having difficult conversations with people as long as I remained congruent and empathised with the person, so I was happy to raise my ethical concerns in this circumstance.

On reflection, this may have been easier for me as on this occasion, as there were only three of us in attendance but there was no resistance to the discussion, and it was held in a safe space where everyone could express their views openly without judgement. In this circumstance, the ethical dilemma that was presented contributed to my own experiential knowing. As a registered mental health nurse, I am used to having difficult conversations with patients and service users, however, this was a conversation with co-researchers, individuals who are partners in this work and a situation I had not been in before. Adopting the empathic and open approach and seeing the positive reaction to this, certainly contributed to my own way of knowing.

It was very clear that like the other members of the inquiry group, Jim had both positive and negative experiences to share which reinforced the themes that the group had identified. Jim described living with dementia as a ‘rollercoaster’ and there was a developing idea of a journey coming through from those shared experiences. Sheila shared a further positive experience she had when she was admitted to hospital:

> *‘Following a fall breaking my wrist and injuring my leg, I was told I needed to be admitted to hospital to have a plate inserted in my wrist. I explained that I could not leave my husband as he had dementia and the staff nurse found a room with two beds so he could stay with me. A dementia nurse stayed with him while I had my operation. The group were treated with kindness and compassion, something I will never forget.’* (Sheila – diary extract)

Compassion was something that really stood out in these positive experiences and something the group considered taking forward in our core message. I shared with the co-researchers that I had approached the animator about working with us, and that the animator was keen to be involved. I also shared that I had secured further funding to allow us to go ahead if the inquiry group agreed. Due to financial constraints, and the cost of professional animation the script could be no longer than two minutes. I also explained that I would need to submit an amendment to the ethics board as this constituted a major change in what the group had been given approval to do.

Sheila, Jim and I agreed that we would wait until all members of the inquiry group had approved these steps before moving forward and applying for the ethical amendment.

4.8. Repeating the cycles – Producing a script and an animation

The cycle was repeated a further two times within our inquiry, one cycle for the production of the animation script and another cycle for the production of the animation. It is an important part of the co-operative cycle to have members of the group analysing and considering their original questions (Heron and Reason, 2006). It should also be noted that due to the cyclical nature of co-operative inquiry, data analysis began from the start of the inquiry and the findings continued to be analysed throughout the research process. This involved collaboratively writing and re-writing the script to ensure our three main themes were addressed but within the allocated time scale.

4.8.1 Week 6 – 7th December 2019

This was our final research group meeting of the year and a time to consolidate the data the group had gathered and decide on future plans. We had returned back to Humphrey Booth Resource Centre for this final meeting and all members of the inquiry group were present. The research meeting began with reflecting on the previous weeks, the gathered experiences and how we would proceed with the data that was gathered. I explained for the benefit of the whole group that I had secured funding for the animation, if the group was unanimous in their decision to proceed with the creation of an animation. The co-researchers were in agreement that the group would turn our script into an animation, and I ensured to check that the body language of the group was in align with the verbal agreements that were expressed. This again reflects the ‘authentic collaboration’ method of increasing the validity of the co-operative inquiry in ensuring that every member of the inquiry is engaged in the action and reflection phases. As the co-operative inquiry was an inside inquiry where the actions took place during the group meeting, the decision making was a collaborative and unanimous process.

The inquiry group decided to work with the animator identified earlier, as they expressed that they liked and appreciated his style and felt they would be visible in the animation in a ‘live-drawing’ form. The inquiry group also decided that they would narrate the animation themselves as opposed to using a professional voiceover artist in order to ensure their identity is embedded within the production. ‘Reflection and action’ is a key validity tool in co-operative inquiry and at this stage I felt we had a good balance of the two. The inquiry group had spent the previous weeks reflecting and developing our propositional knowing and then moved into more action-focussed phases where we developed our presentational and practical knowing.

With these agreements in place, we now had to ensure the script was only two minutes long and the inquiry group had to make some careful decisions about what was included and excluded. At this stage in the meeting, I noted a renewed air of excitement as we progressed with the research and a sense of purpose reaffirmed after weeks of collecting data. The inquiry group referred and reflecting back to our three themes of negative experiences, positive experiences and education. The co-researchers originally wanted to include everyone's stories but quickly realised on a read-through that the script would go well over our two-minute time limit. The inquiry group felt strongly that they wanted to include the three themes that had been identified so I suggested they include one negative experience, one positive experience and then our core message. I adopted the skill of 'radical practice and congruence' here as I was consciously aware of our time restrictions and also the purpose and goal of these actions. I ensured to come from a genuine place of acknowledging the experiences of all of the co-researchers and their contributions but also in accepting that we could not include a direct experience of everyone involved. I felt comfortable making the suggestion of one experience for each theme as I felt there was genuine rapport and trust built within the inquiry group. I was met with agreement from the co-researchers, but I did highlight that we should try and incorporate the experience of each individual although it may not be in the direct narration of their story.

We agreed that we would address the themes that had been identified but the challenge now would be ensuring that all of the co-researcher's experiences were evident in some way in the script and the animation. The inquiry group had several experiences to share but at this stage had not identified a takeaway message, what did the they want people to learn from the animation? The inquiry group spent the rest of the meeting exploring what the group wanted our core message to deliver:

> *'It's not rocket science, people just need a bit of time'* (Lesley – field notes)

It was clear that *time,* in a practical sense, was very important to the co-researchers and the group discussed how this needed to feature in our core message. I asked the group what people or the general public needed to do in order to ensure that people living with dementia were given time and the answers were clear. ‘Non-attachment and meta-intentionality’ was employed by myself here. As described by Heron and Reason (2006), this is the skill of not imposing one’s individuality and emotional security on an action. I wanted to be fully committed to addressing this question, but I ensured not to invest my own perceptions and character on to the discussion. The co-researchers felt that with some education around what dementia was, people would have a better understanding of what it is like to live with dementia and how that might impact the person. Reflecting back on Lesley’s experiences of people forgetting ‘ME. The Person’, and Sheila’s experience of the nurses supporting her in the hospital, I felt that compassion was also something that was necessary and when I suggested this as another part of the message, the group were in agreement, as these statements attest:

> *‘Once you’re diagnosed, you do not just move into a care home. There is a life to be lived. You do not just disappear into the background. You do not need to be isolated if people give you a bit of time and space.’* (Lesley – field notes)

> ‘*The group live in a world where everyone wants things at 100 miles per hour but all the group need is a bit of time and patience’* (Jim – field notes)

To help us develop ideas for the core message I asked the group to list the words that came to their minds when I said the word ‘Dementia’ and fed these into a word cloud on my laptop to create a visual representation of their thoughts (see Appendix 13). ‘Chaos and order’ is encouraged within co-operative inquiry to develop validity and this was adopted through the ‘chaos’ of listing off-words that had meaning to the co-researchers whilst bringing a sense of ‘order’ in the word cloud which presented visual representation of their thoughts. This action also added to the presentational knowing of the inquiry group with the emergence of this expressive imagery. With the word cloud, the inquiry group could identify what was important to the them. The co-researchers identified several core messages that they wanted to deliver: time, patience, education, understanding and compassion and as a whole, the inquiry group needed to figure out how this could be delivered. The group worked expressively with words and statements to develop some core ideas that they wanted to be delivered through the animation which are represented below:

Talk to people living with dementia, ***people should be more open about dementia***

Be aware of your reactions,

People coming together, ***the kindness of strangers***

People going out of their way

To act as naturally as possible, but **be patient***, treat people as they are*

Do not take things too seriously

What do people living with dementia look like? You or I

(field notes)

One of the co-researchers suggested they could encourage people to have a ‘cup of compassion’ which led to us exploring people having a cup of ‘something’ as a metaphor. I noted at the time how I felt so privileged to be part of this inquiry group who were adopting such a creative method to expressing what was meaningful to them. The group explored breaking down the word ‘cup’ to compassion, understanding and patience and felt this would deliver the core message in a relatable and accessible way but would also be memorable:

> ‘*Have a CUP, not of tea or coffee but of compassion, understanding and patience.’* (Jim – field notes)

This propositional knowing shows their ideas of how to educate and increase understanding of dementia amongst the general public. As the inquiry group had finalised what they wanted to do with the script, I agreed to submit an ethics amendment to the appropriate research ethics committee. I was nervous about submitting an amendment after my previous experiences with research ethics committee, but I did not want to cause any distress by admitting this. This could perhaps be viewed as being incongruent and not adopting the validity of ‘Managing Distress’ which encourages inquiry groups to embrace and explore emotional difficulties. However, I felt in this situation it was more appropriate to adopt the skill of ‘Emotional competence’ and keeping the action free from distortion. The group were crucially aware that this could take time, which as

I have already highlighted, was limited with only six more research meetings to follow. In order to ensure the inquiry group had time for the amendments to be approved before the group moved forward, we agreed to meet again on 1st February 2018. As well as submitting ethical approval, I would re-evaluate our script based on our discussions and send a new draft to the co-researchers in January so they could reflect and add to it before our next meeting. I did ask if any of the co-researchers would like to take on the role of amending the script but there were no volunteers and when I offered to do it, I noted a sense of relief. This may have been due to a lack of confidence in their own abilities or that at this stage, there was an established relationship of trust and rapport between myself and the co-researchers and that they trusted me to take on this task.

I submitted an ethics amendment to the research ethics committee on the 12th December 2017 which was approved on the 20th December 2017 (see Appendix 14) and I had the pleasure of emailing the inquiry group just before Christmas to confirm the good news. In January 2018, as agreed, I sent the co-researchers a further draft of our script for their comments.

4.8.2 Week 7 – 1st February 2018

I felt there was a real air of excitement in this meeting as the group knew exactly where our research project was taking us. It had been nearly two months since we had last met but interestingly, this did not seem to have made a different with the ease and rapport of the group and we greeted each other with warmth and a sense of eagerness. This meeting was at our usual meeting place in the Humphrey Booth Resource Centre and all members of the inquiry group were present. A new inquiry cycle had begun as the inquiry group took forward the new two-minute script and planned ahead for its development into an animation. The first part of our meeting involved reviewing the script I had sent to the co-researchers in January. In amending the script, I was very conscious of trying to include a part of everyone's individual experiences whilst ensuring the group could keep it under two minutes long. This was a developing area of practical knowing for both myself as facilitator as well as the co-researchers. I had included one negative experience of Lesley's and one positive experience of Sheila's. I attempted to incorporate Wilf's, Margaret's and Jim's experiences into our overall message by reflecting on the journey (Wilf and Margaret) and that the group are all human beings (Jim). I was critically aware of my role as facilitator of the group and to ensure that all of the co-researchers felt their voice was being heard, I practised the co-operative inquiry skill of 'being present and open' with a particular focus on the resonance and attunement of the inquiry group. I ensured to remind the co-researchers that if they did not want to speak about any concerns in front of the rest of the group, they could speak with me privately after our meeting or call or email me at any time.

All members of the inquiry group verbalised that they were happy with the new shortened script and I ensured to check with everyone's body language that this was congruent with what is being said. I was aware of the potential level of power I could be perceived to be holding over the group with my taking the role of shortening the script but I did not sense or interrupt any resistance to this. 'Challenging consensus collusion' is a recognised validity tool within co-operative inquiry and I did not want to allow this consensus of accepting the shortened script to be accepted without discussion. I asked the group to be honest and if they felt any parts of the script should be changed in any way to let me know, either during our inquiry group meeting or privately, however, no concerns were raised or made known to me.

Corresponding to our three themes, there were three parts to the script and the inquiry group now had to collectively decide who would narrate the script. I originally suggested that all five co-researchers narrate the script over the animation but two members of the group (Margaret and Wilf) declined. Adopting an 'emotional competence' stance I could see that Margaret and Wilf were very reluctant to narrate and did not push the matter with them further. Lesley was very keen to be one of the narrators and Sheila also showed an interest. Jim initially declined as he felt that two narrators would be enough, but the inquiry group felt with three themes and three parts to the script, it would be a good fit to have three narrators. After this discussion, Jim volunteered to read part of the script. We then proceeded to have a short break where I double checked with each narrator that they were confident and happy to take this role and re-iterated that there was no pressure from myself or any other member of the inquiry to take part in this action. All three co-researchers, Lesley, Sheila and Jim were happy to proceed with a narrating role.

After the break, I ensured that our three volunteers were happy to try narrating the script for the first time and the group proceeded to have a short run through. It felt natural for Lesley to begin with her own experience, Sheila to follow with her story and therefore Jim took the final part of the script in presenting our core message. Before sending the new draft in January 2018, I had practised reading it aloud and it took approximately two minutes, but it was important to recognise with different narrators the time length could vary. Each narrator had a copy of the script and I highlighted each individual section in a different, so it was clear who was reading what part. The group had a few run-throughs of the script to see how each narrator felt in saying their part and if there was a natural flow to the words. The group changed some of the word orders in the final part of the script to ensure it sounded conversational but with purpose, as Jim noted it stagnated slightly in the last couple of sentences. I felt during this time, that my role as facilitator was not needed as the co-researchers took ownership of the script and balance of power was equalised.

Although I was always aware of my intentions with this research, I felt a sense of gratitude to the research process for this development. With the words finalised, the group then proceeded to time the read-throughs. I ensured that our narrators felt comfortable and not pressurised to read quickly and explained we could always remove parts of the script if the narration went over the two-minute limit. On all attempted read-throughs, the narrators took just under two minutes to read the script, therefore the inquiry group did not need to remove any words or make any amendments. The amendment and narrating of the script contributed towards the practical knowing of the group in the developing knowledge of writing scripts and also in delivering them in a short period of time.

With our script finalised and narrators identified, I asked the inquiry group if they would like to meet the animator before the group sent him the script. I had contacted the animator in January to confirm the inquiry group had been given ethical approval and secured funds to proceed with the animation and the animator was still enthusiastic to work with our group. The animator had suggested that they come to one of our research group meetings in order to meet everyone involved and get ideas for the animation but also to offer reassurance that the inquiry group's work was in good hands. The animator also offered to create a still drawing whilst they were there to capture the group's discussions on the day, and everyone was in agreement that they would be keen for this to happen. On reflection, this development added to the sense of excitement that I had noted at the beginning of this meeting and I could see the co-researchers were keen to show others their work. Up until this point, the data and script has only been shared within the inquiry group. I agreed to contact the animator and see if he was available to attend our next meeting.

The group felt strongly about narrating the animation themselves as it ensured that their voice was recognised and would be relatable to other people going through similar experiences. With our narrators selected, I also agreed to find a recording studio that could offer the services required within our budget. It was important that the recording studio the group visited, was centrally located, accessible and that the employees would have patience and understanding with our narrators. Essentially, what our core message was! The research group meeting concluded with agreed actions for moving forward. I agreed to keep the inquiry group up to date by email with the status of our next meeting and my search for a recording studio and the co-researchers agreed to reflect on today's meeting, the development of the script and the narration of the script. I reinforced that if there were any concerns at all or if anyone felt uncomfortable with their new role, to please get in touch with me. At this stage in the research process, I genuinely felt that our relationship as an inquiry group meant that any problems would be dutifully raised. I noted on my journey home that I was excited myself at the progress that had been made and the action output that was coming together.

4.8.3 Week 8 – 1st March 2018

I had confirmed with our inquiry group before this meeting that the animator could attend this week to meet our inquiry group and get some ideas for the animation along with a clear understanding of the core message. We met again at the Humphrey Booth Resource Centre but there was a change to the composition of our inquiry group this week as Sheila was unable to attend and Lesley had brought a friend and supporter along. It was made clear to the co-researchers before the group commenced the co-operative inquiry, that they could bring along anyone to support them at any stage and this was detailed in the participant information sheets. The person Lesley brought along was well-known to the other co-researchers and was also a member of Open Doors so interestingly it did not change the group dynamic in any way and the same humour and tone was evident throughout the meeting. It could be hypothesised that a new person attending an established group could contribute to 'chaos and order' but this was not the case and the research group meeting proceeded without incident.

I had arranged for the animator to arrive 15 minutes after our meeting started so I could ensure that all of the co-researchers who were present were still happy to invite an external partner into the group space. There were no objections and the animator was invited to join us for the remainder of the meeting. The animator was introduced to the inquiry group and each co-researcher then introduced themselves. It was interesting to observe that none of the co-researchers seemed fazed or concerned about a new person, who none of them had met before, joining in with the research. I reflected this was likely because they all had experience of working with external partners before, wherever that be researchers or healthcare professionals. I did ensure to adopt an ‘emotional competence’ stance to observe and act upon any signs of distress but none were noted. The first part of the meeting was spent discussing what had brought the group together and the experiences they all had of living with dementia. The animator captured this in a live drawing (see Figure 8). The group’s use of humour is evident in the drawing and how the members of the inquiry group can often be self-deprecating as a coping mechanism. The drawing also included portraits of the co-researchers which the group appeared to really appreciate; in that they could see themselves in the visual storytelling. There was also a true likeness between the drawings and the co-researchers themselves. The animator’s drawing also highlighted the rollercoaster that the group felt they had experienced in living with dementia, with there being highs and lows, something which the group felt was also demonstrated in their script.

An interesting discussion arose around awareness of dementia and how the inquiry group felt it was only in the last five years that there was more public awareness of the condition. This may have been due to their own personal experiences arising during that time, but they also felt high profile stories of people living with dementia such as that of author, Terry Pratchett and the cartoonist Tony Husband, who documented his father’s experiences of living with dementia, had given the public more awareness of the condition. The co-researchers expressed that they hoped that with their own animation, they could raise even more awareness of what it is like to live with dementia. This discussion also facilitated further propositional knowing, in the inquiry group’s knowing by ideas and theories and their understanding of awareness of dementia.

The group ended the meeting by having a run-through of the animation script. This ensured the co-researchers had further time to reflect on the script and ensure they were happy with it but also allowed the animator to hear it being narrated for the first time. The animator being the first person outside of the inquiry group to hear it, also allowed for some external feedback. As Sheila was not able to attend this week, Lesley read Sheila’s section of the script alongside her own. The animator was positive in his feedback of the script and felt it would work well alongside an animation and I could see the helpful and positive effect this had on the group. The animator's feedback also contributed to the 'Reflection and action' validity aspect of co-operative inquiry as with his feedback, the inquiry group could reflect on what they had achieved and continue with the proposed actions. Up until this point, the inquiry group hadn't had any feedback on what we were doing and with no previous experience of this kind of project, it was reassuring to have this positive feedback and approval. At this stage, I acknowledged in my reflections that I felt a sense of responsibility for the research but also the co-researchers in supporting them to develop and complete a piece of work that had meaning to them. I did not feel this responsibility in a paternalistic way but in one of facilitation and partnership.

Figure 8: Live drawing of the co-operative inquiry by the animator

As part of the ethics amendment that was submitted in December 2017, I had included the option to interview the animator about his participation in the research process. After the animator had agreed to collaborate with the inquiry group on the research process, I approached him about taking part in a semi-structured interview with me after the animation was completed. The animator expressed an interest in doing this and I sent him a participant information sheet and consent form (See Appendices 15 and 16) in advance of this taking place. The animator's own reflections and thoughts on the research process will be presented in the following chapter.

Our next meeting was going to be in an entirely different venue as I had booked a recording studio in order to record the script. The animator would not be able to attend the studio with us but offered to call in during the recording session to give feedback on the narrations and the group was grateful to accept this.

4.8.4 Week 9 – 22nd March 2018

This week, the group had our meeting at a recording studio in Manchester City Centre. The co-researchers would travel by car and bus to our regular meetings at the Humphrey Booth Resource Centre but on this occasion, I booked taxis for the group to ensure they felt safe travelling into the city and arrived at the correct location. The inquiry group agreed to meet at a café/bar beside the recording studio first for some refreshments as we would not be allowed these in the recording studio. This also gave me some time to ensure that our narrators in the group were still happy to proceed and to alleviate any nerves, however this concern was unwarranted. The narrators were enthusiastic to take part in the recording and appeared excited about this new and unfamiliar experience.

The recording studio was on the fifth floor of an office block and I had checked in advance that there was lift access. Unfortunately, on the day, the lift was out of order. The recording studio did not make us aware of this until the group arrived otherwise, I would have rearranged for another day. Some of the co-researchers used walking aids and had difficulties with walking so the situation was not ideal. I noticed within my own feelings that I was frustrated and angry about the situation, particularly as I had not been warned in advance about the lift being out of order. I adopted the ‘emotional competence’ skill again at this stage and ensured to keep my feelings away from distorting the actions of the day. I offered to cancel the session and re-arrange but the co-researchers were eager to get the recording completed today. Taking the stairs, I ensured everyone had the support they needed and went at their own pace. I followed the group at the rear to ensure no-one was left behind or felt pushed to go beyond their own limits.

This situation contributed to my own practical knowing as I reflected that in the future, I would call ahead on the morning of any activities to ensure there were no access difficulties. On reaching the studio, the group were shown into a room that had a sound-proofed recording booth in one corner and behind a glass wall were the control panels for recording where the studio staff member sat. The staff member explained that the group had the studio booked for an hour and could have as many run throughs as the group wanted in that time. They also explained that each narrator could take as many turns at they liked at their section of the script and that the studio would piece the three sections together to send on to the animator.

Before the group started, the animator called in and gave advice to the narrators including speaking slowly and clearly, and to keep going if they made a mistake as errors could be edited out. Although the booth was sound-proofed to ensure sound quality, the studio staff could still connect the animator on the telephone and the rest of the group in the studio to the narrator through headphones.

Each narrator, Lesley, Sheila and Jim narrated their section and appeared to gain confidence with each attempt. No nerves were evident and the narrators, along with the rest of the co-researchers appeared to be having fun. This was a new experience for us all and none of us knew what to expect but despite the accessibility difficulties, the studio staff were kind, patient and helpful which made a real difference to the experience of the inquiry group. The humour that is always evident with this group transpired with the co-researchers calling for Jim to start a career as a voice-over artist and the animator whole-heartedly agreeing over the phone. Each of the narrators recorded their section three or four times and with this number, The animator and the studio staff member said they would have enough to edit a full, clear read through of the script into one two-minute recording. The studio staff member would complete the editing for us and send a copy of the full narration to both me and the animator. With the full narration, the animator would first produce a storyboard of how he envisioned the animation would run and send it the group for approval and agreed to have this produced for our next meeting in April.

Leaving the recording studio, the co-researchers took the pre-booked taxis home and I agreed to forward over the storyboard for them to reflect on as soon as it was available. The whole experience of the day contributed to the inquiry group's practical knowing. Not only did we reflect on accessibility issues but also how recording studios work and for the narrators, what it is like to professionally record for an animation.

4.8.5 Week 10 – 19th April 2018

Back at the Humphrey Booth Resource Centre, the inquiry group had been sent the storyboards (see Appendix 17) by the animator to get an idea of how the animation would look. All of the co-researchers were present for this meeting and in the storyboard, every co-researcher was visibly represented, and the natural progression of the script was evident. Although Margaret and Wilf's story was not explicitly narrated in the script, their experience had been brought to life in the storyboard with a visual representation of a journey and the colours of British traffic lights used as the primary colours. The initial storyboard had represented Lesley's story in amber, Sheila's story in red and the final message in green. However, the inquiry group felt it would make more sense and would be clearer visually if Lesley and Sheila's colours were swapped so the animation went through the colours like a traffic light would starting at red, progressing to amber and finishing on green. I agreed to contact the animator with our feedback before the animation was completed. The co-researchers particularly liked how the core message was delivered with the visual representation of having a 'CUP of compassion, understanding and patience' (see Figure 9). 'Reflection and action' was evident here as the group continued to develop their practical knowing of the creation of an animation.

Figure 9: Visual representation of the core message from the animation storyboard.

Other than changing the colours around, the inquiry group had no other amendments that they wanted to make to the storyboard. The animator had informed me that once the group had given him feedback on the storyboards, he would put a rough version of the animation together for us to review at our next meeting so there was a chance for any last-minute changes before the final version.

For the remainder of the meeting, the group discussed what the group wanted to do with the animation. I reminded the co-researchers that although I was working with them as part of a doctoral study, this was their voices, their experiences and their animation. It would be publicly available via YouTube, but the group should ensure that the public knew it was there and take ownership of their work. The group discussed the use of social media to promote it and had an interesting discussion on how prominent dementia activists used Twitter and how the group in turn could also use Twitter to send our message. People living with dementia are actively engaging with Twitter to raise awareness, challenge stigma and provide support to their peers (Talbot et al., 2019). Twitter has a global reach and could reach a wide spectrum of individuals. The use of Twitter has been shown to be a modern, straight-forward, cost effective and easy way to disseminate research (Schnitzler et al., 2016). Alongside using Twitter, the group discussed creating our own website. The poems Lesley had written, 'STIGMA' and 'The Good Samaritans' had been removed in our revising of the script down to two minutes and the inquiry group were keen to ensure these were recognised as part of their work. With the creation of a website, the group could feature the animation, the poems and also give some background to the narrators and writers of the script. I agreed I would approach my supervisory team and the ESRC as my funders to enquire if funding towards this was possible.

The co-researchers also discussed how to make it accessible to people who do not use social media and Lesley suggested having it played on the screens commonly seen in doctor's surgeries. The group felt this was an excellent idea as not only would it challenge and hopefully educate people about dementia, but it might also encourage people with concerns about their memory or cognitive abilities to seek help from their general practitioner (GP) whilst they were there. I reflected on how creative people could be with potential dissemination activities and how privileged I was to work with this group. Due to the time constraints placed on this doctoral study, the group agreed this was something they would explore after the animation was completed. Looking to the near future, the inquiry group decided to have a launch party for the animation and invite friends, family and other healthcare professionals. The co-researchers had been involved with other research being carried out as part of Open Doors and had thoroughly enjoyed the launch party for the previous project and the recognition it gave them. The inquiry group decided to hold a launch party in the summer after our research was completed and the group had an animation. Lesley volunteered to read her poems and the group would also invite guests to give feedback and to see what had been achieved. The inquiry group agreed to discuss this in greater detail at the next meeting but in the meantime, they would wait for the rough edit of the animation.

4.8.6 Week 11 – 17th May 2018

The day before this meeting, I had been sent a first version of the animation. It was missing a title screen and the end credits, but the main body of the animation had been drawn and was set to music that the animator had chosen. I did not send this to the co-researchers before the meeting in order to ensure everyone was able to view it at the same time. As this was an inside inquiry, I felt it was appropriate to wait for comments on the animation once we were all together. On reflection, I should have asked the inquiry group in advance if they wanted to view it all together or be sent the animation as soon as it was complete. The meeting started with reflecting on the previous meeting and I explained that I had passed on our feedback from the storyboards and the inquiry group now had an animation. I played the animation for the group on my laptop and rather than watch the animation with them, I took the liberty to watch their reactions. On reflection, observing their initial reactions would not have been possible if I had sent them the animation in advance. There were some visible nerves from the narrators as we viewed their individual sections, but this quickly changed as they saw how skilfully the animator had brought their experiences to life. At the end of this first showing, there were smiles on each co-researcher's face and verbal acknowledgments of how well they thought it was done. It was acknowledged that although not everyone's individual experiences were able to be described in the animation, each co-researcher's experience was highlighted in some way. Wilf and Margaret were the only co-researchers not to narrate any part of the script, but their journey was still evident in the animation (See Figure 10).

Figure 10: Wilf and Margaret's journey of dementia in the animation.

The inquiry group noted that they particularly enjoyed the 'live drawing' aspect of the animation (see Figure 11). It was felt that this helped support the idea of it being a journey. The animator had also taken our feedback on with regards to the colour scheme and the colours changed from red (negative experience) to amber (positive experience) to green (core message) and thus reflected our identified themes clearly. I played the animation twice more to the group and also emailed it to them to give them time to reflect on it at home. One thing that the inquiry group realised at this stage was that there was no title for the script or the animation. I felt it was important for the animation to have a title so it could be shared widely on social media so the inquiry group spent some time reflecting on what would be appropriate. The words 'dementia' and 'stigma' were identified as being important by the co-researchers as this had been what we set out to research. As the facilitator and being conscious that due credit was not always given to people living with dementia for their contributions, I suggested they include a personal aspect in the title. Several titles were suggested including:

> 'Living with dementia: Our Story'
>
> 'Dementia and Stigma: Our Journey'
>
> 'Our stories of living with dementia and stigma'
>
> (field notes)

I felt that ‘Dementia and Stigma: Our Journey’ reflected what the group has accomplished in acknowledging what had been chosen to be researched but also highlighted that it was their experiences, their journey. The co-researchers unanimously agreed, and I would send this title on to the animator to include in the final animation. The group also had to decide what would be written in the end credits. I felt very strongly that the co-researchers should be acknowledged as the writers and narrators of the animation and advised that I would not be comfortable including myself in this section. I did remind the co-researchers that them being identified by animated drawing and full name was entirely optional, however each co-researcher verbally acknowledged they would to be recognised for their work by their full names and pictures. I helped to facilitate this work, but this was their stories not mine. Therefore, it was decided that I would ask the animator to include a slide on the co-researchers as the creators of this work followed by a slide of people, the group wanted to thank for their support. I would be included in this final slide and I felt that I had utilised the skill of ‘Being present and open’ in the discussion of this. I wanted credit to go to the people who deserved it and on reflection, I feel this was achieved.

With the animation near completion, and our research project coming to the end, there were a few things left to finalise. I had secured funding to develop a website and would work on this over the coming weeks with regular feedback from the co-researchers. The launch party also had to be planned. The inquiry group decided it should be held somewhere familiar and with easy access, therefore our regular meeting place of the Humphrey Booth Resource Centre in Swinton, Salford was chosen. Our practical knowing was further developed in this phase as we further developed our knowledge around the creation of an animation but also in planning an event for dissemination. Several of the co-researchers had holidays coming up in June and it was important that the entire group could attend so I agreed to find out the availability for the centre in July. The inquiry group decided to think about what they would like to do in the launch party for our next meeting and I agreed to send over the final animation once received from the animator.

Figure 11: Still frame from the live drawing aspect of the animation.

4.8.7 Week 12 – 12th July 2018

This was our final research meeting and meeting of the co-operative inquiry and took place in the familiar Humphrey Booth Resource Centre. The animator had sent me a final version of the animation a couple of weeks before which I had emailed to the co-researchers in advance. We spent the first half hour watching and reflecting on the animation and I could see by the smiles on the co-researchers faces that they were not only happy but proud of what they had achieved. 'That's really good, that!' from Lesley reinforced this observation. I reflected that I was also proud of what we had achieved and how a long and drawn out process which had profound difficulties in ethical approval had resulted in a powerful and emotive output.

Next, the inquiry group planned the launch party that would be occurring the following week. Via email, I had contacted the co-researchers to confirm a date that they were all able to attend and had asked for suggestions of who to invite. The co-researchers would take ownership of inviting their own friends and family, but I offered to contact others of their choosing. This included the service manager of Open Doors and other individuals working in the dementia sector such as AGE UK. A list was agreed via email contact with the co-researchers and I took responsibility of sending invites out in advance. Based on replies on this date, we were expecting roughly 15-20 people to attend the launch party. I agreed to arrange catering, including lunch, for the day. We planned to have two hours in which to have lunch with our friends and colleagues and introduce them to the animation. I suggested a member of the inquiry group starts off proceedings with introductions and a brief outline of what we would be doing.

None of the co-researchers volunteered for this part and seemed relieved when I offered to do it myself. It can be intimidating speaking in front of groups of people, particularly when there may be people you do not know, and I did not want any of the co-researchers to feel uncomfortable so was happy to take on this role. It may have increased the validity of the co-operative inquiry if I had adopted ‘Challenging consensus collusion’ and encouraged the co-researchers to step outside their comfort zone but as a facilitator and registered mental health nurse, I had to put the emotional well-being of the group first. It would not sit ethically or morally with me to not put well-being first.

The inquiry group wanted to not only showcase their animation at the launch event but also the poems that Lesley had written. Lesley offered to read one of the poems but felt that another co-researcher should read the other one. Sheila volunteered to read the other poem and was reassured that no memorising was required but it would give a stronger voice to their message to have people with the lived experience of dementia reading the poems. I suggested a brief outline for the launch party consisting of introductions followed by the poems being read on either side of the animation viewing. To conclude the day, I suggested we finish with a discussion with the opportunity for our guests to ask questions of the research process or the final animation. I ensured that all of the co-researchers were happy with this and checked in to see if there is anything else that should be included on the day. Our practical knowing continued to develop as we planned the launch event and considered logistics and operational orders for the day. We agreed to meet 30 minutes before the start of the launch party to ensure everyone felt prepared and to give the co-researchers time to ask any last-minute questions. Before concluding the meeting, I reminded the co-researchers again that they could approach me privately if they had any concerns or queries that they did not want to discuss in the inquiry group setting.

4.8.8 The Launch Party – 19th July 2018

The launch party for the animation took place from noon until 2 p.m. as this enabled us to incorporate lunch into the planning. We had met earlier in the day to answer any last-minute queries within the group and to ensure everyone was still happy with their roles. I had brought my laptop in order to show the new website (www.dementiastigma.com) and the final version of the animation which was now hosted on YouTube (https://www.youtube.com/watch?v=5_QMRMqHU0k). However, the correct connectors were not available in the room and I ended up borrowing a member of staff's laptop for the launch party. I had thought I was completely prepared for the launch party, but incorrectly assumed the right technology was available. Not everything going to plan again contributed to my own practical knowing and I reflected on ensuring technology would be compatible in the future as opposed to assuming it would be.

In total, 14 guests attended the launch party and I began with introductions. I explained why we were doing this research, why it was important and what we had achieved. The co-researchers introduced themselves and each gave a short biographical speech. After this, I introduced Lesley as our first reader reading her 'STIGMA' poem. This was followed by a showing of the animation which received a wonderful round of applause. I asked if our guests would like to view it again as it was only two-minutes long and there was resounding agreement, so it was played again. Sheila read Lesley's other poem, 'Good Samaritans' and then I facilitated a group question and answer session. I did not record this data as I did not have ethical approval to gather the opinions of others outside of the inquiry group, but the feedback was favourable and positive.

Reflecting on the launch party, I could see how this was an important step for the co-researchers to share their work with their loved ones and colleagues. We decided to hold this launch party in July and on reflection, I think we could have waited until the end of the summer as many people were unable to attend due to holiday commitments. Indeed, we had only one meeting to prepare for the launch party due to the holiday commitments of the co-researchers and I believe that more time to prepare for it and hosting it a later date would have resulted in bigger turnout and allowed for the message and animation to be shared more widely.

4.8.9 A final meeting - 6th September 2018

The group had completed their co-operative inquiry and had produced an impactful animation where the voice of people living with dementia was recognised. I felt it was important to meet one last time as a group to not only thank the co-researchers for their incredible work but to allow us a chance to reflect on what worked well and what did not. I arranged a final meeting at the

Humphrey Booth Resource Centre to give us this opportunity. The animation was now live on YouTube and had gained hundreds of views in only a few short weeks. Both Lesley and I, were active users of Twitter so had been tweeting it out to raise awareness of the animation. I thanked the co-researchers for their contributions and re-iterated how it was down to their hard work and sharing of their experiences that they had produced such a powerful outcome with a clear message.

I was keen to understand what worked well and what did not. I felt we had a good working relationship but there may have been ‘an aim to please’ element to this and when I asked for feedback on what could have been done differently, little was said. I knew time had been a big factor in this project and when I suggested this to the co-researchers they did not entirely agree. The co-researchers felt they had enough time to work on the research and reflect at home in-between meetings, however, there was some frustration with the time it took for ethics to be secured and then with later amendments. I did keep in contact with the group throughout the ethics process, but perhaps further information about what it actually entailed would have reassured the group further. I was honest with the group in that the ethics application had not gone smoothly with an explanation that the first research ethics committee did not understand what we were trying to do, but I did spare them some of the detail around the ethical challenges as I did not want to put them off being involved in future research.

I found it particularly interesting with what was said when I enquired about the research topic. It had taken us some time to the form the inquiry group and decide what was going to be researched and the co-researchers felt that if I had come to them with a topic in the first place, it would have been a more straightforward process. I did re-iterate that the aim of this doctoral project was to ‘co-research’ and explore something that was meaningful to them and ensure that the voice of people living with dementia was recognised in research. However, for the co-researchers in this study, choosing the research topic did not seem to have been of great importance to them which I will reflect on in more detail in the next chapter.

As we came to the end of this meeting, we had a further conversation about where to go next with the animation. I reinforced the message that this was their work and they could essentially do whatever they wanted with the animation, but I was given the impression that the co-researchers wanted me to take a lead on dissemination. I had spent a lot of time developing the website and sharing the animation on social media and I agreed I would continue to do this. I had been in contact with a lecturer on social media who worked at a different institution who had asked to show the animation to medical students and when reporting this back to the inquiry group, this was strongly encouraged. There had been previous discussions around sharing it with GP surgeries and introducing it in schools but unfortunately, as I came towards the end of my doctoral studies, I did not have the time or resources to facilitate this myself. As members of Open Doors, the co-researchers were involved in many other different projects and I encouraged them to use the animation whenever they thought it was appropriate.

4.9 Reflections on the co-operative inquiry

Facilitating this co-operative inquiry was a new experience for me. I had extensive experience working with people living with dementia prior to undertaking this doctoral study, but not in a research role. I was very fortunate to work with such a passionate group of people and I believe the initial decision to build relationships within the wider ‘Open Doors’ community supported this. I aimed to be open and approachable and this aided me in getting to know the co-researchers well from the beginning of the inquiry process. Being open to creative methods also supported the success of this co-operative inquiry. I would never have envisioned at the beginning of this process, that the final output of this inquiry would be an original and inspiring animation written and narrated by the co-researchers. The use of diaries was also particularly helpful as it ensured the co-researchers could note their experiences and own reflections in their own time and there was never any pressure to share anything unless they were comfortable doing this.

On reflection, time was one of the biggest challenges of this co-operative inquiry and I would start the research process a lot earlier if I was to facilitate another research project of this kind in the future. I underestimated the time it would take to initiate the inquiry group, decide on a topic to explore, and to gain ethical approval which left the actual co-operative inquiry process feeling slightly rushed. Also knowing that it is perfectly acceptable for an initiating researcher to propose a topic, I would bring a list of possible subjects to explore at the initial meetings to support the co-researchers in identifying a topic that is meaningful to them. With regards to ethics, I would make the benefits of people living with dementia being involved in research, explicitly clear and highlight the Mental Capacity Act (2005) as a supportive piece of legislation as opposed to one that would limit participation.

For a novice researcher, adopting an unfamiliar and sometimes complex methodology was a challenge but the outcome of co-researching in partnership with a group of people living with dementia, and ensuring their voices were heard in the research was rewarding, and a privilege to be a part of.

4.10 Summary

This chapter has explored the practical element of what was accomplished in the co-operative inquiry. The phases of co-operative inquiry have been presented with consideration of the achievements completed by the inquiry group on a week-by-week basis including my own reflections and with reference to the ways of knowing. The finished product of the co-operative inquiry, the animation, has been discussed and shown through picture-based stills and the concluding meetings with the inquiry group explored. A critique of the data collection methods that were used by the facilitator concluded the chapter. The next chapter will investigate how this co-operative inquiry was fulfilled and will include a reflexive component exploring the role of the facilitator and the concept of power.

Chapter Five: The Stepping Model: A model of group facilitation in co-operative inquiry

5.1 Introduction

This chapter will consider the findings from Chapter Four but within relation to ‘how’ the co-operative inquiry was facilitated. A brief exploration of group facilitation will be followed by the introduction of a model of group facilitation for working with people living with dementia. The chapter will include the experiences of myself in the role of the facilitator of the co-operative inquiry and with supporting statements extracted from the semi-structured interview carried out with the animator. A discussion of the use of ‘power’ and its potential imbalances will conclude the chapter.

5.2 Group Facilitation

Group facilitation involves supporting a group of people to achieve their goals (Hogan, 2002). Facilitation is not about putting ideas into people’s heads or making all of the decisions, but of pulling and drawing these ideas out and supporting the group to make their own cohesive decisions (Avery, 2016). It is argued that the term ‘facilitation’ is often misunderstood and misused as individuals may think or say they are facilitating a group when in fact they are leading or directing the group instead (Hogan, 2002). Schiola (2010) argues if a member of the group feels it is important for their voice to be heard in the groupwork then it is best that the person does not facilitate.

Avery (2016) proposes that facilitators should have ten key attributes:

- Understanding of group behaviours including why people act or behave the way they do in group situations
- An awareness of self-care with regards both themselves and members of the group
- A commitment towards achieving the group’s goals by seeing themselves as an integral part of the team and using creative methods to promote inclusion
- An awareness of their own views and judgements and ensuring they can separate these from the goals of the group
- The skills to initiate activity and help provide direction
- Competent in managing difficult emotions in the group such as tension and conflict

- The ability to emphasise the positive aspects of the group such as learning from each other and supportive relationships
- Provides a nurturing environment which supports individuals to develop ideas and solutions to problems themselves, without being told what to do
- Have a commitment to the wellbeing of group members and are willing to go that extra mile to ensure everyone feels supported
- Has respect and values each member of the group and identifies that although there is a common goal within the group, each member is still an individual.

A further important attribute to consider is that the facilitator recognises their limits in knowledge and skills in their role (Hogan, 2002). Even though these attributes are recommended for facilitators, when it comes to ways of facilitating, there are very few set rules (Hogan, 2002). Group facilitation can be separated into two different types. Basic facilitation occurs when the facilitator is employed to improve the group process on a temporary basis whilst developmental facilitation is viewed to be a more permanent solution (Schwarz, 1994).

There are numerous models of facilitation (Hogan, 2002) of which a pertinent one to this study is John Heron’s model of facilitation styles (Heron, 1993). As the architect of co-operative inquiry, Heron has also written extensively about facilitation. Heron first wrote about facilitation in the 1970s and presented his six dimensions of facilitation model (see Figure 12) and viewed these dimensions as options and strategies for the facilitator in whatever work they were undertaking (Heron, 1993).

Heron (1993) later expanded upon this model by incorporating 18 different styles of facilitation (see Table 6) and introduced the concept of power and how it may be distributed within the group. Heron (1993) viewed this idea of power as being allocated through three different methods, hierarchical, co-operative and autonomous. The hierarchical distribution of power involves the facilitator directing the learning for the group, making decisions, managing emotions and identifying structures and pathways of work.

Figure 12: Six dimensions of facilitation (Heron, 1977).

Directive	Nondirective
Interpretative	Noninterpretative
Confronting	Nonconfronting
Cathartic	Noncarthartic
Structuring	Unstructuring
Disclosing	Nondisclosing

A co-operative method of power distribution sees the power being shared between the group members and the facilitator and with an autonomous distribution of power, the power sits with the group members in order to facilitate complete self-determination (Heron, 1993). Heron (1993) proposed seven ‘criteria of excellence’ by which a facilitator’s competency can be judged:

- **Authority:** Facilitators should be able to apply authority in the group process but without forcing their own views, bias and opinions on to the group members and the work being carried out
- **Confrontation:** Facilitators feel confident challenging inflexible or defensive behaviour by group members
- **Orientation:** The facilitator has the ability to give clear conceptual direction to the groupwork when appropriate.
- **Care:** The facilitator is genuinely caring and empathetic
- **Range of methods:** Facilitators should have wide range of skills, techniques and exercises to draw on in assisting the progression of work.
- **Respect for persons:** Facilitators should respect all group members and appreciate their autonomy and right to choose what they contribute to the group
- **Flexibility of intervention:** Facilitators can move with the methods and styles described in his model (See Table 6)

Table 6: Heron's (1993) facilitation style model. Any combination of dimensions and modes may be used to assist facilitation.

Dimensions **Modes**	**Planning**	**Meaning**	**Confronting**	**Feeling**	**Structuring**	**Valuing**
Hierarchical						
Co-operative						
Autonomous						

Heron (1993) suggests that there are three different types of authority available to the facilitator: tutelary, political and charismatic. In a tutelary role, the facilitator uses various learning styles such as open learning, real learning, and peer learning to pass on their skills and knowledge to learners. Political authority is viewed as when the facilitator makes decisions about subject matter, approaches and timing of learning in the group. Charismatic authority can also be viewed as personal power but not in a negative interpretation of controlling others, instead Heron (1993) views charismatic authority as a form of empowering others through recognition of one's own abilities and resources.

Although some of Heron's work and in particularly his earlier work on facilitation has been criticised for the use of abstract language (Hogan, 2002), his contribution towards models of facilitation and indeed group work in co-operative inquiry are significant. The acknowledgement of power as a concept is particularly relevant to this study as will be discussed later in this chapter.

5.2.1 Group facilitation with people living with dementia

Group work and group activities with people living with dementia are viewed as being an important tool in supporting individuals to maintain a good quality of life and as a nonpharmacological intervention in managing the symptoms of dementia (Cohen-Mansfield, 2018). Existing research has explored the effectiveness and benefits of group work with people living with dementia

(Brooker and Duce, 2000; Chien and Fung, 2002; Mason et al, 2005; Vella-Burrows and Wilson, 2016) yet there is limited discussion of the facilitation of such groups, particularly with consideration of research groups with people living with dementia. Current literature tends to explore the facilitation of exercise groups (Vseteckova et al., 2018), day care activities (Strandenaes et al., 2019) and interventions such as group singing (Unadkat et al., 2016) and woodland therapy (Puslford et al., 2000). Mason et al (2005) highlighted that up to three quarters of all interactions in a support group for people living with dementia involved the facilitator which highlights the important role that facilitation plays in working with people living with dementia. Group facilitators have also been shown to encourage individuals living with dementia to develop their own knowledge and learn new skills and are generally viewed with high regard (McConnell et al, 2018). On the one hand, existing research has suggested that facilitation is crucial for groups involving people living with dementia due to the potential influence of cognitive impairment (Yale, 1995; Cheston et al., 2003). On the other hand, McConnel et al. (2018) suggest that effective facilitation empowers and promotes the independence of people living with dementia.

The importance and benefits of facilitation in working with groups of dementia have been suggested but what has yet to be explored is exactly how these groups are facilitated and with particular consideration of participatory research groups. As highlighted in Chapter One, participatory research is an emerging field with the dementia research sphere and the following model explores the facilitation process for working with people living with dementia in a collaborative and participatory way. Heron's (1993) models of facilitation are too generic to be applied to unique groups such as people living with dementia and do not consider important factors such as the issue of capacity and experience in the research in the process. Therefore, I will now present a new model of group facilitation that has been developed with consideration of working with and collaboratively with people living with dementia in the reported co-operative inquiry and in reflecting upon the process of engagement.

5.3 The Stepping Model: An interactive and dynamic approach to facilitating a co-research group involving people living with dementia

Drawing on the processes involved in this PhD study, the Stepping model (see Figure 13) has been developed as an approach to group facilitation with people living with dementia and has particular application to co-research and co-production groups such as co-operative inquiry and action research groups. I had numerous discussions with my supervisory team about the need for a specific model of group facilitation for co-researching with people living with dementia as, at present, there is no such model in the literature. There has been guidance developed on involving people living with dementia in research such as the core principles for involving people living with dementia in research (Scottish Dementia Working Group Research Sub-Group, 2014) and the COINED model (Swarbrick et al., 2019), but no model of group facilitation for this particular population and to guide actions. I wanted to introduce a model of facilitation that had collaboration at its core, to address the emerging field of co-research in the dementia research sphere and that guided the facilitator on when to step in, and step back, in their role. As a result of these discussions, and in acknowledging the work that has already been completed, I developed the Stepping model as an interactive and dynamic approach to facilitating a co-research group with people living with dementia.

Figure 13: The Stepping Model.

In the Stepping model (see Figure 13), there are four cyclical stages to the model which although presented in a numerical order, are fluid and dynamic and the group facilitator may find themselves visiting some stages in a different order than presented; repeatedly or going back a stage before moving forward. Each stage will now be presented with reference to the co-operative inquiry that took place as part of this study and with reflections from both myself and the animator who worked collaboratively with the inquiry group on this study. The facilitator should embody a number of traits and skills which will be discussed in each stage.

5.3.1 Stepping Forward

In this initial stage the inquiry group facilitator takes charges of initiating the inquiry group. This includes practical aspects of the inquiry such as finding and securing a suitable meeting place for the inquiry group to meet, recruiting to the inquiry group and providing initial leadership and direction. This stage reflects the initiating phases of the co-operative inquiry where as the facilitator and initiating researcher, I stepped forward to develop the inquiry group. As discussed, I was awarded a studentship to conduct participatory research with people living with dementia as part of the Neighbourhoods and Dementia study and worked closely with the Open Doors group to recruit co-researchers for the inquiry. I identified the Humphrey Booth Resource Centre as a suitable location to hold these initial meetings. I attended both the peer support groups and dementia cafes ran by the Open Doors group to talk about what I hoped to initiate, to co-research with people living with dementia on a topic of their choice that had meaning to them:

> *In late 2016 and early 2017, I attended four meetings ran by the Open Doors group to gather interest and explain what I hoped to do. This included attending the dementia café at Roe Green twice and peer support group at Humphrey Booth Resource Centre twice. On all four occasions, I presented my study to the group …I explained to those present, that I would like to work collaboratively and co-research with a group of people living with dementia to identify a research subject that was meaningful to them.* (Initiating the inquiry – Researcher's observations)

Although the stepping forward phase primarily reflects the initiating stages of co-researching, there will also be occasions where the facilitator will step forward again to take a lead on actions. I stepped forward again when ethical approval was required during the research process as a practical element that the novice co-researchers would not be expected to lead on. As this co-operative injury was the main feature of my doctoral study, the power for this action would naturally sit with me. It's something I also reflected on during the early weeks of the co-operative inquiry:

> *I was always consciously aware that this study was being a carried out as a doctoral study where I had an end-goal and an emotional and practical investment in the research. I attempted to be as congruent as possible in my reflections to the group in that I genuinely felt the inquiry group was developing a rich and vibrant amount of data but did not want the co-researchers to think that this was a 'creation' for the doctoral study aspect of the research.* (Week 3 of the co-operative inquiry– Researcher's observations)

Another specific occasion when I stepped forward was when it came to making amendments to and reviewing the script. By week 6 of the co-operative inquiry, the inquiry group had decided to proceed with the development of an animation and in doing so, required the script to be reduced down a length of two minutes. Interestingly, stepping forward in this case, appeared to relieve some anxiety in the co-researchers:

> *I did ask if any of the co-researchers would like to take on the role of amending the script but there were no volunteers and when I offered to do it, I noted a sense of relief. This may have been due to a lack of confidence in their own abilities or that at this stage, there was an established relationship of trust and rapport between myself and the co-researchers and that they trusted me to take on this task.* (Week 6 of the co-operative inquiry– Researcher's observations)

Further practical considerations such as making contact with the animator and arranging the recording studio session can also be viewed as a stepping forward role for the facilitator. In my interview with the animator, he described how having a main point of contact in the inquiry group and a facilitator to liaise with was a key component in successfully working with an external collaborator:

> *… it really helped with that the main point of contact had a good relationship with the group, you know, the group seemed really open, eager to talk and I think that relationship you had, the key person had with the group… working with someone who knows the groups well, knows them personally and had a good connection with the group and can filter through their stories to get the best of them…* (Quote from transcript of interview with the animator)

Dissemination of the animation proved an interesting point of consideration in the Stepping model. I had hoped that the co-researchers would take a lead on the ownership of the animation and use their own networks to share it with the wider public. However, this was not the case and I noted an expectation that I would facilitate this final part of the inquiry process:

> *I reinforced the message that this was their work and they could essentially do whatever they wanted with the animation, but I was given the impression that the co-researchers wanted me to take a lead on dissemination. I had spent a lot of time developing the website and sharing the animation on social media and I agreed I would continue to do this.* (A final meeting– Researcher's observations)

I had stepped forward in certain aspects of the dissemination of the animation as reflected in the quote above, however, on reflection it is clear that the co-researchers expected more of a lead to come from the facilitator and that stepping forward would play a bigger part in this action. Expectations of the role of the facilitator in disseminating the research and subsequent action outputs should be set at the beginning of the research process.

Stepping forward is a critical part of any kind of inquiry or co-researching project. This stage reflects the desire to achieve an outcome, that should be shared by the group, but when the facilitator is required to take a lead on actions to ensure progression of the research process. It is a stage that should be carried out sensitively as too much influence in this action could result in a power imbalance that adversely reflects the co-operative nature of the research. Knowing when to step forward, will rely on the experience and skills of the facilitator, however, beyond the initiating stages of the co-research, this stage should still be carried out in collaboration and with agreement of the research group.

5.3.2 Stepping Together

In this stage, the inquiry group facilitator starts to hand over responsibilities of inquiry group actions. This is a gradual process marked by the lessening of directive decision-making by the inquiry group facilitator and is evident in several phases of the co-operative injury. In the initiating phase, stepping together is evident in the developing of a research question. The inquiry group started to assume responsibility for, and ownership of, the research question and aims of the research. In this co-operative inquiry, the development of the research topic was quite difficult as the co-researchers were used to researchers approaching them with a question that had already been developed but embedding ourselves in the co-operative inquiry process allowed for a collaborative approach to be taken. A topic was identified that had meaning to the researchers and collectively, we identified three themes in the data:

> *From our discussions, the inquiry group collaboratively agreed on three broad themes: positive experiences of living with dementia, negative experiences of living with dementia and that the group had a core message that the group wanted to deliver to educate the general public… These three themes were incorporated into the play script but in keeping with the co-operative inquiry process, we would continue to re-visit these themes throughout the research process.* (Week 3 of the co-operative Inquiry– Researcher's observations)

In this stage of the model, actions begin to emerge from within the inquiry group which is apparent in the establishing phase of the inquiry. As the inquiry group began to gather their own experiences of living with dementia, inside inquiry actions developed where time was taken between meetings to reflect on the experiences which was then brought back for group discussion. This was a continuous action of stepping together throughout the co-operative inquiry process.

The third theme identified from the data was education. The inquiry group were keen to educate the general public with a core message. Developing this core message was when stepping together played a pivotal part in the development of a creative and meaningful message for the action output.

> *The co-researchers identified several core messages that they wanted to deliver: time, patience, education, understanding and compassion and as a whole, the inquiry group needed to figure out how this could be delivered. The inquiry group worked expressively with words and statements to develop some core ideas that they wanted to be delivered through the animation…One of the co-researchers suggested they could encourage people to have a 'cup of compassion' which led to us exploring people having a cup of 'something' as a metaphor. The group explored breaking down the word 'cup' to compassion, understanding and patience and felt this would deliver the core message in*

> *a relatable and accessible way but would also be memorable…* (Week 6 of the co-operative inquiry – Researcher's observations)

The development of the script was another collaborative action, where the co-researchers and facilitator stepped together to combine and condense the data that had been collected into a two-minute script with a clear educational message within it. Although I took a lead on this action as described in stepping forward, it was continually brought back to the group for feedback and discussion.

> *The first part of our meeting involved reviewing the script I had sent to the co-researchers in January… This was a developing area of practical knowing for both myself as facilitator as well as the co-researchers.* (Week 7 of the co-operative inquiry – Researcher's observations)

Stepping together was also evident in the initial meeting with the animator. Meeting with the animator was a new experience for the inquiry group as until this point, there had been no other external influences. It was only with unanimous agreement that this external partner was invited into the inquiry group space and the meeting subsequently had a positive impact on all of those involved. The animator reflected on how useful this was in our partnership:

> *… I found coming and meeting them really, really helpful, it's not on every project that I get to meet the people who the project is for or with and that was so helpful, not only do the sketches for them but to hear their stories first-hand. That really made a difference...* (Quote from transcript of interview with the animator)

The group also reflected how beneficial this was to them in meeting the person who was going to develop their experiences and gain some feedback on what they had worked so hard on bringing together:

> *The animators was positive in his feedback of the script and felt it would work well alongside an animation and I could see the helpful and positive effect this had on the group. Up until this point, the inquiry group hadn't had any feedback on what we were doing and with no previous experience of this kind of project, it was reassuring to have*

> *this feedback and approval.* (Week 8 of the co-operative inquiry – Researcher's observations)

Stepping together is where the foundation of co-research lies. Without this stage, the collaborative nature of this type of research would not exist. This stage reflects the cohesion of the research group and then coming together of the facilitator and co-researchers in equal partnership. This stage is where the richest data will be collected and analysed and will form the basis of the desired outcome of the co-research. The importance of this stage of the Stepping model cannot be undervalued and if the facilitator of a group is not continually returning to this phase it could be queried wherever the research is indeed participatory. This stage helps the facilitator to keep sight of the goals and desired outcomes of co-research and assists in re-balancing the power between initiating researchers and co-researchers. Stepping together ensures the co-researchers feel empowered and involved in the research process but also supported if they find themselves exploring unfamiliar territory. This is of particular relevance to co-researchers who may not have an academic or research background.

5.3.3 Stepping Aside

This third stage of the model is where the inquiry group facilitator withdraws from the inquiry group but is fully prepared to step in again should this be necessary. It involves gradual but continual observing of the inquiry group in action. Stepping aside occurred during some of the reflective phases of the co-operative inquiry. After the group was established and we had decided to collate the lived experiences of living with dementia, I naturally stepped aside. I do not have any experience of living with dementia and therefore my contributions would not be appropriate at this stage. The co-researchers gathered their experiences and reflected on them in their own time, away from the inquiry group and it was important to ensure they had space for this.

> *As the inquiry group had decided that they would explore the experiences of living with dementia with reference to stigma, the co-researchers agreed to take their diaries home and record their experiences to share with the rest of the group at the next meeting.* (Week 1 of the co-operative inquiry – Researcher's observations)

I also stepped aside when it came to the narration of the animation. Stepping aside in this case ensured that the power of the inquiry group sat squarely with the co-researchers. Being critically aware of my influence on the co-researchers and the underlying agenda of completing doctoral research, I was conscious that sometimes the power differential lay with myself as the facilitator.

> *The group felt strongly about narrating the animation themselves as it ensured that their voice was recognised and would be relatable to other people going through similar experiences.* (Week 7 of the co-operative inquiry – Researcher's observations)

This was something that the co-researchers really took ownership of and at no point did I feel it was necessary or appropriate for me to step back in at this stage. It is also interesting that the animator also highlighted the group's self-narration as a real stand out point of the animation:

> *… I think it really helped that they were doing the voiceover for the animation and that made it extra special, quite a lot of the time you use professional voiceover artists and or even with nurses or caregivers doing the voiceovers and with professional voice overs it's very slick and very clear but you do not get the real person or the real personal feel like you have with your project…* (Quote from transcript of interview with the animator)

As the undertaking of a co-operative inquiry was a new experience for all members of the inquiry group, this stage in the model was used less than others as I was often looked to for guidance in an unfamiliar process. Stepping aside is underpinned by time and confidence in the resilience and functioning of the inquiry group. On reflection, I propose that if the same group of co-researchers were to form another co-operative inquiry, the stepping aside stage would be used far more frequently as the co-researchers develop in self-belief and ability. As a researcher, I also believe that as my skills grow in the facilitation of participatory and collaborative research, my own confidence would enable further application of this stage.

5.3.4 Stepping Away

This is the final stage of facilitation and is when the inquiry group comes to an end, this title marking this transition. However, it is important to note that role of the facilitator does not end at this stage. In stepping away, there is a direct link back to stepping in, for example to finalise report writing and dissemination activities working alongside inquiry group members but in a more egalitarian and co-operative way wherever this is possible.

This stage is observed in some further practical aspects of the study including writing the final ethical report for the research ethics committee, developing this model and writing this thesis. Stepping away is also observed with the acknowledgement of ownership of the animation that was developed as part of the inquiry. The animation was the co-researcher's experiences, voices and result of their hard work and contributions, therefore ownership lay with them. Although I had planned to showcase this outcome in this thesis, this final product, the animation was not mine:

> *I reminded the co-researchers that although I was working with them as part of a doctoral study, this was their voices, their experiences and their animation. It would be publicly available via YouTube, but the group needed to ensure that the public knew it was there.* (Week 10 of the co-operative inquiry – Researcher's observations)

The ownership of the animation highlights the difficulty in stepping away, particularly with regards to dissemination of the production. The co-researchers had wanted me to take a lead on ensuring the animation was seen but I had limited time and resources for this.

Stepping away also encourages the opportunity to reflect on what may or may not have been done differently. Towards the end of the inquiry, I personally felt the time pressure and with particular reference to the launch party, I felt that could have been planned differently:

> *Reflecting on the launch party, I could see how this was an important step for the co-researchers to share their work with their loved ones and colleagues. We decided to hold this launch party in July and on reflection, I think we could have waited until the end of the summer as many people were unable to attend due to holiday commitments. Indeed, we had only one meeting to prepare for the launch party due to the holiday commitments of the co-researchers and I believe that more time to prepare for it and hosting it a later date would have resulted in bigger turnout and allowed for the message and animation to be shared more widely.* (The launch party of the co-operative inquiry – Researcher's observations)

After the animator had stepped away from the process, he had also had the time to reflect on his participation and interestingly how being involved in the inquiry group had actually changed his perceptions of people living with dementia:

> *Yeah it did change, it really changed my perceptions of dementia and yeah how people, you know it seemed like your group were really living full and interesting lives and I kind of initially thought that dementia was a slow road, you know, a slow decline but it just seemed that your group were really inspirational in showing that they… you know they say they just have to go on diversions, if their brain doesn't let them think a certain way, they have to go on a diversion around it and if they have forgotten a word, come from a different angle and that was interesting to hear and really opened my eyes to what living with dementia is all about* (Quote from transcript of interview with the animator)

Stepping away continues to be underpinned by time and relationships, including the emergence of friendships that involve the inquiry group facilitator. Although I stepped away at the end of this study, I had built a good rapport with all of the co-researchers and continued to stay in touch with them but also work collaboratively with them in delivering sessions about dementia to student nurses using the animation.

5.3.5 Skills and attributes of the facilitator

At the centre of the Stepping model is the facilitator. The facilitator embodies the inner circle within the Stepping model that the links and cycles through the outer circle's phases. In order, to embrace and conduct co-research using this model, the facilitator should possess and develop particular skills and attributes.

- Be Open-minded: This attribute involves approaching co-research without preconceptions and being open to whatever arises. It includes being open to different ways of considering and developing a research question and in what ways the co-researchers may wish to explore the chosen topic. Being open-minded in this study gave me a renewed appreciation for the perspectives and worldview of people living with dementia. I did not anticipate when I started this study, that by the end of the co-operative inquiry, the inquiry group would have produced such a powerful and emotive animation, nor did I appreciate the value the lived experiences that would be shared with me as a member of the group. Being open-minded is particularly important in the stepping forward phase of the Stepping model. As the facilitator steps forward to initiate the research or to take a lead on an aspect of the research process, they should remain open to how this may be perceived by the rest of the research group. The facilitator should be aware that the co-researchers may wish to make their own contributions to aspects of the research where the facilitator is stepping forward. There may be difficult conversations to be had if members of the research group disagree on decisions to be made during the course of the research and this should be handled sensitively and with respect for all parties involved. Being open-minded will also be good practice in the stepping together phase in being open to ways of collaborating and the different way each individual researcher will approach this. It is also a valuable attribute in the stepping aside and stepping away phases in trusting the research process and recognising when it is appropriate to adopt these phases.

- Be Creative: This skill is a fundamental part of co-researching with people living with dementia. Creativity can positively affect accessibility, understanding and impact of research. It can enable individuals to express themselves, their feelings and their experiences in ways that make sense and having meaning to them and others similar lived experiences. Creativity played an important part in the success of the co-operative inquiry including the collation of lived experiences of living with dementia, creation of a script and subsequent development of an animation. In the stepping together phase of the Stepping model, creative methods and thinking can enhance the collaboration between facilitators and co-researchers. Being creative can also be a useful skill in the stepping forward phase as the initiating researcher adopts imaginative methods for engaging with potential collaborators. The facilitator may also need to be creative in the way in which they step away from the research group in order to ensure that the co-researchers do not feel abandoned or left without any closure in the research process. In this study, I ensured to have a final meeting after the launch party to allow the inquiry group to reflect on what had been achieved, what had gone well and where adjustments could be made.

- Be Curious: This attribute contributes to the active exploration and facilitation of the research question. Curiosity opens new perspectives and creates new opportunities for alternative ways of undertaking taking research. In this study, curiosity allowed me to sit with the experiences of the co-researchers and develop a deeper level of empathy. Curiosity in exploring stigma and the lived experience of dementia facilitated a transformative and informative co-operative inquiry. As described by Heron (1996), a transformative inquiry includes the development of skills whilst an informative inquiry produces suggestions and ideas of the topic that has been explored. In this study, skills were developed by the inquiry group in producing a script and animation and in the art of action and reflection. The inquiry group also produced further knowledge in the development of the core message of '*Have a CUP, not of tea or coffee but of compassion, understanding and patience.'* Curiosity can be embedded in all four phases of the Stepping model by the facilitator in how they approach each individual phase and the potential impact of their approach on the co-researchers and the research process.

- Be Approachable: This attribute instils confidence in the co-researchers in the facilitator's administration of the co-researching process. Being approachable will not only assist with the recruitment of co-researchers but also with the creation of a safe space in which co-researchers can raise concerns or make queries about the research process. This trait will assist in developing trust and rapport within the research group which is fundamental to the success of co-researching. In this study, I strived to be approachable before, during and after the co-operative inquiry. Being approachable, ensured that I recruited people living with dementia to research with me and that they felt safe to ask questions as part of the inquiry group or individually. The co-researchers were given my work telephone number and email address and could contact me at any time during the inquiry process. I also ensured to remind the inquiry group that they could approach me at any time, particularly when we had recently made important decisions such as deciding on an animator to work with or who would narrate the script for the animation. Being approachable is an important train in all of the four phases of the Stepping model. It facilitates introductions and supports the building of relationships between the facilitator and co-researchers. In the stepping aside and stepping away phases, it ensures the co-researchers feel supported even when the facilitator may not be active in the research process at that time.

- Be Organised: This skill will develop over time as the facilitator becomes practised in facilitating co-researching with people living with dementia. Being organised does not just apply to the practical set up of the research but also includes setting expectations such as what the facilitator will contribute to the research process and what is expected of the co-researchers. This is something I have reflected on in this study and although I believe I was very organised with regards to the practical aspects of the co-operative inquiry, I feel I could have been stronger in setting expectations with regards to roles. I was clear with the co-researchers that I sought to collaborate on a research project with them, but I could have been clearer and defined expectations from the outset of the research. I expected to take a lead on the ethical approval process due to the inquiry being embedded in this thesis. However, I had hoped that the dissemination of the final action output, the animation, would be led by the co-researchers. As the animation was a result of the co-researcher's lived experiences and was so powerfully narrated by members of the group, I had anticipated that they would take ownership of the animation, yet this was not the case. It could be proposed, that setting the expectation of the co-researchers taking possession of their work from the outset may have encouraged them to consider early on in the research process how they would approach the dissemination of the animation and what support may be required. Being Organised is an essential skill throughout the four phases of the Stepping model but as highlighted above, it is particularly relevant when stepping forward. When stepping together, some of the organisation can be shared between the facilitator and the co-researchers including in setting expectations. As the facilitator steps aside, practical organisation considerations may then fall with the co-researchers, however the facilitator should be prepared to step back in to support if necessary. The same consideration should be given to stepping away as further support and guidance may be required by the co-researchers as the research comes to a close.

- Be Self-aware: As discussed throughout this thesis being reflexive and using the language of co-operative inquiry, being critically subjective, is a fundamental skill to possess in co-researching. It is not about disowning your beliefs or values during the research process but is about bringing attention to yourself and how your own thoughts and feelings may influence the research. Being self-aware is about acknowledging your potential influences and building on them in the search for objectivity. It is a concept I have reflected upon throughout this study and is evident in my discussions in Chapter Four. I was critically aware in my influence I had upon the group as person without any lived experiences of dementia. An example of this occurred when it came to discussing the core message in the script and animation. It was important for the voices of the co-researchers to be heard and I did not influence the message they wanted to convey to the general public. Although I helped to facilitate their thinking and reflecting through the use of a word cloud, these words were their own with their own particular meaning attached. I was aiming to be self-aware by stepping aside and ensuring the co-researchers found their own message that was embedded in what was meaningful to them. Another aspect of self-awareness for me in this study, was in my perspective of facilitating the co-operative inquiry through beginner's eyes. This was my first time facilitating a research group of any kind including co-operative inquiry and the process was as new to me as it was for the co-researchers. As an inquiry group, we were experiencing and working our way through a new and unfamiliar process and I often reflected on this whilst ensuring I offered appropriate guidance and support to the co-researchers when necessary. Self-awareness should be adopted during all phases of the stepping model as it is a vital part of co-researching with people living with dementia. It can cultivate a valid sense of consciousness with regards to our influences and perceptions of what is occurring in the research process and how we make sense of it along with the other co-researchers.

5.4 Power and group facilitation

Although I have aimed to address the traditional power imbalance in research through the use of participatory research (de Koning and Martin, 1996), this study was conducted as part of a doctoral project that was being produced to gain a postgraduate qualification. Therefore, there was an element of power that is solely controlled by myself. For example, findings have been produced by the research and presented in this doctoral thesis which the co-researchers have not directly contributed too such as the stepping model and the actual thesis writing itself. With reference to Heron's (1999) model of facilitation styles, there was a strong element of hierarchical authority existing within the inquiry. However, in acknowledging this and being critically aware of this idea from the outset of the study, I ensured to approach my facilitation from a caring, empathic and collaborative way. This involved honesty with the fact that this study was part of a doctoral study and that I had a limited time to achieve this. A factor that helped me to overcome any threat of dominating the inquiry was the building of relationships in the initiating phase. Whilst retaining my awareness of professional boundaries (Nursing and Midwifery Council, 2018), I spent time getting to know the co-researchers, listening to their personal histories and sharing some of my own and thus built up a level of rapport and mutual respect which was a crucial element to successfully completing the co-operative inquiry.

There was also the consideration that ethically, I could have determined that a person living with dementia no longer had the capacity to give informed consent to be a part of the study or that continuing to take part in the research is detrimental to their well-being. The power in this case lies with me to exclude the person living with dementia from taking any further part in the research, if a consultee could not be sought, even if the person with dementia still wants to participate. I had stipulated in my research protocol that if this situation were to occur, I would act in a sensitive and caring manner but would also engage with appropriate third parties such as carers, family members and the supervisory team to ensure that support to transition back to their day to day environment is in place (Dewing, 2007). However, I was not put in this position.

5.5 Summary

This chapter has explored the theory behind group facilitation with a broad focus but also considered group facilitation specifically with people living with dementia. The Stepping model has been introduced as a new and original model of facilitating research with people living with dementia and the four dynamic steps have been discussed with referred to the co-operative inquiry that took place including those reflections of myself as facilitator and the animator, our external collaborator. An exploration of the skills that support the facilitation of co-research with people living with dementia is also presented. A brief discussion of power and the imbalances that can occur was explored but with reference to the importance of relationships and their role in addressing power imbalances.

Chapter Six: Discussion and conclusions

6.1 Introduction

This chapter will present an overview of the main findings of this study including an exploration of the co-operative inquiry that was implemented with a group of people living with dementia and the original contribution to the research. The four study objectives will each be explored in turn with consideration of the findings. The Stepping model will be revisited with a discussion around how it contributes to the emerging field of co-research with people living with dementia and its potential use with other groups. Following this, I will explore the limitations of this study and critically reflect on my role as facilitator of the inquiry. The chapter will conclude with an outline of the implications this research has for policy, research, education and practice.

6.2 Original Contribution to the Literature

This study provided an original contribution to the literature by involving two people living with dementia and three care partners in the development of a co-operative inquiry. The lived experiences of the co-researchers were collected and analysed through cycles of action and reflection. Three broad themes were identified by the inquiry group: Positive Experiences, Negative Experiences and a Core Message (Education). These themes were adopted into a script which involved the narration of the lived experiences of the members of the inquiry group. Based on the observations of the facilitator and an external partner, a new and dynamic model of group facilitation was presented to support the facilitation of co-researching with people living with dementia.

6.2.1 Reflections on the existing literature

At the beginning of this study, there was very little written about co-researching with people living dementia. An initial scoping search in May 2016 identified only one article (Tanner, 2012) which explicitly considered and adopted the research approach of co-researching with people living with dementia. It was clear at this time, therefore, that the idea of co-researching with people living with dementia had not been given much attention in the literature compared to other groups such as people living with a mental health problem or people with a learning disability. Yet, as identified in Chapter Two, researchers had been involving people living with dementia in research beyond that of being participants but had not identified this collaborative working as co-researching. This highlighted the real difficulties with terminology in identifying appropriate literature to review and thus exploring what was a developing field of research. In the last couple of years, research in this area has moved on and is now developing a place in the literature with researchers identifying the benefits of involving people living with dementia as co-researchers (Mann and Hung, 2018; Swarbrick et al., 2019, Waite et al., 2019). Several studies have involved people living with dementia in data collection (Captick, 2011; Ward et al., 2011; Bartlett, 2012; Capstick and Ludwin, 2015) and further studies have involved people living with dementia in the data collection and data analysis of the research (Pipon-Young et al., 2011; Tanner, 2012; O'Sullivan et al., 2014). Few studies have involved people living with dementia in the design of the research, however Caine (2014) involved people living with dementia in the design of a study exploring the use of music to increase wellness within the home by adopting a participatory action research approach. Mann and Hung (2018) explored the treatment of people living with dementia in acute care settings and one of the researchers (Mann) was a person living with dementia. Mann and Hung (2018) identified that research in acute care was typically carried out on people living with dementia as opposed to with them and aimed to involve people living with dementia using an action research approach to "*co-develop knowledge for change"* (p. 573). The study by Mann and Hung (2018) presents the greatest involvement of people living with dementia in the research process that I have found in the literature, although it not clear how involved Mann, the person living dementia was in the design of the study.

Although co-researching with people living with dementia is an emerging field in dementia research, as my updated literature review in this thesis revealed, the actual voice of people living dementia is often lost or their role in the research process is not obvious. In an attempt to address this knowledge and practice deficit, this PhD study set out to address these concerns and identified the following objectives:

- To explore the creation of a co-operative inquiry with a group of people living with dementia and how this is subsequently facilitated.
- To develop an action output that had meaning and resonance for the formed group.

- To examine the facilitators and barriers in working collaboratively with people living with dementia in research.
- To evaluate the position of researcher reflexivity during the different stages of the co-operative inquiry.

This study aimed to explore the development, implementation and facilitation of a co-operative inquiry with a group of people living with dementia. These objectives will now be explored in relation to the study findings.

6.2.2 Objective 1: To explore the creation of a co-operative inquiry with a group of people living with dementia and how this is subsequently facilitated

As seen in chapters Three and Four, this study successfully explored the initiation and establishment of the inquiry group with an in-depth consideration of the phases of co-operative inquiry (Heron and Reason, 2006) that the group cycled through in their pursuit of exploring their experiences of living with dementia. The study was viewed through an observational lens by myself, as the facilitator and also incorporated the views and perceptions of an external partner. Whilst co-operative inquiry has been widely adopted as a framework for co-researching for many years (Heron, 1996), its use with people living with dementia has been limited and I believe this is the first in-depth and detailed study that has considered the facilitation of such an inquiry and how the facilitator's role needs further understanding and applied knowledge. As highlighted by Moriarty (2019), people living with dementia and their care partners can be involved in shaping research findings in a way that validates their lived experience and this co-operative inquiry further adds to this knowledge.

The COINED model considers research from the initial consultation phase, to designing, data collection, data analysis, dissemination, evaluation and future work (Swarbrick et al., 2019) and gives example of each of these phases. THE COINED model has been successfully applied within the dementia research field (Morbey et al., 2019) and I drew on its findings for the development of this study. However, the COINED model fails to consider the facilitation of co-research with people living with dementia which was something this study has addressed as I will go on to describe. Swarbrick and Open Doors (2017) do highlight some learning points from the development of the COINED model such as the importance of trust and rapport between co-researchers, minimizing the control of the academic researcher. and they also identified that facilitating as a member of the inquiry group requires certain skills which is also highlighted by Heron (1993) in his discussion of group facilitation. These learning points were all reflected upon in this study, in the discussion and reflections in Chapter Four.

The co-operative inquiry was initiated and established with a group of people living with dementia from the Open Doors Service in Salford, Greater Manchester. As reflected in Chapter Three, there were difficulties in engaging potential co-researchers without having a research question or topic to explore and this should be considered by the initiating researchers from the outset. Consultation meetings, before the application for ethical approval, were essential in developing the research question and providing clarity for the co-researchers. As the facilitator, I embedded the knowledge that this research was about what was meaningful to the co-researchers, and throughout the inquiry process it was evident how this had a meaningful impact on the exploration of self and their experiences.

At present, there is little evidence in existing literature that explores the facilitation of research groups with people living with dementia. Current evidence tends to explore the facilitation of exercise groups (Vseteckova et al., 2018), day care activities (Strandenaes et al., 2019) and interventions such as group singing (Unadkat et al., 2016) and woodland therapy (Puslford et al., 2000). When considering the literature on facilitation of research groups with people living with dementia, it would be of greater relevance to consider the guidelines and models that have been developed for researching with people living with dementia. For example, the COINED model (Swarbrick et al., 2019) which is of particular relevance to this study aims to consider research from a lens of a collaborative partnership in all phases of the research.

With consideration of this study, I followed this model to ensure that the co-researchers were involved in the co-operative inquiry from the initial consultation phase. The two final phases of evaluation and future work were not considered as part of the co-operative inquiry but in discussion with the co-researchers after the inquiry had ended, it was agreed that evaluating the animation was a potential piece of future work if time and resources allowed. At the heart of this model is the concept of research training and education for co-researchers (Swarbrick et al., 2019) and this was something that I was critically aware of however, facilitating and being part of the co-operative inquiry, was a new and experimental experience for myself as well as the co-researchers. On reflection, as an inquiry group, we learned and developed our knowledge as we went through the phases of action and reflection. In consideration of future work, I believe some elements of research training could be beneficial for co-researchers living with dementia such as understanding the ethics process and some basic understanding of thematic analysis. However, it would be important and authentic to ask the co-researchers what they would like training in, if anything, and evaluate the training collaboratively afterwards.

The core principles for involving people living with dementia in research (Scottish Dementia Working Group Research Sub-group, 2014) offers guidance for researchers on the involvement of people living with dementia as participants but can also be applied to co-researcher involvement. One of the risks highlighted by the paper is that people living with dementia can be ‘used’ by researchers or involved as a token gesture (Swarbrick, 2016) and as I have highlighted in Chapter Four, this was something I was critically aware of. I attempted to address this by ensuring the co-researchers were aware that they could withdraw from the co-operative inquiry at any time and keep the focus of what we were researching on what was meaningful to them. I found the guidance from this paper, incredibly useful in my facilitation of the co-operative inquiry as although I have a history of working with people living with dementia, this has primarily been in clinical settings and research environments are a completely different setting, in particular in the community. The core principles offer some guidance for attributes that researchers should possess in working with people living with dementia such as empathy, compassion and tolerance and I feel that these are attributes that I naturally brought to the research process and displayed in Chapter Four. However, there is little discussion about the skills that researchers require in the core principles (Scottish Dementia Working Group Research Sub-group, 2014) and guidance on when to step forward or away from the research process.

The co-operative inquiry may have been different if people without the lived experience of dementia were included. I did aim to avoid being paternalistic in this approach, but I also wanted to ensure that the research was accessible. I avoided the use of any complicated software or technology and adopted an approach to data analysis that was loosely based on thematic analysis but avoided the use of technical jargon. The facilitation of the co-operative inquiry could have involved the wider inquiry group if the process consent model did not have to be used. However, as I set out to actively involve people living with dementia in this research, adaptions did have to be made and accessibility to the research had to be considered at all times.

6.2.2.1 Terminology in co-operative inquiry

Before starting this PhD, I was unfamiliar with the concepts of co-operative inquiry. As I began to research the methodology, it was evident it had been used widely in various settings including healthcare (Manley et al., 2008; Trollvik et al., 2012; Nkomazana et al., 2016). Within the mental health field, co-operative inquiry has been used in the study of nurse-service user relationships (Hostick and Mcclelland, 2002) and the exploration of de-escalation techniques in mental health settings (Berring et al., 2016). Co-operative inquiry is a very broad and flexible approach to researching with people as opposed to on them (Heron and Reason, 2006) and that flexibility and creativity ensured it was an appropriate choice of methodology for this study.

One of the main difficulties I had with co-operative inquiry was the intensive use of jargon and terminology that was employed by its creators in the theoretical description of the methodology. The descriptions and conditions of co-operative inquiry go beyond what I have presented in Chapter Three. I have described in detail the practical application of co-operative inquiry from Heron’s (1996) seminal work on the methodology but only briefly discussed the philosophical application. Although the philosophical concepts behind co-operative inquiry are important, this study was focussed on the practical application of the approach. The principles of co-operative inquiry were introduced in Chapter Three, however, my view is that the central meaning and relevance of the research to the co-researchers was what was important, not the philosophical notions behind co-operative inquiry. Reason and Heron (1999) did produce ‘A layperson’s guide to co-operative inquiry’ which was a good introduction to the methodology and could potentially be used with co-researchers and novice researchers to help them understand the approach further. As discussed in Chapter Three, a limitation of co-operative inquiry is that it assumes capacity of all those involved, including capacity to consent and capacity to understand. Whilst the Stepping model is not offered as a replacement for the methodology, it has been developed as an aid in co-researching with people living with dementia using co-operative inquiry or another participatory approach.

6.2.2.2 Ethical challenges in the co-operative inquiry

The COINED model was also developed in the early stages of the Neighbourhoods and Dementia Study and was classified as a PPI activity (Swarbrick et al., 2019), therefore its development did not require ethical approval. In contrast, this PhD study and co-operative inquiry has presented some of the ethical challenges that are associated with co-operative inquiry with people living with dementia which is missing from existing research in this field. Positioning the members of the inquiry group as co-researchers proved difficult with the original ethical submission being rejected and I believe this was due to a lack of understanding of the methods being employed but also consideration for the valuable contributions people living with dementia can make to research. A co-operative inquiry that did not involve people living with dementia would likely have encountered less resistance in the ethics application, particularly with regards to the Mental Capacity Act (2005). However, as discussed in Chapter One, the Mental Capacity Act does highlight that individuals should be assumed to have capacity unless proven otherwise. A diagnosis of dementia does not mean that a person lacks capacity.

The ethical challenges of co-researching with people living with dementia are not unique to co-operative inquiry. Clarke et al. (2018) conducted secondary data analysis with a group of people living with dementia and had aspired to position the people living with dementia as co-analysts in the research. However, on the advice of research ethics boards in both England and Scotland, they were advised and subsequently acknowledged the people living with dementia as participants and not co-analysts. Clarke et al. (2018) are some of the few researchers who have reported on the ethical challenges presented when co-researching with people living with dementia however, the difficulty of research ethics boards not appreciating or understanding the potential contribution of vulnerable groups also exists within the wider disability community (Gustafson and Brunger, 2014).

By adopting the methodology of co-operative inquiry, this study aimed to involve people living with dementia in every part of the research process. There were some limitations to this such the co-researchers not being directly involved in the ethical approval process but I consider the co-researchers to have been involved in the design, data collection and data analysis elements of the co-operative inquiry and I believe there are no existing studies in the literature that have involved people living with dementia to this extent.

6.2.2.3 Disseminating the research

One element of co-research that has not involved people living with dementia in this study is the dissemination of the findings There are two elements to dissemination in this study. The first being that of the dissemination of the action output, the animation. The co-researchers were encouraged to take ownership of their animation and there was a reluctance on their part on how this could be approached, Despite this one, of the co-researchers is an active Twitter user and we both used this form of social media to raise awareness of the animation and share it with our networks. The use of social media and in particular Twitter, has been shown to have potential use in engaging with hard to research and diverse communities (Schnitzler et al., 2016). People living with dementia are actively engaging with Twitter to raise awareness, challenge stigma and provide support to their peers (Talbot et al., 2019) and therefore our use of Twitter as a dissemination method is particularly relevant with the target group of people living with dementia and their networks. The use of Twitter has been shown to be a modern, easy, cost effective and fast way to disseminate research (Schnitzler et al., 2016) and therefore was a suitable way to raise awareness of the animation with our limited time and resources towards the end.

The co-researchers in this study have been involved in the dissemination of the final action output, the animation but have yet to be involved in the dissemination via written works e.g. journal articles or conference presentations. This is something I hope to involve the co-researchers in when it comes to publishing from this thesis. Writing is a fundamental part of co-operative inquiry (Reason and Heron, 1999) and as part of the dissemination process. Unfortunately, it can be dependent upon funding whether the support required for this is in place. Involving people living with dementia in the dissemination of findings via written works is evident in the literature (Ward et al., 2011; Bartlett et al, 2015; Mann and Hung, 2018) and the placement of people living with dementia as co-authors is visible with the use of their real names. However, not all of the research studies that have included people living with dementia in dissemination have included their real names (Swarbrick and Open Doors, 2017; Swarbrick et al., 2019) and have instead referred to the research groups instead. As a co-author on Swarbrick et al's. (2019) paper, I am aware this was not a logistical decision due to the large number of people but that each contributor was given the opportunity to be named individually, however it was decided by the groups that they wished to be recognised as a collective. In future research, it is important to give credit to people living with dementia who are involved as co-researchers and academic researchers should give them the opportunity to contribute to written works. This is fundamentally about human rights and the right to choose wherever to have their contributions acknowledged (DAI, 2016; Cahill, 2019). With the adoption of a human rights approach, that decision should lie with the person living with dementia.

6.2.3 Objective 2: To develop an action output that had meaning and resonance for the formed group.

The aim of achieving an action output which had meaning and purpose to people living with dementia was achieved in the creation of a script that reflected the co-researcher's experience of living with dementia, which was subsequently developed into an animation as decided by the inquiry group. This script was formed through the identification of three key themes from the lived experiences of the co-researchers. These themes were developed by the use of an adapted form of thematic analysis. The use of thematic analysis was appropriate for this study as it fits well with the qualitative nature of the research and exploration of human experience. The use of thematic analysis has also been employed in other studies that involved co-operative inquiry (Hostick and McClelland, 2002; Tee et al., 2007) and the flexibility in the approach of this method was particularly useful in working with people living with dementia as there was not a rigid, prescribed method to follow. The group did not adopt a rigorous analysis method such as Braun and Clarke's (2006) six phases of thematic analysis as the training was not in place to support this, however, the co-researchers were naturally following a deductive approach (Braun and Clarke, 2012) and deriving the data from the collected experiences. The inquiry group collaboratively agreed on three broad themes: positive experiences of living with dementia, negative experiences of living with dementia and that the group had a core message that the group wanted to deliver to educate the general public,

From these themes, a script was developed and there was a discussion over a number of inquiry group meetings as to what the co-researchers would like to do with the script. Subsequently, it was agreed by the inquiry group that the script would form the basis of an original animation. The animation was created with an external partner, a professional animator who worked closely with the inquiry group to bring their experiences to life. The animator had not working with people living with dementia before and as well as reflecting on what worked well for them in collaborate process, they also highlighted how it changed their own perceptions of what dementia is and what it is live with the condition. Ensuring their voices were heard was recognised in that the co-researchers narrated the script themselves as opposed to using a professional voiceover artist.

6.2.4 Objective 3: To examine the facilitators and barriers in working collaboratively with people living with dementia in research.

The practical aspect of conducting this study reinforced that co-research with people living with dementia can be successfully realised but that further guidance in the facilitation of co-researching with people living with dementia was necessary. There were a number of facilitators, methodological challenges and barriers to co-researching which were evident in this study and will now be discussed in further detail.

Barriers

- **Time** was a critical component in this study. I underestimated the time it took to initiate and establish the co-operative inquiry group and with the subsequent ethical delays, the research did not commence until the beginning of my third year of the studentship. It took over a year to recruit and establish the inquiry group and gain ethical approval, and this experience is a key consideration for future work. As highlighted in the core principles of involving people living with dementia (Scottish Dementia Working Group Research Subgroup, 2014), people living with dementia need time to process and reflect on their involvement and contributions. The inquiry group initially met fortnightly and on reflection, I believe this was an appropriate length of time between meetings. Weekly meetings would have felt too rushed and when we moved to monthly meetings in the final six months of the research process, it often felt like there was too much time between meetings. However, at some points in the inquiry process this was helpful as there were ethical amendments to apply for and to give the animator time to create the animation.

- **Recruitment** to the inquiry group was initially difficult. I had the support of an enthusiastic service manager and was recruiting from a research active group of people living with dementia, but I believe that one of the difficulties in initiating the group as reflected on in Chapter Three, was that I was very vague about what we were going to research. I wanted to stay true to the co-operative inquiry process by researching a topic that was meaningful to the inquiry group members but without some ideas to present at these initial consultation and initiating meetings it proved difficult to gauge any interest. In the future, I would look to present specific research ideas that may be of interest to potential co-researchers but ensure they were aware that this could change and develop as we began the inquiry.

- **Power** has been running a theme throughout this thesis and one that I was critically aware of from the beginning of the research process. As highlighted in Chapter Five and earlier in this chapter, there was always going to an underlying agenda with this research in its contribution to this thesis. However, I believe that by being aware of this, I adopted a position of critical subjectivity and tried to actively minimise my influence on the group and step aside and away from the research process when appropriate. Another consideration of power is that of research ethics committees and their potential to deny people living with dementia to have their voices heard in the research that concerns them. There is a gap in the knowledge and understanding of this kind of participatory research and as Clarke et al. (2018) highlighted advice is sometimes given to position people living with dementia as participants, even if their involvement extends beyond that.

- **Capacity** is a consideration for all research involving people living with dementia and is often viewed as a barrier to implementation. The initial ethics protocol stated that I would like to include people living with dementia who may not have capacity to consent and I had included a robust structure of gaining consent via a consultee, however this protocol was rejected and on the next attempt at gaining ethical approval I removed the request for including people who may lack capacity to consent. In this study, the people living with dementia were stable in their presentation of symptoms in the initiating and establishing phases of the inquiry and had capacity to consent to take part as co-researchers. As described in Chapter Three, capacity was continually assessed by the process consent method (Dewing, 2007), however I successfully argued that should the people living with dementia taking part in the research become unable to consent to take part that efforts would be made to gain consent through the consultee process. I felt strongly about this due to the nature of the co-operative inquiry and that it would be ethically and morally unfair to automatically deprive someone of their rights to take part in research that they had helped to design and develop and that had meaning to them.

- **Ethics** is a repetitive theme of concern throughout this thesis and the difficulties that were experienced in gaining ethical approval for the study have been highlighted in previous chapters. I have a deep appreciation and understanding for the role in research ethics committees play in protecting some out most vulnerable members of society, however this should not be at the detriment of ensuring that those members of society have their voices heard and acknowledged in the research process. With appropriate support and rigorous capacity assessment processes, safeguarding and distress protocols in place, vulnerable populations such as people living with dementia can be supported and empowered to lead on research that has meaning and relevance to them.

Facilitators

- **Creativity** was a key facilitator in this study. Creative methods have been used widely in dementia research including the use of music (Riley et al., 2009; Dowlen, 2019) and visual art (Miller and Hou, 2004; Cummings et al., 2005). As highlighted by Bellass et al. (2018) creativity plays an important part in inclusive research practices and supports the idea of personhood. Creativity allowed the inquiry group to gather and analyse their personal experiences and produce an action output that was accessible and presented in an engaging way. Creativity also empowered the co-researchers to construct a core message based around the metaphor of having a cup of tea. The core message was relatable but also powerful in its construction.

- **Activism** is a growing component within the dementia community. As highlighted in Chapter One, significant numbers of people living with dementia are actively campaigning for social change and for their human rights to be acknowledged (Bartlett, 2015). Groups such as the Scottish Dementia Working Group have helped to establish the creation of a UK-wide network of groups (DEEP) committed to advocating for the rights of people living with dementia (Thomas and Milligan, 2017). The Open Doors service is also a member of DEEP and members of Open Doors are active in campaigning locally and developing services that contribute to their sense of citizenship. Being passionate about voicing their opinions and experiences of living with dementia, ensured the co-researchers involved in this study, had their voices heard and acknowledged in the research and subsequent action output. Involving people who are active in raising awareness of living with dementia was an important facilitator in this study.

- **Relationships** are a vital social construct of our society and the relationships I had with the co-researchers played a key part in the success of the co-operative inquiry. I spent a significant amount of time in the consultation and initiating phases getting to know the members of the co-operative inquiry and building up trust and rapport. Having these attributes in the relationships with the group contributed to a space where all members of the inquiry group, including myself, felt we could talk honestly and openly about the research process. I viewed and approached the co-researchers as partners and with the establishment of the ground rules that were presented in Chapter Three, there was a firm sense of respect, trust and genuineness amongst the inquiry group. I believe that spending that time getting to know the co-researchers contributed to the success of the inquiry.

- **Support** was a consideration that was built into the research protocol for this study. Not only could the co-researchers approach myself as the facilitator for additional support, they also had access to a clinical psychologist as part of the Neighbourhoods and Dementia study. The co-researchers could ask to be referred to the psychologist by myself or they could self-refer giving them more than option to gain further support. I have also reflected on the additional support that I was afforded in the co-operative inquiry process. The support of the service manager of the Open Doors service was invaluable to the recruitment of the co-researchers and the support of my supervisory team was essential in guiding me through the PhD process. Further support came from approaching external experts in creative writing when it came to the development of the script and also in a skype call, I had with John Heron in November 2017, prior to initiating the inquiry. As the creator of co-operative inquiry, I had emailed him asking for guidance on the process and he had kindly offered to talk with me from his home in New Zealand. Heron's main piece of advice was to focus on what the action output would be. At the time that I spoke with him, the inquiry group had not yet been established so I did not know what our output would be, but I kept this advice with me throughout the initial stages of the inquiry.

- **Flexibility** on the part of the facilitator was a crucial part of the success of this co-operative inquiry. I ensured to be flexible with time and availability in order to ensure that we could meet as an inquiry group as often as the co-researcher's availability would allow. There was a limit to the flexibility of time due to the constraints of the studentship and being required to complete the research by September 2018 but with regards to times and dates of meetings, I worked around what suited the co-researchers. Being flexible in the approach to the research also allowed for creative methods to arise.

6.2.5 Objective 4: To evaluate the position of researcher reflexivity during the different stages of the co-operative inquiry.

A critical aspect of participatory research is the on-going consideration of researcher reflexivity (Vallianatos et al., 2015). As discussed in Chapter Three, the idea of reflexivity draws parallels with the co-operative inquiry concept of critical subjectivity and is critical part of the research process. Reflexivity was a critical component in this study and without it, would not have produced the findings in Chapter Five. The Stepping model was constructed based on my own reflections and the reflections of an external partner. In my field notes, I noted not only my observations of the co-operative inquiry process but also my reflections which allowed me to be critically aware of my influence on the inquiry group. To be fully involved with the co-operative inquiry process, I shared my reflections with the inquiry group, often when I felt like the power dynamic was shifting towards me as the facilitator. Interestingly, the co-researchers never voiced any concerns about this and seemed to appreciate and understand that was an underlying agenda with this research in that it would form the basis of my PhD thesis.

Although I would share concerns about potential power imbalances, one thing I did not share and was perhaps disingenuous about was my concerns and frustrations with the research ethics approval process. I believe this was out of concern for the potential impact this could have on the co-researchers. Whilst Heron and Reason (2006) state that in order to truly understand our world views and experiences, we should be willing to embrace difficult subjects and distress, I still had an ethical responsibility to minimise distress which was built into my research protocol (See

Appendix 18). Reflecting back on this, I can understand this my own moral and ethical struggle in managing the desire to embrace the methodological process and managing distress as a researcher and registered mental health nurse.

It is a consideration for future work whether it would be ethically or morally responsible to consider distressing and sensitive topics with people living with dementia in co-research and how this could be facilitated. Stigma, which was the chosen topic of inquiry for this study can be distressing and emotive yet there were no episodes of distress witnessed by or made known to me. Ultimately, if an inquiry group decided that they would like to explore a distressing topic as this had meaning to them, it would be up to the facilitator to manage this sensitively. This would also depend on ethical approval being granted, which as this study has shown is not always straightforward.

Reflexive skills have been built into the Stepping model and are a fundamental part of co-researching. Without reflexivity, the influence of the facilitator could have a detrimental effect on the co-researching process and result in an outcome that does not reflect the goals of the co-researchers or inquiry group.

6.3 The Stepping Model: Considerations for Future Application

The findings of this study incorporated two distinct considerations of the co-operative inquiry, ‘what’ we did and ‘how’ we did it. As reflected in Chapter Four, ‘what’ we did was explored through a week by week analysis of the research process and cycling through the phases of a co-operative inquiry. Although the COINED model (Swarbrick et al., 2019) offers considerations of the phases of research to work collaboratively with people living with dementia, it does not offer guidance on how to facilitate these phases. The core principles of involving people living with dementia (Scottish Dementia Working Group Research Sub-group, 2014) offer guidance on conducting research that involves people living with dementia but does not specifically address co-researching and the additional skills and considerations that are required for this type of research. This is where the Stepping model offers an original contribution to the growing body of knowledge in this area.

Chapter Five discussed ‘how’ the co-operative inquiry took place including an exploration of group facilitation and introduced the Stepping model as a tool for group facilitation when co-researching with people living with dementia. The Stepping model (See Figure 13) introduced a four step, dynamic and interactive approach to facilitating co-research with people living with dementia. The Stepping model specifically considers the facilitation of co-research with people living with dementia with directions on when to step in, step together, step away and step away in the research process. In these steps or phases, guidance was also given on both personal and research skills and attributes that assist the facilitator in successfully supporting the research process. As far as I am aware, there is no model in the current literature that supports co-researching with people living with dementia in research.

The Stepping model was developed based on the findings in Chapter Four and in discussion with my supervisory team as reflected upon in Chapter Five. The next step would be to apply and evaluate the model in a future piece work involving co-researching with people living with dementia. Evaluation is an important part of research in assessing wherever the findings or in this case, the model is applicable in the settings it has been designed for (Dane, 2011). As the model was designed based on the empirical findings of this study, it would be proposed that it does apply to what it was designed for, but this should always be evaluated further. As this model is dynamic and interactive, it would appropriate to evaluate it in a real-world setting with input from the co-researchers involved in the inquiry group as well as the facilitator’s reflections. The input of the co-researchers in this inquiry would have strengthened the development of and supported the validity of the model. Bringing a critical eye to the model from a different perspective than that of the facilitator would limit the inherent bias that occurs within co-researching.

The Stepping model is designed to be accessible and avoids the use of complex jargon in that it could be applied and used with any research population including other vulnerable and under-represented groups in co-research such as people with learning disabilities. Co-researching with people with a learning disability has a much broader literature base and strong history in disability studies (Nind and Vinha, 2013) compared to co-researching with people living with dementia. Co-researching has been applied to such diverse topics as health improvement with people with learning disabilities (Walmsley, 2004), in an exploration of daily life in Ireland (O’Brien et al., 2013) and in examining the human rights of people with learning disabilities (Roberts et al, 2012). Co-operative inquiry has also been successfully applied in research with a group of people living with a learning disability in an educational setting (Scott, 2011). It is a consideration for future work to apply the Stepping model and evaluate its use in working with people with learning disabilities.

The Stepping model could also be applied in working with other vulnerable groups and groups of people where capacity would be assessed such as people with severe and enduring mental health problems and people with brain injuries. In keeping the model accessible, it could be proposed that this model could be used by people from vulnerable and underrepresented groups without the input of an academic researcher who aimed to facilitate research independently. Although, I anticipate this could be difficult without any formal research training, if a methodology such as co-operative inquiry is adopted which has a very broad and creative remit, it could be possible. As I have already discussed, I believe that the co-researchers in this study and myself learned as we proceeded through the phases of co-operative inquiry and this could be the outcome for others interested in these methods.

6.4 Study Limitations

Although this study showed the successful implementation and facilitation of a co-operative inquiry with people living with dementia, and met the study objectives, there were a number of limitations with this approach. With regards to the use of co-operative inquiry, there are some queries raised about generalisability. Co-operative inquiry is concerned with exploring a subject that is meaningful to the inquiry group (Heron and Reason, 2006). Therefore, what is explored may be very individualistic and specific to that group. Forming a co-operative inquiry with another group of people living with dementia could produce an entirely different topic of exploration. Even if the same topic, in this case being stigma, is explored, the action outcome could vary dramatically as co-operative inquiry is concerned with exploring and making sense of the inquiry group’s own perceptions and experiences (Heron and Reason, 2006). Reflecting on the personhood (Kitwood, 1997a) and social citizenship (Bartlett and O’Connor, 2010) models of dementia, it is clear that every person living with dementia is a unique individual and will view the world differently from their peers. After viewing the animation that was produced as a result of this co-operative inquiry, people living with dementia may be able to relate and have empathy with experiences of the individuals who created the animation, however, they may not have created or produced the same outcome. However, Heron (1996) would argue that co-operative inquiry is not concerned with external applications of its findings but of the internal validity of the process. As discussed in Chapter Three and reflected upon during the research process in Chapter Four, there are a number of validity procedures that are suggested by Heron and Reason (2006) to improve the quality of knowing and action.

A second limitation of this study was the demographic background of the recruited co-researchers. As mentioned earlier in the thesis, the co-researchers were recruited from the Open Doors service based in Salford, Greater Manchester. Salford has not attracted the same culturally diverse and minority ethnic groups as other parts of Greater Manchester (Cooper, 2005) and based on the last census from 2011, 84.4% of people living in Salford identity as White British (Office for National Statistics, 2011). This was reflected in the inquiry group as all members of the group were White British and thus the voice of people from other ethnic backgrounds was not evident in this research.

A third limitation of this study which has been reflected on throughout this thesis is that of ethics and the ethical approval process. As this study was focussed on researching a subject that was meaningful to people living with dementia, it was important that the co-operative inquiry group had been initiated and formed prior to the ethics submission. This limited the data collection prior to ethical approval which would have added a further level of information to the study. The ethical approval process was particularly difficult, and I felt that there was limited understanding from the research ethics committee of the importance of ensuring that people living with dementia were involved in the research process. Although ethical approval was eventually obtained, the experience I had showed a need for wider recognition of co-researching, particularly with vulnerable and under-researched groups of people within the research community.

6.5 Implications and Directions for Future Work

The findings of this study have a number of implications policy, research, education and practice. The following section will summarise the recommendations for each of these areas. With regards to practice, I have viewed this area from the perspective of a healthcare professional.

6.5.1 Recommendations for Policy

- This study shows that co-researching with people living with dementia is possible and can be successful with the right support in place such as a skilled facilitator. There have been calls to action for the recognition of people living with dementia and their contributions to research (Scottish Dementia Working Group Research Sub-group , 2014 Gove et al., 2018) but it is yet to be firmly embedded in policy.
- Policy needs to recognise that the voice of people living with dementia is an important driver towards ensuring appropriate care and support is available for people living with dementia.
- Policy should be driven by what is important and meaningful to the group that it is being directed at and should acknowledge the expertise of those with lived experience. At the same time, policy should also recognise that what is meaningful to a person will differ based on that individual’s needs and wants.
- There is a need to address the policy of ethics boards at institution and national level in recognising the contributions of people living with dementia to research. This study was given ethical approval with the condition that the people living with dementia involved in the study had capacity to consent. It should be acknowledged that those who may lack capacity still have human rights and therefore the right for views and opinions to be acknowledged.

6.5.2 Recommendations for Research

- The application of the co-operative inquiry framework in future research with people living with dementia will add to this developing field where research is built around what is meaningful to them.
- The use of the Stepping model will provide a framework for assisting researchers in their facilitation of co-operative inquires and other creative methods of working with people living with dementia. The model will provide guidance on when it is appropriate to ‘stepping forward’ such when as applying for funding and ethics. ‘Stepping together’ when a collaborative approach is needed such as developing a research question, identifying ways of collecting data or analysing data. ‘Stepping Aside’ in order to address any incongruent balance of power that may be resting with the facilitator and ensuring

ownership of the work with the co-researchers and 'stepping away' as the research reaches its conclusion but doing this sensitively and ensuring all co-researchers involved feel the process has come to a natural end.

- Reflecting on the difficult experience I had with gaining ethical approval for this study, this work could be used as guidance in recognising the importance of the voice of people living with dementia and their role as co-researchers with ethics boards and approval panels. This study has shown that co-research with people living with dementia can be successful and this should be recognised as a valid way of developing our knowledge further in the dementia research field.
- There are possibilities for developing the Stepping model further with other groups of people including people with mental health problems, people with learning disabilities, care leavers or others who have traditionally struggled to have their voices heard and recognised.
- The Stepping model could also be evaluated and enhanced in collaboration with people living with dementia to explore their perceptions of the model and wherever it goes far enough to aid facilitation in co-researching. This would increase the validity of the model.
- The inclusion of diverse populations in co-researching with people living with dementia is an important consideration for future research as what is important for people such as those from black and ethnic minority backgrounds may differ from what was identified to be meaningful in this study. Researchers can take a lead on this by purposefully 'Stepping in' with under-represented groups to facilitate this opportunity.
- Reflecting on the difficulties I encountered with terminology in the literature review, there is a recognisable need for consensus on the use of language in co-researching with people with dementia. I highlighted in Chapter Two what I view the distinctions are between peer research, participatory research and co-research yet the terms are often used interchangeably. Agreement within the research community about the terminology used in this type of research would add a significant contribution to this emerging field of research.

6.5.3 Recommendations for Education

- In the teaching of research methods, it is important to acknowledge the strengths and benefits of creative and participatory methods such as co-operative inquiry that challenge the traditional researcher/participant paradigm.
- There must be a broader understanding of the benefits of co-researching with people living with dementia and how can this contribute to a wider understanding and development of the dementia research sphere.
- The use of creative action outcomes such as the animation in this study has been used in higher education as an example of co-researching with people living with dementia and further creative output methods will enhance this reach, particularly in an ever-increasing digital world.
- PPI is often now used in educational settings in the development of core programmes such as the nursing undergraduate degree. The Stepping model could be implemented here to support academics in their facilitation of this as I am not currently aware of any models that are used in higher education for the development of curriculums with external stakeholders such as members of the public.
- The language of co-research with people living with dementia should also be consolidated in education with a consensus reached to ensure accessibility for researchers and educators alike, looking to explore the valuable contribution people living with dementia can make towards education on the topic of dementia.

6.5.4 Recommendations for Practice

- The concept of co-researching with people living with dementia is a developing field and research in the dementia care sphere tends to focus on involving people living with dementia as participants with little consideration of wherever the research has meaning to this group. This study shows that meaningful and powerful findings and contributions can be achieved with the involvement of people living with dementia as co-researchers.
- Since the introduction and development of personhood (Kitwood, 1997) to dementia research and care, there has been a growing focus on the ‘person’ and their history but there still remains a lack of consideration for what is meaningful to that individual. Exploring what is meaningful to the co-researchers involved in this study has essentially

put the co-researchers at the centre of the research and enriched the data and findings that came about from it.

- The use of observation can be a powerful tool when co-researching with people living with dementia, however as other studies have found the use of video and audio as a data collection method can bring a sense of embodiment to the data and offers a further creative method to allow people living with dementia to explore the data (Dowlen, 2019).
- The Stepping model is a dynamic, model of group facilitation for working collaboratively with people living with dementia and therefore could be utilised in the context of service development, evaluation of care and co-production, particularly within healthcare settings.
- Healthcare professionals should move away from the view of people living with dementia as patients or service-users and ensure they are treated and involved in care planning, assessment and treatment as partners in their own care making decisions.
- This study reflects on what is meaningful to a small group of people, who all identify as White British, are over the age of 65 and are from Salford in Greater Manchester. Practitioners should be aware that applying co-operative inquiry and the Stepping model to other diverse communities will likely produce different results but are essential towards the development of this field of practice.

6.6 Summary

The aim of this study was to form, develop and conduct a co-operative inquiry with a group of people living with dementia. This was achieved by working collaboratively with a group of people living with dementia from the Open Doors Service in Salford and the initiating, establishing and facilitating of this inquiry group has been explored in this thesis. An action output that had meaning and resonance to the inquiry group was developed by the collection of their lived experiences of living with dementia and the merging of these stories into a script. This script was subsequently developed into an animation with an external partner, which was narrated by the co-researchers themselves. The process of the co-operative inquiry was explored on a week by week basis through my own observations as facilitator. From these observations, I identified facilitators and barriers in working collaboratively with people living with dementia in research. These findings also identified that although models of group facilitation exist, there was no model that specifically considered the facilitation of a group of people living with dementia in the roles of co-researchers. Subsequently, the Stepping model was introduced as a dynamic and interactive approach to working collaboratively with people living with dementia. The Stepping model is an original contribution to the research that considers the position of the researcher in the facilitation of co-research with people living with dementia. The Stepping model's applicability to other fields of practice has also been considered. The concept of reflexivity was embedded throughout the findings in recognised that there is a position of power that the researcher has initiating this kind of inquiry. Co-researching as an approach to research within the dementia research field is very much emerging at this time and this study has shown that with the use of creative methods, what is meaningful to people living with dementia can be embedded in future research and discourse.

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Appendices

Appendix 1. Quality Assessment – Critical appraisal guidelines (Modified from Wright et al. 2010).

Study	Is the rationale for involving users clearly demonstrated?	Is the level of user involvement appropriate?	Is the recruitment strategy appropriate?	Is the nature of training appropriate?	Has sufficient attention been given to the ethical considerations of user involvement and how these are managed?	Has sufficient attention been given to the methodological considerations of user involvement and how these were managed?	Have there been any attempts to involve users in the dissemination of findings?	Has the 'added-value' of user involvement been clearly demonstrated?	Has there been any attempts to evaluate the user involvement component of the research?
1	Yes	Yes	Yes	Yes	Yes, process consent	Yes, insights discussed	No	Yes	Some, no evaluation of user involvement on length of study, financial cost but examples of the impact of user involvement given

2	Yes	Yes	Yes	n/a	Yes, written consent still obtained despite no formal research taking place	Yes, insights discussed	Yes, involved in writing of the publication	Yes	n/a
3	Yes	Yes, PAR	Yes	n/r	n/r	Yes, insights discussed	No	Yes	No
4	Yes	Yes, adaptations made as necessary	Yes	Yes	Yes, process consent, real names used with permission, consent by editing used on film	Yes, insights discussed	Some, participants credited as narrators on the film	Yes	Some, no evaluation of user involvement on length of study, financial cost but examples of the impact of user involvement given
5	Yes	Yes	Yes	n/a	Yes, process consent, editorial decisions	No	No	No	No

6	No, study doesn’t claim to be participatory	No	Yes, for aim of study	n/r	No	No	No	Yes, with regards to IPA	No
7	Yes	Yes	Yes	n/r	Yes, considerable discussion about positioning of participants	Yes	No	Yes, with co-creation of analysis	Yes, evident in discussion
8	Yes	Yes, constructing Narrative	Yes	n/a	No, although written and verbal consent was attained, no evidence of a process consent was reported	Yes, methodological considerations such as reflexivity discussed	No	Yes, with regards to the production of narrative	Some, no evaluation of user involvement on length of study, financial cost but examples of the impact of user involvement given

9	Yes	Yes, co-production	Yes	Yes	Yes, process consent	Yes	No	Yes	Some, no evaluation of user involvement on length of study, financial cost but examples of the impact of user involvement given
10	Yes	Yes	Yes	n/a	Consent from a personal nominee but no active process of consent	Yes	No	Yes	Some, no evaluation of user involvement on length of study, financial cost but examples of the impact of user involvement given
11	Yes	Yes, involved in data collection, analysis and design of a framework	Yes, although not obvious for the co-researcher	n/r	Yes, person with dementia was involved in ethical approval process	Yes	Yes, 1st author on paper	Yes, has highlighted barriers to this	Yes, including reflection

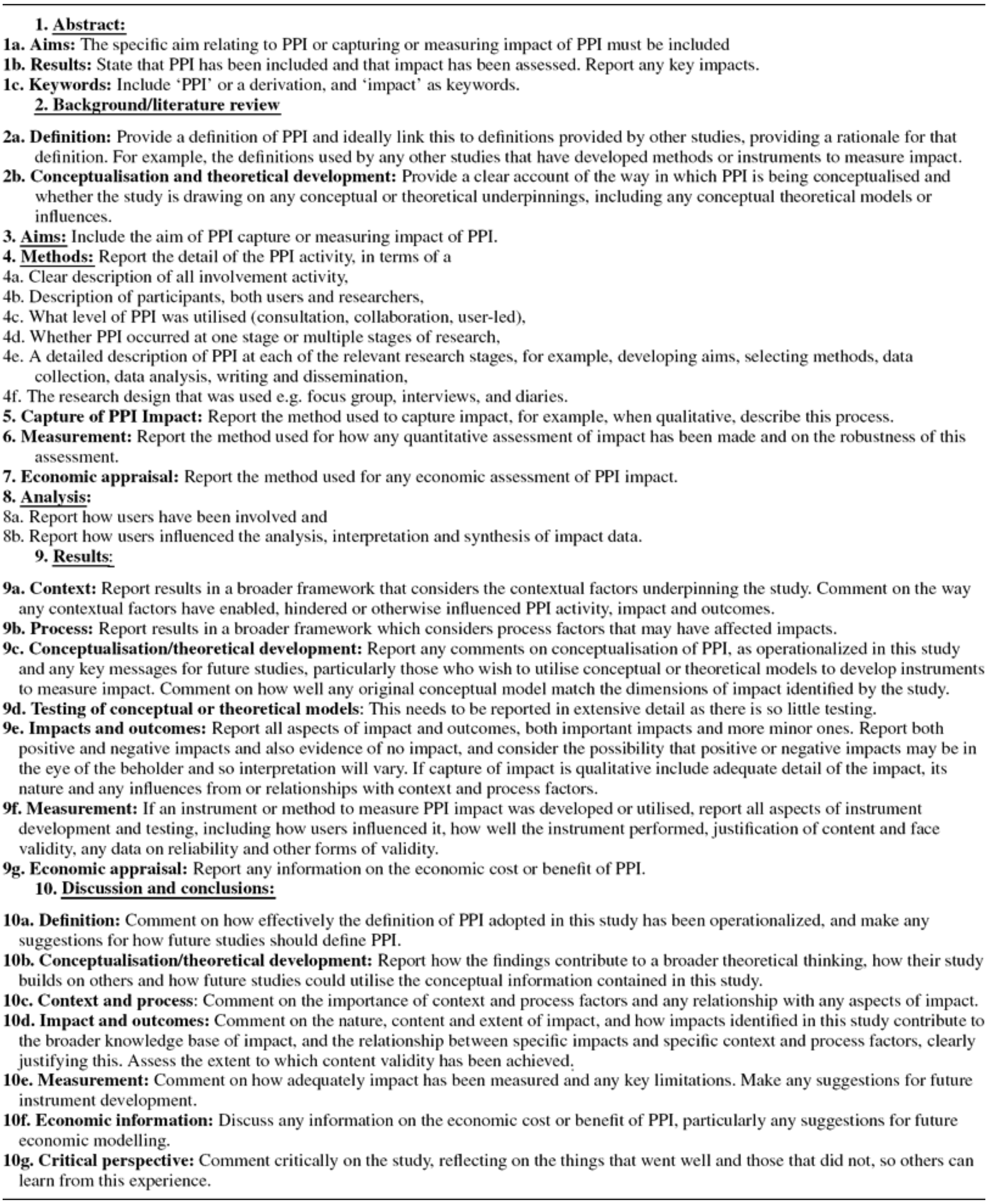
12	Yes	Yes, participatory action research	Yes	n/r	No	Some, discussion around use of action research but no in-depth examination of methodological considerations for user involvement	No	Yes	Some, no evaluation of user involvement on length of study, financial cost but examples of the impact of user involvement given
13	Yes	Yes	Yes and detailed difficulties	n/r	No, article reports ethics board approval but not methods when working with individuals	Some, discussion around use of action research but no in-depth examination of methodological considerations for user involvement	No	Yes, with regards to action research	Some, does discuss problems with recruitment and time (2 years to recruit 11 couples)

14	Yes	Yes, action research	Yes	n/r	Yes, process consent	Yes, limitations discussed	No	Yes and limitations discussed	Some, no evaluation of user involvement on length of study, financial cost but examples of the impact of user involvement given and suggestions for the future
15	Yes	Yes, design	Yes and detailed back-up plan	Yes, around design	No, discussion of data being anonymised but no reporting of consent process	Yes and adaptions made as appropriate	No	Yes and adaptions discussed	No, although brief acknowledgement of value of people living with dementia being involved
16	Yes	Yes	Yes	n/r	No, ethical approval was obtained but no discussion around on-going consent procedures	Yes	No	Yes	Yes, limitations were also discussed

17	Yes	Yes	Yes	n/r	No, was framed as a PPI activity	Yes	Yes	Yes	Some, highlighted that it should be meaningful
18	Yes	Yes	Yes	Yes	Yes, process consent	Yes, insights discussed	No	Yes, detailed discussion	Some, no in-depth evaluation, however discussion around people with dementia as co-researchers discussed in detail
19	No	Yes	n/a	n/a	No, although part of the article was written completely by a person with dementia there is no mention of ethical support, the evaluation received university ethics approval	No, although does present discussion around friendship facilitation and participatory methods	Yes, co-author on paper and contributed own personal narrative	Some, briefly mentions benefits of participatory methods and move towards this in research and co-production	Some, evaluation of a peer-support group includes impact and benefits of user involvement

20	Yes	Yes	Yes	Yes and discussed practicalities	Yes, discussed in depth	Yes, methodological considerations discussed in depth	No, although discusses including them in dissemination and how this may be done	Yes	Yes, discussed practicalities including moral and ethical challenges. No discussion of financial implications though.
21	Yes	Yes, co-construction	Yes	Yes	Yes, process consent	Yes	No	Yes, within co-construction	Yes, with regards to impact but not with time and cost implications although the study was longitudinal
22	No, study doesn’t claim to be participatory	Yes, with IPA	Yes	n/r	Yes for the interview stage. No process consent is described for those taking part in Data Analysis	Some, in the discussion of IPA	No	Some, in the validating of the themes developed from IPA	No, not a focus in the reporting

Appendix 2: Quality Assessment – GRIPP Checklist (Modified from Staniszewska et al., 2011).



1. Abstract:

1a. Aims: The specific aim relating to PPI or capturing or measuring impact of PPI must be included

1b. Results: State that PPI has been included and that impact has been assessed. Report any key impacts.

1c. Keywords: Include 'PPI' or a derivation, and 'impact' as keywords.

2. Background/literature review

2a. Definition: Provide a definition of PPI and ideally link this to definitions provided by other studies, providing a rationale for that definition. For example, the definitions used by any other studies that have developed methods or instruments to measure impact.

2b. Conceptualisation and theoretical development: Provide a clear account of the way in which PPI is being conceptualised and whether the study is drawing on any conceptual or theoretical underpinnings, including any conceptual theoretical models or influences.

3. Aims: Include the aim of PPI capture or measuring impact of PPI.

4. Methods: Report the detail of the PPI activity, in terms of a

4a. Clear description of all involvement activity,

4b. Description of participants, both users and researchers,

4c. What level of PPI was utilised (consultation, collaboration, user-led),

4d. Whether PPI occurred at one stage or multiple stages of research,

4e. A detailed description of PPI at each of the relevant research stages, for example, developing aims, selecting methods, data collection, data analysis, writing and dissemination,

4f. The research design that was used e.g. focus group, interviews, and diaries.

5. Capture of PPI Impact: Report the method used to capture impact, for example, when qualitative, describe this process.

6. Measurement: Report the method used for how any quantitative assessment of impact has been made and on the robustness of this assessment.

7. Economic appraisal: Report the method used for any economic assessment of PPI impact.

8. Analysis:

8a. Report how users have been involved and

8b. Report how users influenced the analysis, interpretation and synthesis of impact data.

9. Results:

9a. Context: Report results in a broader framework that considers the contextual factors underpinning the study. Comment on the way any contextual factors have enabled, hindered or otherwise influenced PPI activity, impact and outcomes.

9b. Process: Report results in a broader framework which considers process factors that may have affected impacts.

9c. Conceptualisation/theoretical development: Report any comments on conceptualisation of PPI, as operationalized in this study and any key messages for future studies, particularly those who wish to utilise conceptual or theoretical models to develop instruments to measure impact. Comment on how well any original conceptual model match the dimensions of impact identified by the study.

9d. Testing of conceptual or theoretical models: This needs to be reported in extensive detail as there is so little testing.

9e. Impacts and outcomes: Report all aspects of impact and outcomes, both important impacts and more minor ones. Report both positive and negative impacts and also evidence of no impact, and consider the possibility that positive or negative impacts may be in the eye of the beholder and so interpretation will vary. If capture of impact is qualitative include adequate detail of the impact, its nature and any influences from or relationships with context and process factors.

9f. Measurement: If an instrument or method to measure PPI impact was developed or utilised, report all aspects of instrument development and testing, including how users influenced it, how well the instrument performed, justification of content and face validity, any data on reliability and other forms of validity.

9g. Economic appraisal: Report any information on the economic cost or benefit of PPI.

10. Discussion and conclusions:

10a. Definition: Comment on how effectively the definition of PPI adopted in this study has been operationalized, and make any suggestions for how future studies should define PPI.

10b. Conceptualisation/theoretical development: Report how the findings contribute to a broader theoretical thinking, how their study builds on others and how future studies could utilise the conceptual information contained in this study.

10c. Context and process: Comment on the importance of context and process factors and any relationship with any aspects of impact.

10d. Impact and outcomes: Comment on the nature, content and extent of impact, and how impacts identified in this study contribute to the broader knowledge base of impact, and the relationship between specific impacts and specific context and process factors, clearly justifying this. Assess the extent to which content validity has been achieved.

10e. Measurement: Comment on how adequately impact has been measured and any key limitations. Make any suggestions for future instrument development.

10f. Economic information: Discuss any information on the economic cost or benefit of PPI, particularly any suggestions for future economic modelling.

10g. Critical perspective: Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience.

Study	1. a	1. b	1. c	2. a	2. b	3	4. a	4. b	4. c	4. d	4. e	4. f	5	6	7	8. a	8. b	9. a	9. b	9. c	9. d	9. e	9. f	9. g	10. a	10. b	10. c	10. d	10. e	10. f	10. g
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Appendix 3. Quality Assessment – GRIPP2 Checklist (Modified from Staniszewska et al., 2017).

Section and topic	Item
Section 1: Abstract of paper	
1a: Aim	Report the aim of the study
1b: Methods	Describe the methods used by which patients and the public were involved
1c: Results	Report the impacts and outcomes of PPI in the study
1d: Conclusions	Summarise the main conclusions of the study
1e: Keywords	Include PPI, “patient and public involvement,” or alternative terms as keywords
Section 2: Background to paper	
2a: Definition	Report the definition of PPI used in the study and how it links to comparable studies
2b: Theoretical underpinnings	Report the theoretical rationale and any theoretical influences relating to PPI in the study
2c: Concepts and theory development	Report any conceptual models or influences used in the study
Section 3: Aims of paper	
3: Aim	Report the aim of the study
Section 4: Methods of paper	
4a: Design	Provide a clear description of methods by which patients and the public were involved
4b: People involved	Provide a description of patients, carers, and the public involved with the PPI activity in the study
4c: Stages of involvement	Report on how PPI is used at different stages of the study
4d: Level or nature of involvement	Report the level or nature of PPI used at various stages of the study
Section 5: Capture or measurement of PPI impact	
5a: Qualitative evidence of impact	If applicable, report the methods used to qualitatively explore the impact of PPI in the study
5b: Quantitative evidence of impact	If applicable, report the methods used to quantitatively measure or assess the impact of PPI
5c: Robustness of measure	If applicable, report the rigour of the method used to capture or measure the impact of PPI

Section 6: Economic assessment	
6: Economic assessment	If applicable, report the method used for an economic assessment of PPI
Section 7: Study results	
7a: Outcomes of PPI	Report the results of PPI in the study, including both positive and negative outcomes
7b: Impacts of PPI	Report the positive and negative impacts that PPI has had on the research, the individuals involved (including patients and researchers), and wider impacts
7c: Context of PPI	Report the influence of any contextual factors that enabled or hindered the process or impact of PPI
7d: Process of PPI	Report the influence of any process factors, that enabled or hindered the impact of PPI
7ei: Theory development	Report any conceptual or theoretical development in PPI that have emerged
7eii: Theory development	Report evaluation of theoretical models, if any
7f: Measurement	If applicable, report all aspects of instrument development and testing (eg, validity, reliability, feasibility, acceptability, responsiveness, interpretability, appropriateness, precision)
7g: Economic assessment	Report any information on the costs or benefit of PPI
Section 8: Discussion and conclusions	
8a: Outcomes	Comment on how PPI influenced the study overall. Describe positive and negative effects
8b: Impacts	Comment on the different impacts of PPI identified in this study and how they contribute to new knowledge
8c: Definition	Comment on the definition of PPI used (reported in the Background section) and whether or not you would suggest any changes
8d: Theoretical underpinnings	Comment on any way your study adds to the theoretical development of PPI
8e: Context	Comment on how context factors influenced PPI in the study
8f: Process	Comment on how process factors influenced PPI in the study

8g: Measurement and capture of PPI impact	If applicable, comment on how well PPI impact was evaluated or measured in the study
8h: Economic assessment	If applicable, discuss any aspects of the economic cost or benefit of PPI, particularly any suggestions for future economic modelling.
8i: Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so that others can learn from this study

Study	1a	1b	1c	1d	1e	2a	2b	2c	3	4a	4b	4c	4d	5a	5b	5c	6	7a	7b	7c	7d	7ei	7eii	7f	7g	8a	8b	8c	8d	8e	8f	8g	8h	8i
1	√	√	√	√			√	√		√	√	√	√					√	√	√	√					√				√	√			√
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Appendix 4: Example of coding used in the literature review.

From Theme 2: **Being Involved**

…broader application of the diary interview method in dementia-related research, on the grounds that it mediates an equal relationship and makes visible the "whole person," including the environment in which that person lives. **Bartlett (2012)**

…resulting in a film narrative, in which the voice of the person with dementia provides the commentary **Capstick & Ludwin (2011)**

Within a PAR approach, there is a strong emphasis on trust and relationship building. (**Caine) 2014**

Pam and Carol thus took on an active role in the film as its narrators, and are credited as such whenever it is shown to an audience. **Capstick (2011)**

During Phase Two, themes generated from Phase One were fed back to participants. Participants were invited to comment on the themes identified, with all of those attending the action research groups describing them as fair. **Pipon-Young et al (2011)**

Rather codes were noted on the transcripts and interpretations were discussed with the participants at follow-up meetings. New ideas were discussed with the participant dyads and focus groups, thus questions regarding the adequacy of the categories were answered before becoming initial themes. Discussing findings progressively with participants and going back over what was said at previous meetings for confirmation or correction helped to establish credibility. **O'Sullivan et al (2014)**

Reminding people of what they have lost is not a problem specific to the diary interview method, because interviewers have found this troublesome, as well… **Bartlett (2012)**

Partnership working was evident throughout, with the researchers, practitioners, technicians and participants enjoying a relationship based on mutual respect and recognition of each other's expertise… **Hanson et al (2007)**

…the analysis as co-produced between the researcher and lead author (SW) and the participants, Ben and Mary. **Williams & Keady (2012)**

Data collection and analysis, which were reciprocally integrated, initially focused on gathering and interpreting data in a small group context. **O'Sullivan et al (2014)**

Our co-research approach was premised on the belief that the shared identity of being someone with dementia would facilitate relationships between researchers and participants, thus enhancing the experience of the interview process for both parties, as well as enriching the data obtained. **Tanner (2012)**

Appendix 5: Leaflet for recruiting co-researchers.

The STIGMA RESEARCH GROUP is looking to explore stigma and how we can challenge it.

The group is open to **people living with dementia and their families and carers** and new members are welcome to attend.

Our next meeting is:

Date: Tuesday 21st March 2017

Time: 1pm - 3pm

Place:

Refreshments provided

If you have any questions, please contact Katie

using the details below:

Telephone:

Email:______________________

Appendix 6: BPAS capacity assessment tool.

Group Member ID:	Date of assessment:

Name of Assessor:

Assessment of capacity

1. Is there an impairment of, or disturbance in, the functioning of the person’s mind or brain?

[ ] No (patient should be deemed to have capacity; go to box 8)

[ ] Yes (specify the disorder or condition)

2. Is person able to understand information relating to participating in the study?

[ ] Yes

[ ] No Give evidence or examples:

3. Is person able to sufficiently retain information related to participating in the study?

[ ] Yes

[ ] No Give evidence or examples:

4. Is person able to use and weigh up the information in relation to making this decision?

[ ] Yes

[ ] No Give evidence or examples:

5. Is person able to communicate this specific decision by any means?

[ ] Yes

[ ] No Give evidence or examples:

6. Additional evidence or information from other sources (e.g. family, friends, advocate etc):

7. Is it concluded that the person lacks capacity to make this specific decision at this time?

[ ] Yes (follow study procedures for patients who lack capacity)

[ ] No (go to box 10)

Decision Taken

8. What is the decision at this time?	
10. Decision Maker (Print name): Signature: Date Decision Made:	Tel: Email:

Appendix 7: Research Ethics Committee rejection letter.

Health Research Authority

London - Camberwell St Giles Research Ethics Committee
Level 3, Block B

Whitefriars Lewins Mead
Bristol BS1 2NT

03 August 2017

Miss Katie Davis

XXXXXXXXXXXXXX

Dear Miss Davis

Study title:	**Involving people living with dementia in research: collaboration and facilitation**
REC reference:	**xxxxxxx**
Protocol number:	**Not stated**
IRAS project ID:	**xxxxxxx**

The Research Ethics Committee reviewed the above application at the meeting held on 21 July 2017. Thank you for attending to discuss the application along with Dr Caroline Swarbrick, Academic Supervisor.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact hra.studyregistration@nhs.net outlining the reasons for your request.

Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Ethical opinion

The members of the Committee present decided to issue an unfavourable opinion for the following reasons:

1) **Changes to the PIS**

a) There are a number of grammatical errors in the PIS for patients and Consultees.

b) Please state clearly the ground rules for the group work.

2) **All Phase 2 PIS**

a) Information sheets should be clear that the reward is £10 per month up to £60.

3) **Phase 2 and 3 PwD PIS**

a) Add safeguarding arrangements.

4) **Phase 2 PwD Consent Form**
a) Make clause 12 (co-researcher identifiability) clearly optional.

5) **Phase 2 Care Partner PIS**
a) It's unclear if the PwD must participate too (protocol says ‘and/or’).
b) Document says “they” a lot which adds to the confusion about who is doing what in the study.

   i. “You will not be identified in any publications or presentations unless you express a desire to be named and consent to this happening. This is not standard practice in research but as you will be a co-researcher in this project, it is appropriate that they are given credit for their work where due.”

   ii. Please proof-read this PIS.

6) **Phase 2 Care Partner Consent Form**
a) More “their/my” confusion (e.g. “my care”).
b) Make 13 (co-researcher) clearly optional.

7) **Phase 2/3 Consultee Consent form**
a) Assumes they are the carer – please correct this.

8) **Changes to the protocol**
a) Please state clearly why people with dementia will benefit from taking part in this study.
b) Phase 1; the inclusion criterion does not mention the carers involved in this study.

9) **Further consideration needs to be given on the design of the group work in particular the data obtained from public involvement member who may provide some bias in the results and provide answers they think the applicants may want to hear.**

The Committee would like to refer the applicants to Professor Graham Thornicroft’s work, a Professor of Community Psychiatry who has produced a number of papers and an author of the significant work on MI and stigma (including dementia) 2006 which can be seen at:
https://www.mentalhealth.org.uk/sites/default/files/actions_speaklouder_0.pdf

I regret to inform you therefore that the application is not approved.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact REC Manager, Tina Cavaliere.

Mental Capacity Act 2005

The committee did not approve this research project for the purposes of the Mental Capacity Act 2005. The research may not be carried out on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Options for further ethical review

You may submit a new application for ethical review, taking into account the Committee’s concerns. You should enter details of this application on the application form and include a copy of this letter, together with a covering letter explaining what changes have been made from the previous application. Please highlight any changes made to study documentation and include a revised version number and date on the documents where applicable.

The application should be booked through the Central Booking Service (CBS) and would be allocated for review in the normal way.

Alternatively, you may appeal against the decision of the Committee by seeking a second opinion on this application from another Research Ethics Committee. The appeal would be based on the application form and supporting documentation reviewed by this Committee, without amendment. If you wish to appeal, you should notify the relevant Research Ethics Service manager (see below) in writing within 90 days of the date of this letter. If the appeal is allowed, another REC will be appointed to give a second opinion within 60 days and the second REC will be provided with a copy of the application, together with this letter and other relevant correspondence on the application. You will be notified of the arrangements for the meeting of the second REC and will be able to attend and/or make written representations if you wish to do so.

The contact point for appeals is:

Catherine Blewett
HRA Improvement & Liaison Manager
Health Research Authority

Email: hra.appeals@nhs.net

The Committee welcomed you and Dr Caroline Swarbrick to the meeting and advised you that there were two observers in the room. You and Dr Swarbrick confirmed that you were content for the observers to remain in the room whilst the discussions took place.

Summary of discussion at the meeting

Social or scientific value; scientific design and conduct of the study

Relevance of the research to the impairing condition

The Committee agreed the research is connected with an impairing condition affecting persons lacking capacity or with the treatment of the condition.

The Committee stated that it was uncertain that this study is research as it appeared to be a public involvement project to obtain evidence to support a hypothesis.

You were asked to explain to the Committee how the script in the play constitutes a scientific project that improves knowledge and understanding.

You replied to say that the study involves looking at patients with dementia, working together with these patients and researchers as a research project; it's about how we are approaching this study.

The Committee acknowledged the purpose of the study design but was unclear how it was considered to be research.

Justification for including adults lacking capacity to meet the research objectives

The Committee considered that the research could be carried out equally effectively if it was confined to participants able to give consent for the following reasons:

You advised the Committee that they were advised at the time of booking their study that their study met the Mental Capacity Act 2005 criteria. The Committee asked you if the study could be conducted on adults who have the capacity to consent.

You replied that this study is about being inclusive as possible, if participants lack the capacity to consent then they can still contribute to the study.

The Committee acknowledged the response and asked if you were aware that you must justify why their research cannot be conducted on adults on do not lack the capacity to consent.

You responded to say that you are able to recruit patients with dementia that do not lack the capacity to consent for this study. Dr Swarbrick responded to say that this would mean excluding adults who lack capacity to consent and their experiences and stigmatising this group of people.

The Committee clarified to you that the point of this ethical question is to ascertain why the research cannot be conducted on adults who do not lack capacity, rather than providing a justification as to why you *are* including adults lacking capacity to consent.

Dr Swarbrick concluded to say that she had received advice from the Research Governance team to conduct this study and it is funded by the NHS.

The Committee were not assured that a valid reason had been given to justify why this research could not be carried out on adults lacking capacity to consent.

It was unclear to the Committee how the participants in phase three would be able to adequately understand and answer the questions and participate fully if they lack capacity to consent at the time of approach.

You agreed to reflect on this ethical issue in more detail.

In terms of the interviewing questions and involving adults lacking capacity it is unclear to the Committee how you will validate the responses you receive in an objective manner. There is not system in place to assess the outcomes.

Dr Swarbrick responded to say that there are no tools in place and no outcome measures as this is not a scientific outcome study. It is a qualitative study and not generalizable. This study is about sharing experiences and empowering people with dementia.

The Committee did not consider the findings of the study to be generalizable and so the study would not count as research.

The Committee advised you that this there is a legal obligation to ensure that all studies involving adults lacking the capacity to consent meets the MCA criteria;

section 30-33 criterions. The Committee advised you that your study does not meet section 30-33 point 2; the research could not be carried out as effectively if it was confined to participants able to give consent.

Dr Swarbrick replied to say that it would respect the Committee's view of the study. Dr Swarbrick confirmed that this study could be conducted on adults who are able to consent, but the difficulty would be what would happen if they lose the capacity to consent and how she would advise the participant of this.

The Committee acknowledged the sensitivity involved but concluded that this study could be carried out effectively if it was confined to participants able to give consent.

It is unclear how you will assess the participant's capacity to consent and what will happen if the participant loses the capacity to consent.

You advised the Committee that you will conduct an initial assessment of capacity and will follow the process (see appendix 3: Assessing Capacity included in the protocol) and will liaise with the service management team. You added that you will continue to assess capacity throughout the study duration, this is called 'process consent' whereby there is a continuous cycle of checking with the participant at every meeting. If the participant loses capacity then they will not be withdrawn from the study. The family members of participants who can consent will be approached to check that they are happy for their relative to take part in the study and give them an opportunity to discuss the study further.

The Committee accepted this response.

Recruitment arrangements and access to health information, and fair participant selection

Arrangements for appointing consultees

The Committee considered the arrangements set out in the application for appointing consultees under Section 32 of the Mental Capacity Act to advise on whether participants lacking capacity should take part and on what their wishes and feelings would be likely to be if they had capacity.

After discussion the Committee agreed that reasonable arrangements were in place for identifying personal consultees and for nominated consultees independent of the project where no person can be identified to act as a personal consultee.

The inclusion criteria are researchers who have taken part in participatory research with people with dementia and individuals with a diagnosis of dementia (self or professional reported). The Committee queried the validity of 'self-reported' diagnosis and how patients will be able to clinically diagnose themselves as having dementia. It was noted that people who are living with dementia and have been part in the Open Doors project will be recruited.

You explained to the Committee that patients with dementia recruited to this study will be accessing a post-diagnosis service, a peer support service, on an informal basis.

Diagnosis of dementia will be made by the assessment team. You clarified that all patients recruited to this study will have a formal diagnosis of dementia and inclusion of participants without a formal clinical diagnosis of dementia is not necessary.

The Committee accepted this response.

Favourable risk benefit ratio: anticipated benefit/risks for research participants (present and future)

Balance between benefit and risk, burden and intrusion

After discussion the Committee concluded that, although the research has the potential to benefit participants lacking capacity, it would impose a disproportionate burden on them.

The risks of distress to the participant are underplayed in the IRAS REC application form (question A22 and A23) and it appears that the applicants are focused on the stigma attached to dementia rather than the potential to uncover some shocking revelations derived from the participant’s acceptance and understanding of dementia. There is a possibility that people with dementia will be suffering from depression and may become distressed during the interviews and group work.

You acknowledged that there is a risk that participants may become distressed and that there is a stigma with dementia and that people with dementia feel very passionate about taking part and getting their voices heard. If a participant does get upset during the study then they will receive support and she can put them in touch with a psychologist.

The Committee accepted this response.

The Committee stated that it is important that you take great care when providing feedback to the participant following phase three of the study. It would be appropriate to provide only positive feedback.

You and Dr Swarbrick agreed to take this advice forward.

The Committee decided that the research required Site-Specific Assessment at non-NHS sites in order to provide assurance that the study will be conducted and managed appropriately at each site and that the requirements of the Mental Capacity Act will be complied with.

Care and protection of research participants; respect for potential and enrolled participants’ welfare and dignity

Additional safeguards

The Committee was not completely satisfied with the arrangements in place to comply with the additional safeguards set out in Section 33 of the Mental Capacity Act.

There are some areas of the safeguarding policy that are not clear to the Committee and appear not standard practice. The Committee clarified to you that the safeguarding policy is in place to protect the safety and well-being of patients/participants and to ensure that the appropriate steps are taken to report disclosures of abuse, or self-harm, for example. *Dr Swarbrick replied that if a participant discloses information about abuse then she will advise the participant that she will not disclose this information and provide them with an appropriate contact telephone number to get support. Dr Swarbrick added that she will only follow the safeguarding policy if the participant is in immediate danger. You added that if there is a suggestion of patient neglect or a risk of harm then she will follow the local policy if the patient is in immediate danger, or there is a suggestion of danger. The safeguarding policy was taken from another project and its use in this study is not your personal preference.*

The Committee acknowledged your response and asked you how you would protect participants from abuse within the group.

You replied that the group facilitator will make sure there is no abuse within the group. These participants will know each other and it is a small group. The participants in the group work will have met you before as they will have taken part in the Open Doors project. You added that there will be ground rules for the group work and participants will be advised of these ground rules at the beginning and they will be advised that their confidentiality will be breached if there is an incident of abuse.

The Committee accepted this response and requested that the ground rules are included in the PIS.

You agreed to amend the PIS accordingly.

The Committee queried with you how you will avoid undue persuasion (coercion) if the participant already knows you and feels obliged to take part.

You replied that all the participants in the Open Doors project were volunteers and wanted to be part of the study design process. All participants recruited to the study have been told that it is their choice to take part or not.

The Committee accepted this response.

It was noted that participants will be asked to complete online questionnaires. You were asked what would happen to the participant’s data if the participant decides to withdraw from the study.

You replied that the data specific to the participant will be removed from the study if this is the participant’s wish.

The Committee accepted this response.

Participants will be offered the opportunity to receive a copy of the study’s findings at the end of the study.

It is unclear what will happen to the participant's data if the participant does not consent to have their interviews audio/video recorded. *You replied that you will keep your own records using a diary and will produce a script of the data captured. Participants will be given a diary to complete or an easy-to-use audio recorder and they do not have to share their information if they do not wish to. The data will be kept confidential and the script will be edited together with the participant.*

The Committee accepted this response and asked the applicants if they had considered the potential for participants to give bias answers; in particular those that are public involvement representatives and the co-researchers.

You agreed to reflect on this ethical issue in more detail.

You were further advised that there is a duty of care to report disclosures of malpractice and that the co-researchers would need to be advised that confidentiality would be breached in this instance.

You acknowledged this legal responsibility and advised the Committee that the co-workers will not have honorary contracts.

The Committee accepted this response.

Informed consent process and the adequacy and completeness of participant information

Information for consultees

The Committee reviewed the information to be provided to consultees about the proposed research and their role and responsibilities as a consultee.

The Committee was satisfied that the information was adequate to enable consultees to give informed advice about the participation of persons lacking capacity.

You were asked to clarify the role of the carers as their involvement is not mentioned in the study protocol or in the PIS.

You replied that the care partners will be involved in the group work (phase

two). The Committee requested that a separate PIS is produced for the care

partners. *You agreed to take this forward.*

The Committee stated to you that it is clear to them that there is an assumption that participants who have dementia will benefit from taking part in the study, but there is no justification for why this is beneficial.

You explained that the justification is based on the disability rights and that people with *dementia should have their voices heard and involved in research. You agreed to amend the protocol to state this.*

The Committee agreed that the protocol needs to be amended accordingly and advised you that the benefit for taking part in the study needs to be separated from the scientific understanding for doing the research.

You agreed to amend the protocol accordingly.

The Committee asked you if they had any questions for the Committee to which you replied you had no questions.

You were thanked for attending the meeting and you left the room.

Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

Documents reviewed

The documents reviewed at the meeting were:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance confirmation letter - University of Manchester]	1	12 June 2017
Interview schedules or topic guides for participants [Phase 3 Interview Schedule]	1	06 June 2017
IRAS Application Form [IRAS_Form_19062017]		19 June 2017
IRAS Checklist XML [Checklist_27062017]		27 June 2017
Letter from funder [Letter from ESRC]	1	15 April 2015
Letter from sponsor [Sponsorship approval - University of Manchester]	1	12 June 2017
Letters of invitation to participant [Phase 1 Preliminary email]	1	06 June 2017
Letters of invitation to participant [Phase 1 Invitation email]	1	06 June 2017
Letters of invitation to participant [Phase 1 Reminder email]	1	06 June 2017
Other [Employers Liability Insurance - University of Manchester]	1	12 June 2017
Other [Public Liability Insurance - University of Manchester]	1	12 June 2017
Other [Phase 1 Survey Questions]	1	06 June 2017
Other [RE 17LO1128 - Full Application - Valid Under Consideration - Please Respond by 2706]		27 June 2017
Participant consent form [Phase 2 Care partner]	1	06 June 2017
Participant consent form [Phase 2 Consultee]	1	06 June 2017
Participant consent form [Phase 2 Person with dementia]	1	06 June 2017
Participant consent form [Phase 3 Consultee]	1	06 June 2017
Participant consent form [Phase 3 Person with dementia]	1	06 June 2017
Participant information sheet (PIS) [Phase 1 Participant Information Sheet]	1	06 June 2017
Participant information sheet (PIS) [Phase 2 Care partner]	1	06 June 2017

Participant information sheet (PIS) [Phase 2 Consultee]	1	06 June 2017
Participant information sheet (PIS) [Phase 2 Person with dementia]	1	06 June 2017
Participant information sheet (PIS) [Phase 3 Consultee]	1	06 June 2017
Participant information sheet (PIS) [Phase 3 Person with dementia]	1	06 June 2017
Research protocol or project proposal [Involving people living with dementia in research: collaboration and facilitation]	1	06 June 2017
Summary CV for Chief Investigator (CI) [Katie Davis CV]	1	07 June 2017
Summary CV for student [Katie Davis]		07 June 2017
Summary CV for supervisor (student research) [Professor John Keady]		01 April 2017
Summary CV for supervisor (student research) [Dr Caroline Swarbrick]		01 June 2017
Summary CV for supervisor (student research) [Dr Penny Bee]		27 June 2017

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at http://www.hra.nhs.uk/hra-training/

17/LO/1128 **Please quote this number on all correspondence**

Yours sincerely

Pp Tina Cavallo

Mr John Richardson
Chair

Email: nrescommittee.london-camberwellstgiles@nhs.net

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments.*

Copy to: *Ms Lynne Macrae*
Rachel Rosenhead, Greater Manchester Mental Health NHS Foundation Trust

London - Camberwell St Giles Research Ethics

Committee Attendance at Committee meeting

on 21 July 2017

Committee Members:

Name	*Profession*	*Present*	*Notes*
Ms Justine Antill	Deputy Director, Dept of Health Legal Adviser	No	
Dr Ana Bajo	Lecturer	No	
Mr Sean Bolton	Lay Public Involvement Advisor	Yes	
Mrs Jennifer Bostock (Alternate Vice Chair)	Philosopher of Psychiatry	Yes	
Mrs Stephanie Cooper	Solicitor	Yes	
Ms Biddy Gillman	Retired Biology Teacher/ Head of year 12	Yes	
Mrs Naomi Hare	Modern Matron for Research in Abdominal Medicine and Surgery	Yes	
Ms Deborah Horney	Research Associate / Trial Manager	No	
Dr Hilary Lavender	Retired General Practitioner (GP)	Yes	
Mr Robert McDowall	Research Coordinator	Yes	
Mr John Richardson (Chair)	Retired Director of COREC: former Ecumenical Officer for Churches Together in South London	Yes	
Dr Caroline Shackleton	Retired Clinical Psychologist	Yes	
Dr Mark Tanner (Vice Chair)	Consultant Psychiatrist	Yes	
Mr James Uwalaka	Regulatory Compliance Officer	No	

Also in attendance:

Name	*Position (or reason for attending)*
Tina Cavaliere	REC Manager

Appendix 8: Research Ethics Committee Approval letter.

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan
Lywodraeth Cymru
Funded by
Welsh Government

Pwyllgor Moeseg Ymchwil
Cymru 4 Wales Research
Ethics Committee 4
Wrexham

G1/G2
Croesnewydd Hall Wrexham
Technology Park Wrexham,
LL13 7YP
Telephone : E-mail:
xxxxxxxxxxxr@wales.nhs.uk
xxxxxxxxxxx@wales.nhs.uk
Website : www.hra.nhs.uk

14
September
2017

Miss Katie Davis PhD Student
xxxxxxx xxxxxxxxxxxxxx@postgrad.manchester.ac.uk

Dear Miss Davis

Study title: **Involving people living with dementia in research: exploring collaboration and facilitation**
REC reference: **17/WA/0264**
IRAS project ID: **233798**

Thank you for your letter of 13 September 2017. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 11 September 2017

Documents received

The documents received were as follows:

Document	*Version*	*Date*
Participant consent form [Phase 2 Consent Form Carepartner]	3	12 September 2017
Participant consent form [Phase 2 Consent Form Consultee]	3	12 September 2017
Participant consent form [Phase 2 Consent Form Person with Dementia]	3	12 September 2017
Participant consent form [Phase 3 Consent Form Person with Dementia]	3	12 September 2017
Participant information sheet (PIS) [Phase 2 Participant Information Sheet Carepartner]	3	12 September 2017
Participant information sheet (PIS) [Phase 2 Participant Information Sheet Person with Dementia]	3	12 September 2017
Participant information sheet (PIS) [Phase 3 Participant Information Sheet Person with Dementia]	3	12 September 2017
Participant information sheet (PIS) [Phase 2 Participant Information Sheet Consultee]	3	12 September 2017

Approved documents

The final list of approved documentation for the study is therefore as follows:

Document	*Version*	*Date*
IRAS Application Form [IRAS_Form_14082017]	-	14 August 2017
Covering letter on headed paper [Cover letter for resubmission]	-	09 August 2017
Other [Opinion Letter - Camberwell St Gile Research Ethics Committee 17/LO/1128]	1	03 August 2017
Research protocol or project proposal	3	12 September 2017
Participant information sheet (PIS) [Phase 2 Participant Information Sheet Carepartner]	3	12 September 2017
Participant information sheet (PIS) [Phase 2 Participant Information Sheet Consultee]	3	12 September 2017
Participant information sheet (PIS) [Phase 2 Participant Information Sheet Person with Dementia]	3	12 September 2017
Participant information sheet (PIS) [Phase 3 Participant Information Sheet Person with Dementia]	3	12 September 2017
Participant consent form [Phase 2 Consent Form Carepartner]	3	12 September 2017
Participant consent form [Phase 2 Consent Form Consultee]	3	12 September 2017
Participant consent form [Phase 2 Consent Form Person with Dementia]	3	12 September 2017
Participant consent form [Phase 3 Consent Form Person with Dementia]	3	12 September 2017
Letters of invitation to participant [Phase 1 Preliminary email]	1	06 June 2017
Letters of invitation to participant [Phase 1 Invitation email]	1	06 June 2017
Letters of invitation to participant [Phase 1 Reminder email]	1	06 June 2017
Other [Phase 1 Survey Questions]		06 June 2017
Interview schedules or topic guides for participants [Phase 3 Interview Schedule]	1	06 June 2017
Letter from funder [Letter from Funder]	-	15 April 2015
Letter from sponsor [Letter from Sponsor - University of Manchester]	1	10 August 2017
Summary CV for Chief Investigator (CI) [Katie Davis CV]	1	07 June 2017
Summary CV for supervisor (student research) [Professor John Keady CV]	1	01 April 2017
Summary CV for supervisor (student research) [Dr Caroline Swarbrick CV]	1	01 June 2017
Summary CV for supervisor (student research) [Dr Penny Bee]	1	27 June 2017
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Letter - University of Manchester]	1	10 August 2017
Other [Indemnity Insurance]	1	01 June 2017
Other [Employer's Liability Insurance]	1	30 May 2017
Other [Public Liability Insurance]	1	01 June 2017

You should ensure that the sponsor has a copy of the final documentation for the study.
It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

Yours sincerely

Leon Ciumageanu

Norbert Leon Ciumageanu
Research Ethics Service Administrative Assistant

E-mail: xxxxxxx@wales.nhs.uk

Copy:	Sponsor:	Ms Lynne MacRae The University of Manchester xxxxxxxxxxxxxx@manchester.ac.uk
	R&D Office:	Rachel Rosenhead Greater Manchester Mental Health NHS Foundation Trust rachel.rosenhead@gmw.nhs.uk
	Academic Supervisor:	Professor John Keady The University of Manchester xxxxxxx@manchester.ac.uk
		Dr Caroline Swarbrick The University of Manchester xxxxxxx@manchester.ac.uk
		Dr Penny Bee The University of Manchester xxxxxxx@manchester.ac.uk

Appendix 9: Animator Interview Schedule.

Q1. Have you worked with people living with dementia and care-partners before to produce an animation? And if so, can you tell me a bit about how that process worked?

Q2. With regards to the animation produced with our group, did you encounter any challenges in your involvement with the group? What were they?

Q3. What were the facilitators, things that you found helpful, in working with the group?

Q4. What would be your advice/top tips to animators working with this client group in the future?

Appendix 10: Participant information sheet for people living with dementia/care partners.

Involving people living with dementia in research:

collaboration and facilitation

Study information sheet for people living with dementia

My Name is Katie Davis and I am a postgraduate student at The University of Manchester.

I am researching the involvement of people with dementia in research.

My study involves working with people with dementia to explore their involvement in research. I want to find out…

- How to challenge the stigma around dementia?

- How we can work together to produce research?

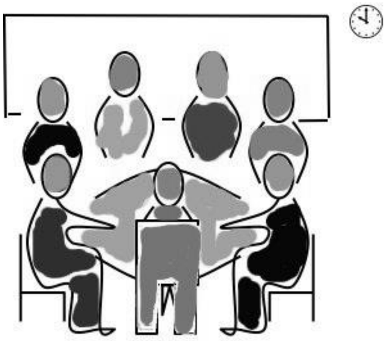
I would like to invite you to take part in my study by joining my research group.

The group will be a small group of up to ten people.

We will meet every fortnight or every three weeks over a period of approximately six months.

Our meetings will last approximately two hours but we can take a break whenever we need too.

We will hold the group meetings in a public and convenient place for all members of the group, such as the Humphrey Booth Centre or the community fire station



What will happen during the group meetings?

We will discuss stigma and the representation of people living with dementia and we are going to produce a play script of those experiences.

The group may decide to audio record the meetings. You can opt out of this at any time.

Being part of the group…

You will be asked as part of the research to keep a diary to record your thoughts on being part of the group. This is entirely optional but if you do keep a diary, you can choose to keep a written or audio diary.

You can choose to share your thoughts with the group but this is completely voluntary.

You can also choose to leave the group at any time.

Checking you are happy to be part of the group…

It is important that you understand what is involved in being part of the group and I need to check that you are happy with this.

I will ask for your permission every time the group meets and make a written note of this at the time.

I will also ask you to sign a consent form.

What happens if…

- I change my mind about being part of the group?

You can change your mind at any time and do not need to give a reason.

What happens to my information?

- Any electronic material will be kept on an encrypted hard drive or a password-protected computer at the University of Manchester. Any printed materials will be kept in a locked cabinet in a locked office at the University of Manchester. Data will be anonymised and stored for ten years before being destroyed.

- No information about you will be shared without your permission, however my supervisors and other individuals at the University of Manchester or the NHS may wish to look at the data to check that the project is going as planned. Information may be shared about you without your permission, if there is any concern for your welfare or the welfare of others.

- I will write reports about the group and will ask you if you wish your information to be anonymised

- I will ask for your feedback on the reports that I write and ask you to contribute them if you would like too.

- The data collected during this study could be used to support research in the future. We may use the data in future studies or share it with other researchers working on other studies. All of the data will be anonymised before it is shared or used for future research so no-one will be able to identify you.

Permission to do this work…

To carry out this work I have been given permission by the University of Manchester and an NHS Research Ethics Committee

Before you decide to become part of the research group…

You can show this information to a friend or family member and discuss it with them

You can contact Katie, the researcher, if you have any questions.

Katie’s number is XXXXXXX

You can also email Katie on

<u>If you agree to take part you will be rewarded for your time and contribution by a gift of £10 per month up to £60</u>

If you would like to take part please complete the form below and send it back to me in the envelope attached.

Name and Address:

Telephone Number:

Email address:

I would like you to speak to my friend or family member about the study too.

Their name & telephone is:

The research is being carried out by Katie Davis (PhD Student). If you have any comments or concerns about the research, you can contact Katie or Professor John Keady (Principle Investigator of the Neighbourhoods and Dementia Study) using the details below.

Katie Davis

xxxxxx

Professor John Keady

xxxxxx

Minor complaints

If you have a minor complaint then you need to contact the researcher(s) in the first instance using the above contact details.

Formal Complaints

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact xxxxxx

Involving people living with dementia in research: collaboration and facilitation

Care-partner participant information sheet

I would like to invite you along with your friend/relative to take part in a research study. Before we do so, it is important for you to understand why the research is being done and what it involves. Please take time to read the following information carefully and discuss it with any others, if you wish.

What is the purpose of this study?

This study is part of a PhD project being undertaken at the University of Manchester. The study aims to bring together a small group of six people living with dementia and their care partners to work together to explore stigma and the representation of people living with dementia. The research will be led by the group, as opposed to the researcher and will add to the growing body of knowledge developing for people living with dementia, by people living with dementia. You and your friend/relative will be considered to be co-researchers as opposed to participants in the group and will help to make decisions about how the area of stigma and representation is explored.

Do you have to take part?

It is up to you to decide wherever you should take part in the research. If you decide to take part, you can withdraw at any time and do not need to give a reason for this. Your involvement in the Open Doors project will not be affected by them being involved or not involved in the research.

What does the research involve?

The group will meet every two or three weeks at a convenient location in Salford such as the Humphrey Booth Resource Centre or the community fire station. The study will take place over a six-month period. The group is going to produce a play script that presents their experiences and stories of stigma. You will be actively encouraged to participate in the discussions and subsequent actions.

You may also wish to keep a diary to document their experiences of the group but this is entirely voluntary.

You will be rewarded for your time and contribution by a gift of up to £60 (£10 per month) if you take part in the project over the six months.

What are the risks of taking part?

This study has been approved by an ethical committee **Wales Research Ethics Committee 4** which believes that any risks have been minimised. It is possible that you may find the meetings tiring and breaks and refreshments will be provided. I may collect personal information about you but I will ensure to keep this confidential.

What are the advantages of taking part?

There may not be any direct advantages to taking part, although you will be helping to developing what is an emerging methodology in the dementia care research, where people living with dementia are viewed as co-researchers as opposed to simply participants. You may also benefit from peer support as you will be working together in a group alongside other people living with dementia and their care partners.

Will their information be kept confidential?

Yes, your personal information will be kept confidential. Any electronic material will be kept on an encrypted hard drive or a password-protected computer at the University of Manchester. Any printed materials will be kept in a locked cabinet in a locked office at the University of Manchester. Data will be stored for ten years before being destroyed.

The data collected during this study could be used to support research in the future. We may use the data in future studies or share it with other researchers working on other studies. All of the data will be anonymised before it is shared or used for future research so no-one will be able to identify you.

Individuals from the University of Manchester, NHS Trust or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data but all individuals involved in auditing and monitoring the study, will have a strict duty of confidentiality to you as a research participant.

Confidentiality will always be maintained and information will not be disclosed without consent, except in cases where a safeguarding issue has been disclosed. For example, if you or another member of the group discloses anything that may mean that they or anyone else is at risk of harm, then confidentiality may be broken.

What will happen to the results of this study?

The results of this study will be included as part of a PhD thesis at the University of Manchester. The results may also be included in scientific journals and presented at conferences. You will not be identified in any publications or presentations unless you express a desire to be named and consent to this happening. This is not standard practice in research but as you will be a co-researcher in this project, it is appropriate that you are given credit for your work where due.

Who has funded the research?

This study is part of a PhD project at the University of Manchester and is being funded by an Economic and Social Research Council (ESRC) studentship as part of the Neighbourhoods and Dementia Study.

Who is carrying out the research?

The research is being carried out by Katie Davis (PhD Student). If you have any comments or concerns about the research, you can contact Katie or Professor John Keady (Principle Investigator of the Neighbourhoods and Dementia Study) using the details below.

Katie Davis

xxxxxx

Professor John Keady

xxxxxx

Minor complaints

If you have a minor complaint then you need to contact the researcher(s) in the first instance using the above contact details.

Formal Complaints

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact xxxxxx

What should I do now?

If you decide you would like to take part, please read and sign the consent form and return it to me (Katie Davis).

Appendix 11: Consent form for people living with dementia/care partners.

Involving people living with dementia in research:
collaboration and facilitation

Consent Form – Person living with dementia

I am asking if you would like to take part in a research study to explore stigma and the representation of people living with dementia. Before you agree to take part in the study, I ask that you read the study information sheet which is about the study, why we have approached you and what the study involves. If you agree to take part please mark each box below with your initials.

Participant Name ______________________

1. I confirm that I have read and understood the information booklet **dated 12/09/2017 (version 3.0)** for the above study. ☐

2. I confirm that I have been able to ask questions and that they have been answered to my satisfaction. ☐

3. I confirm that I fully understand what is expected of me within the study. ☐

4. I understand that taking part is voluntary and will not affect any care or services I receive in any way. ☐

5. I understand that I am free to with draw from the study at any time, without giving a reason. ☐

6. I understand that the discussion during the group may be tape recorded but that I can refuse to answer a question if I wish and leave the group at any time without having to explain. ☐

7. I understand that the content of the group discussion will be typed and that the conversations may be shared with and written about by the researcher. ☐

Information in these will not lead to my identification unless I give my permission.

8. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher may need to share this information with her research programme manager. ☐

9. I understand that data collected during the study may be Looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐

10. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

11. I understand I can request a summary of the study once it is finished and that if I would like a summary, my personal details will be held until the study is complete. ☐

12. I agree to the use of anonymous quotes ☐

13. I would like to be personally identified in the data as a co-researcher and would like to be identified by my first/full name (please delete as appropriate) **(Optional)** ☐

14. I agree to take part in the above study ☐

____________________ _______________ __________________

Name of Participant Date Signature

____________________ _______________ __________________

Name of person
Taking consent Date Signature

Involving people living with dementia in research:

collaboration and facilitation

Consent Form – Care-partner

I am asking if you would like to take part in a research study to explore stigma and the representation of people living with dementia. Before you agree to take part in the study, I ask that you read the study information sheet which is about the study, why we have approached you and what the study involves. If you agree to take part please mark each box below with your initials.

Participant Name _______________________

1. I confirm that I have read and understood the information booklet **12/09/2017 (version 3.0)** for the above study. ☐

2. I confirm that I have been able to ask questions and that they have been answered to my satisfaction. ☐

3. I confirm that I fully understand what is expected of me within the study. ☐

4. I understand that taking part is voluntary and will not affect any care or services I or my friend or family member receives. ☐

5. I understand that I am free to withdraw from the study at any time, without giving a reason. ☐

6. I understand that the discussion during the group may be tape recorded but that I can refuse to answer a question if I wish and leave the group at any time without having to explain. ☐

7. I understand that the content of the group discussion will be typed and that the conversations may be shared with and written about by the researcher. Information in these will not lead to my identification unless I give my permission. ☐

8. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher may need to share this information with her research programme manager. ☐

9. I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐

10. I understand I can request a summary of the study once it is finished and that if I would like a summary, my personal details will be held until the study is complete. ☐

11. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

12. I agree to the use of anonymous quotes ☐

13. I would like to be personally identified in the data as a co-researcher and would like to be identified by my first/full name (please delete as appropriate). **(Optional)** ☐

14. I agree to take part in the above study ☐

____________________ _______________ __________________

Name of Participant Date Signature

____________________ _______________ __________________

Name of person Date Signature
Taking consent

Appendix 12: Early version of the script.

Stigma

S: the **S**tart of our dementia story

T: the **T**rouble we have with our memory

I: for **I**ncidents we cope with daily

G: to **G**ive us a little more time

M: the **M**essage we send to you

A: the bad **A**ttitude we have from a few

This says STIGMA, a word not very nice

A word we have to cope with, that has come into our life

Please be patient and think of our feelings

For as you know, we like you, are human beings

****

Well, four years ago I was diagnosed with Alzheimers. Alzheimer's has a stigma. People forget ME. The person. My first time of experiencing the stigma of my condition was not long after my diagnosis. I went into a big store. Knowing I had a problem with money, I made sure I had the right money but when I was just about to pay I realised I needed something else. I asked the sales lady for the item I needed. Trying to calculate the money I needed which took me a while. The sales woman tutted, said to the lady behind 'I'm sorry *she* is keeping you waiting. This caused me more stress. So I got all worked up and dropped the money I had out, all over the floor. Which I then had to pick up before paying. My husband who was with me was furious. He said if she had a little more patience this wouldn't have happened and we wouldn't have felt humiliated.

…

We were going to Preston to drop off our daughter to catch a train to Glasgow. It was a kind of misty night, and raining and it was winter so it was dark early. We got to Preston after one or two variations of going round and round and every time we went round we kept passing Morrisons yet again. So we got into the middle of Preston and all the traffic was congregating at it was about half 5. We were looking for the railway station and our daughter was in the back getting agitated and Wilf decided it would be better if he got out the car and looked for the train station. So he got out and he was gone! And just as he left the traffic started to move. We then moved into the railway station and my daughter got out and took her case. I was thinking how am I going to find Wilf. I was worried about my daughter catching her train and worried about finding Wilf. I found four police cars and thought I could park there and maybe find a policeman. I went into the train station and spoke to the stall owners to get them to keep an eye out of Wilf. I left and could see through the big glass train windows Wilf walking along a platform with another man. When I eventually got there he had disappeared. He came through another door and started shouting at me! But we found each other! In the meantime, our daughter had been texting me every minute to see if her dad had been found. By the time we got back to the car, I had to get some petrol on the way home.

However, there are as many good experiences. In fact, probably more good than bad.

…

On a warm sunny day sitting by the lake in Southport, my husband who has Alzheimers decided he would like an ice cream. He insisted on going on his own and as the ice cream van was only two hundred yards away I did not think there would be a problem. How wrong I was!

When I saw other people passing with ice creams I realised he was missing and as he had taken off his jacket he had no ID on him. I must have looked distressed because a couple passed and asked if I needed help.

They took one path while I took another. After about 20 minutes they found him still holding my ice cream. I was so relieved to see him and so grateful to these strangers who stopped to help.

…….

Following a fall breaking my wrist and injuring my leg, I was told I needed to be admitted to hospital to have a plate inserted in my wrist. I explained that I could not leave my husband as he had dementia and the staff nurse found a room with two beds so he could stay with me. A dementia nurse stayed with him while I had my operation. We were treated with kindness and compassion, something I will never forget.

…………

The Good Samaritans

When we are struggling
And need a helping hand
There are some people out there
Who will go the extra mile
A few kind words a cheerie smile
Will make us feel much better
What this means to us
With words we cannot explain

But knowing you are there

Will help us once again

So people who help us when we are struggling

And people who go those extra miles

We will call these people
The Good Samaritans

Once you’re diagnosed, you do not just move into a care home. There is a life to be lived. You do not just disappear into the background. You do not need to be isolated if people give you a bit of time and space.

Appendix 13: Word Cloud used to facilitate ideas for the core message.

Words

Stigma, moods, anger, aggression, isolation, sadness, fear, apathy, ignorance, arrogance, intimidation, worry, ashamed

Sympathy, tolerance, insight, guidance, acceptance, awareness, moods, patience, happiness, understanding, time, space, good communication, silence, quietness, coping, empathy, laughter, humour, sensitivity, help

Appendix 14: Research Ethics Committee approval letter for amendment.

Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

Gwasanaeth Moeseg Ymchwil
Research Ethics Service

Ariennir gan Lywodraeth Cymru
Funded by Welsh Government

Wales Research Ethics Committee 4
Wrexham

Mailing address:
Health and Care Research Wales
Support Centre
Castlebridge 4 15-19
Cowbridge Road East
Cardiff, CF11 9AB
Telephone: xxxxxx
Email: xxxxxx@wales.nhs.uk
xxxxxx@wales.nhs.uk

Website : www.hra.nhs.uk

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA

20 December 2017

Miss Katie Davis
Rm. 6.332, Jean McFarlane Building
Division of Nursing, Midwifery & Social Work
University of Manchester,
Oxford Road, Manchester
M13 9PL

Dear Miss Davis

Study title: **Involving people living with dementia in research: exploring collaboration and facilitation**
REC reference: **xxxxxx**
Amendment number: **01**
Amendment date: **14 December 2017**
IRAS project ID: **xxxxxx**

The above amendment was reviewed at the meeting of the Sub-Committee held on 20 December 2017 in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The Sub-Committee noted the amendment proposes to develop their script into a short animation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Interview schedules or topic guides for participants [Interview Schedule Phase 2 Animator]	1	14 December 2017
Notice of Substantial Amendment (non-CTIMP)	01	14 December 2017
Participant consent form [Consent Form Animator]	1	14 December 2017
Participant consent form [Consent Form Phase 2 Animation Carepartner]	1	14 December 2017
Participant consent form [Consent Form Phase 2 Animation PwD]	1	14 December 2017
Participant information sheet (PIS) [Information Sheet Phase 2 Animation PwD]	1	14 December 2017
Participant information sheet (PIS) [Information Sheet Animator]	1	14 December 2017
Participant information sheet (PIS) [Information Sheet Phase 2 Animator Carepartner]	1	14 December 2017
Research protocol or project proposal [Protocol V3.1]	3.1	14 December 2017

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

xxxxxxx:	**Please quote this number on all correspondence**

Yours sincerely,

Dr Kathryn Ann Clarke Chair,
Wales REC 4

e-mail: xxxxxxx@wales.nhs.uk

Enclosures: List of names and professions of members who took part in the review

Wales REC 4

Attendance at the Sub-Committee meeting on 20 December 2017

Committee Members

Name	*Profession*	*Present*
Dr Kathryn A Clarke	Head of Concerns (Chair)	Yes
Mr John A Gittins	Senior Coroner (Vice-Chair)	Yes

In attendance

Name	*Position (or reason for attending)*
Dr Rossela Roberts	RES Manager / Acting REC Manager Wales REC 4
Mr Norbert Leon Ciumageanu	RES Administrative Assistant

Appendix 15: Animator participant information sheet.

Involving people living with dementia in research:

collaboration and facilitation: Animator

I would like to invite you to part in my research study. This information sheet explains why the research is being done and what it would involve if you decide to take part. Please read the following information carefully and if you have any questions, please do not hesitate to contact me using the details provided at the end of this sheet.

What is the purpose of this study?

I am carrying out a PhD within the Division of Nursing, Midwifery and Social Work at The University of Manchester which involves working with people living with dementia as co-researchers. I am working collaboratively with a group of people living with dementia and care-partners and we have developed a script of their experiences into an animation.

Why have I been invited?

I am inviting you as the animator to take part in an interview to explore your experiences and perceptions of being involved in this process.

Do I have to take part?

Participation is entirely voluntary. If you decide not to take part, you do not need to give a reason and you will not be contacted again to take part in this interview.

What am I being asked to do?

I am asking you to take part in a short semi-structured interview by phone or in person. It will take around 30 minutes and will be audio-recorded.

What are the possible benefits of taking part?

There are no anticipated direct benefits to taking part in this study, however, by participating you will add to growing body of knowledge on participatory research with people living with dementia and possibly assist future researchers in this field with acknowledging the barriers and facilitators of participatory research.

What will happen to the results of this study?

I will transcribe the audio myself and analyse the results which will be used to form part of a thesis to be submitted to the University of Manchester for a doctoral award in 2018. The conclusions may also be published in a peer-reviewed journal. You will not be identified in either the thesis or any publication although I may use anonymous quotes. You can request a summary of the results once they are completed. If you decide to withdraw before any results are published, then I will delete the audio-recording, transcript of the interview and any findings from this.

Will my personal details be kept confidential?

All information that is collected about you will be kept confidential, however as the animation will be made public, you may be identifiable in your role as the animator. Individuals from the University of Manchester, NHS Trust or regulatory authorities may need to look at the data collected for this study to make sure the project is being carried out as planned. This may involve looking at identifiable data but all individuals involved in auditing and monitoring the study, will have a strict duty of confidentiality to you as a research participant.

Data will be stored securely on a password-protected computer at the University of Manchester and each participant will be allowed a code number which will identify the individual record instead of names. Data will be archived for ten years. The data collected during this study could be used to support research in the future. We may use the data in future studies or share it with other researchers working on other studies. All of the data will be anonymised before it is shared or used for future research so no-one will be able to identify you.

Who is funding the research?

This research is being funded by an ESRC studentship and is part of the ESRC/NIHR programme 'Neighbourhoods and Dementia; a mixed methods study' [2014-2019].

Who has reviewed the study?

This study has been granted ethical approval by **Wales Research Ethics Committee 4** *and means that the approving committee believes risks to taking part at a minimum and that you are able to make an informed decision about taking part from the information provided. Consent is assumed by virtue of completion of the survey. A summary of the study will be available to all participants at the end of the study from Katie Davis on the contact details below.*

What if I have any comments?

If you have any questions or comments about the research you can contact Katie Davis (PhD Student) or Professor John Keady (Chief Investigator of the Neighbourhoods and Dementia Study)

Katie Davis
Tel: XXXXXXXXXXX
Email: XXXXXXXXXXXXXXXX

Professor John Keady
Tel: XXXXXXXXXXXXXX
Email: XXXXXXXXXXXXXXXXXXXXX

Minor complaints
If you have a minor complaint then you need to contact the researcher(s) in the first instance using the contact details above.
Formal Complaints
If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact

Thank you for your consideration, your involvement is valued and appreciated.

Appendix 16: Animator Consent Form.

Involving people living with dementia in research:
collaboration and facilitation - Animator
Consent Form

I am asking if you would like to take part in a short interview to explore your experiences and perceptions of being involved in the development of an animation with a group of people living with dementia and care-partners. This will take the form of a one-off interview which can be carried out face-to-face or by telephone and it is your choice what way you would like to be interviewed. Before you agree to take part in the study, I ask that you read the study information sheet which includes why we have approached you and what the study involves. If you agree to take part, please mark each box below with your initials.

Participant Name ________________________

1. I confirm that I have read and understood the information booklet **14/12/2017 (version 1.0)** for the above study. ☐

2. I confirm that I have been able to ask questions and that they have been answered to my satisfaction. ☐

3. I confirm that I fully understand what is expected of me within the study. ☐

4. I understand that taking part is voluntary. ☐

5. I understand that I am free to withdraw from the study at any time, without giving a reason. ☐

6. I understand that the interview will be audio recorded. ☐

7. I understand that the content of the interview will be transcribed and written about by the researcher. Information in these will not lead to my identification. ☐

8. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the researcher may need to share this information with her research programme manager. I understand that due to my involvement as the animator, I may be publicly identifiable due to my role in the project. ☐

9. I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data. ☐

10. I understand I can request a summary of the study once it is finished and that if I would like a summary, my personal details will be held until the study is complete **(Optional)**. ☐

11. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

12. I agree to the use of anonymous quotes ☐

13. I agree to take part in the above research ☐

____________________	_______________	__________________
Name of Participant	Date	Signature
____________________	_______________	__________________
Name of person Taking consent	Date	Signature

1x copy for participant

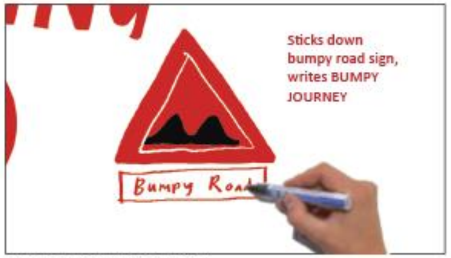
1x copy study file (original)

Appendix 17: Animation Storyboard.

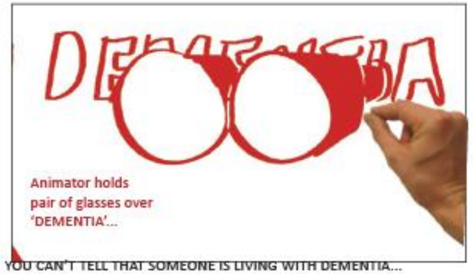
DEMENTIA ANIMATION

PAGE 1

WHEN YOU'RE LIVING WITH DEMENTIA...



...IT CAN BE A BUMPY JOURNEY.



YOU CAN'T TELL THAT SOMEONE IS LIVING WITH DEMENTIA...

AS THERE ARE NO VISIBLE SIGNS...

AND SOMETIMES YOU CAN EXPERIENCE STIGMA

I'VE HAD PEOPLE IN SHOPS TUTTING AT ME WHEN I STRUGGLED WITH MY MONEY...

Silhouettes come forward, saying TUT

APOLOGISING TO OTHER CUSTOMERS FOR HOW LONG I WAS TAKING, I DON'T THINK THEY HAD ANY IDEA HOW THAT WOULD MAKE ME FEEL.

THEY FORGOT ME! THE PERSON!

DEMENTIA ANIMATION

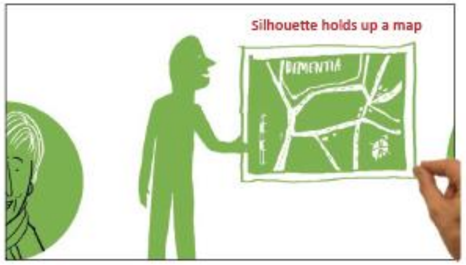
PEOPLE CAN BE IMPATIENT AND LACK UNDERSTANDING AND FOR ME THAT'S SO FRUSTRATING!

LIKE I'M STUCK AT A STOP SIGN!

Draw Sheila

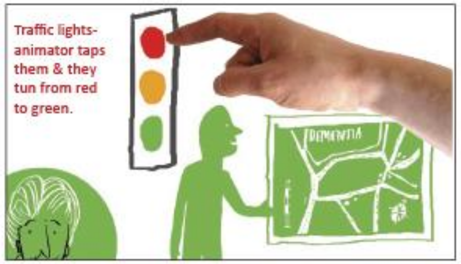
Helpful silhouette-

HOWEVER, ON THIS JOURNEY THERE HAVE ALSO BEEN POSITIVE EXPERIENCES, WE HAVE ALL COME ACROSS THE GOOD SAMARITANS.



Silhouette holds up a map

THE PEOPLE WHO HELP US NAVIGATE THROUGH THIS JOURNEY OF DEMENTIA.



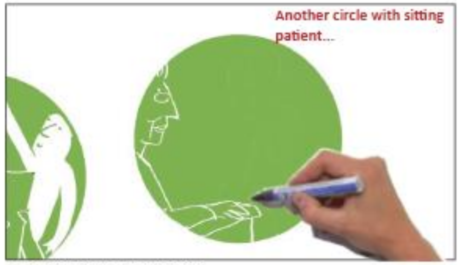
Traffic lights- animator taps them & they tun from red to green.

PEOPLE WHO TURN THE LIGHTS FROM RED TO GREEN.

Circle with hands holding a LOST poster

Silhouettes move forward, helping & pointing

I'VE HAD RANDOM STRANGERS HELP ME WHEN MY HUSBAND WENT MISSING



Another circle with sitting patient...

AND NURSES IN THE HOSPITAL...

DEMENTIA ANIMATION

Nurse comes forward to hold hands

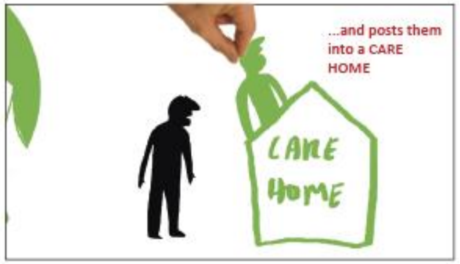
GO OUT OF THEIR WAY TO SUPPORT US DURING A HOSPITAL STAY...

Animator writes KINDNESS & COMPASSION

WE WERE TREATED WITH KINDNESS AND COMPASSION, SOMETHING I WILL NEVER FORGET.

Animator picks up a silhouette....

AFTER A DIAGNOSIS OF DEMENTIA...



...and posts them into a CARE HOME

...YOU DON'T JUST PACK UP AND MOVE INTO A CARE HOME.

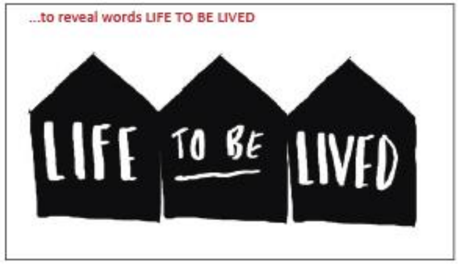
Their remaining silhoette fades away.

YOU DON'T JUST DISAPPEAR INTO THE BACKGROUND.

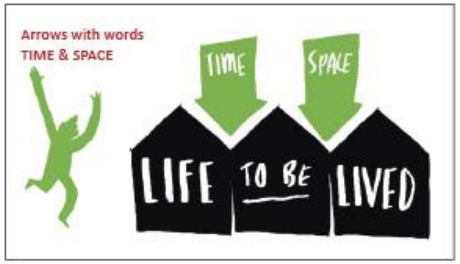
Figure fades back in & jumps for joy!

THERE IS A LIFE TO BE LIVED.

Animator folds out care home ...

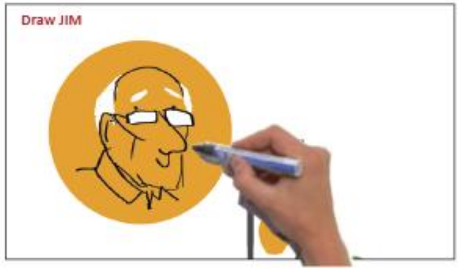


...to reveal words LIFE TO BE LIVED



Arrows with words TIME & SPACE

YOU DON'T NEED TO BE ISOLATED IF PEOPLE GIVE YOU A BIT OF TIME AND SPACE.


Draw JIM


Animator sticks down mugs of tea...

WE WANT PEOPLE TO STOP AND HAVE A CUP NOT OF TEA OR COFFEE...


Writes on COMPASSION, UNDERSTANDING, PATIENCE.

BUT OF COMPASSION, UNDERSTANDING AND PATIENCE.


Figures drinking & chatting...

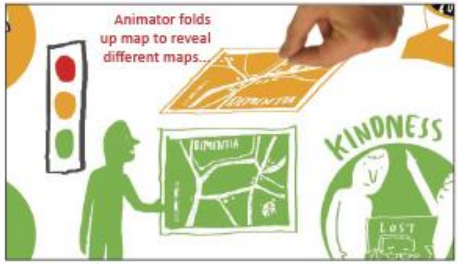
COMPASSION MOTIVATES PEOPLE TO HELP OTHERS...


Speech bubbles say HOPE & INSPIRATION

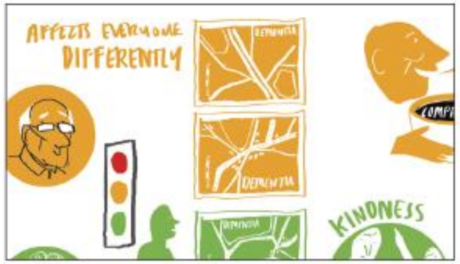
AND WITH THAT, BRINGS HOPE AND INSPIRATION.


Writes AFFECTS EVERYONE DIFFERENTLY

UNDERSTANDING THAT DEMENTIA AFFECTS EVERYONE DIFFERENTLY...


Animator folds up map to reveal different maps...

AND WILL TAKE A DIFFERENT ROUTE FOR EACH PERSON.



Different maps.


Animator sticks down figures holding signs: WE ARE ALL...

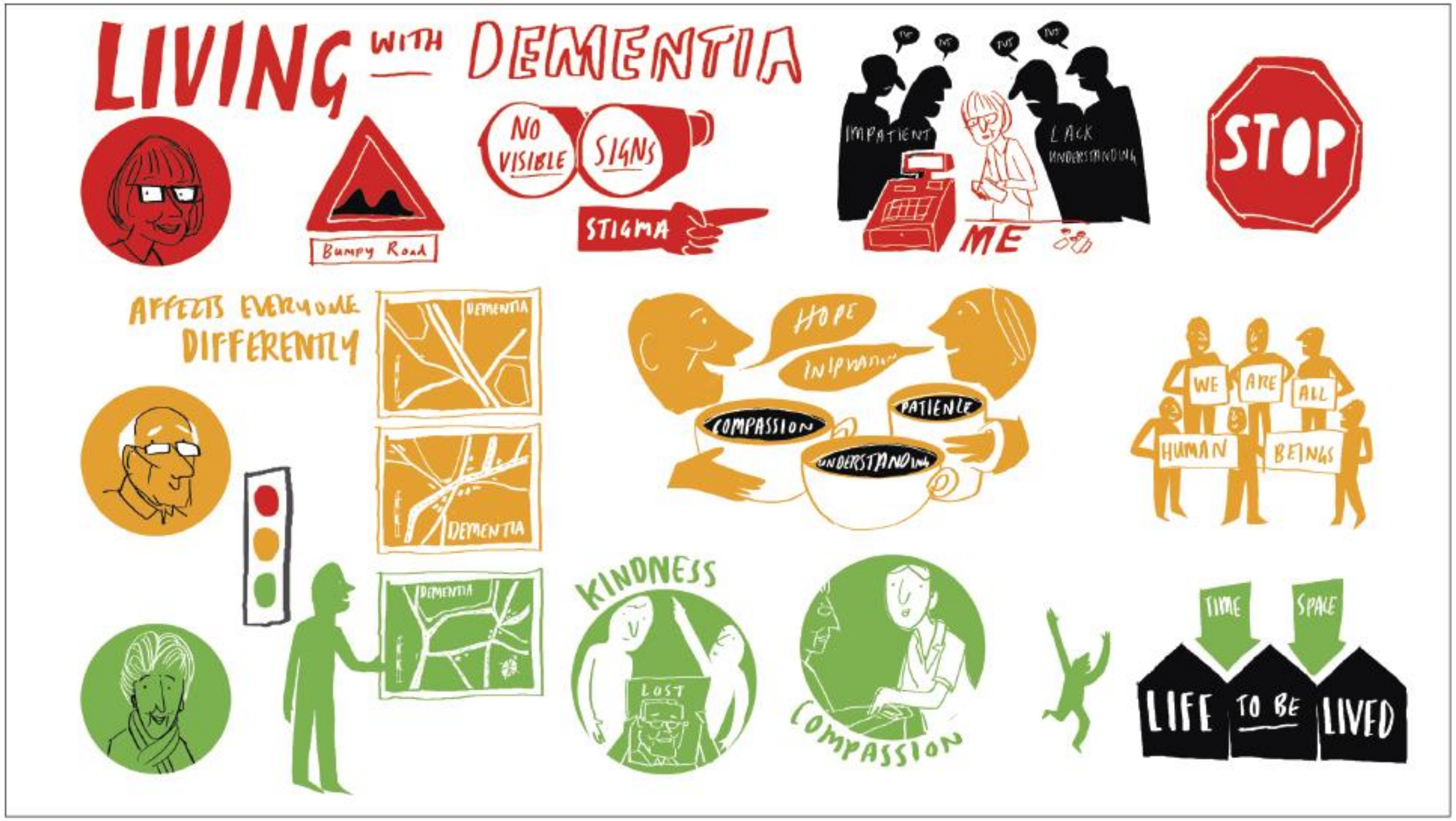
HAVE SOME PATIENCE. WE ARE ALL HUMAN BEINGS...

...HUMAN BEINGS

NO ONE REALLY KNOWS WHAT IT'S LIKE TO TRAVEL THIS JOURNEY.

Zoom out to reveal big picture
(see next page)

Credits & thanks.


LIVING WITH DEMENTIA
NO VISIBLE SIGNS
STIGMA
Bumpy Road
TUT
TUT
TUT
TUT
IMPATIENT
LACK UNDERSTANDING
ME
STOP
AFFECTS EVERYONE DIFFERENTLY
DEMENTIA
DEMENTIA
DEMENTIA
HOPE
COMPASSION
PATIENCE
UNDERSTANDING
WE ARE ALL HUMAN BEINGS
KINDNESS
LOST
COMPASSION
TIME
SPACE
LIFE TO BE LIVED

Appendix 18: Distress Protocol.

Distress Protocol

The safety and well-being of those involved in the study are paramount. Patience and empathy of the researcher is required. Should any participant show signs of distress or become distressed during the interview, the following procedure will be taken:

Research group:

1. The group will be stopped immediately and all recording (audio and text) will cease.
2. The co-researcher will be asked if they would like to leave the room.
3. The co-researcher will be asked if they would like to share their feelings and if they would like to discuss anything.
4. The researcher will offer the co-researcher some water / drink, if appropriate.
5. If the co-researcher remains distressed, the researcher will offer to contact a person of the co-researcher's choice.
6. The researcher will ask the co-researcher how they are feeling. Dependent on the cause of the distress, the researcher will explore the co-researchers' support network and offer to supply contact details of relevant organisations if necessary. As the individuals are being recruited from Open Doors in Salford, the researcher will liaise with Cathy Riley (Service Manager) as appropriate. The individual would be informed of this beforehand.
7. If the co-researcher wishes to continue with the group, then the group will resume. If not, the researcher will make sure the individual has suitable transport home.

Interviews:

1. The interview will cease immediately and all recording (audio and text) will be stopped.
2. The participant will be asked if they would like to share their feelings and if they would like to discuss anything. The researcher will be sensitive to the fact the participant may need time alone and will therefore respond to the situation as appropriate.
3. The researcher will offer the participant some water / drink, if appropriate.
4. If the participant remains distressed, the researcher will offer to contact a person of the participants' choice.

5. The researcher will ask the participant how he / she is feeling. Dependent on the cause of the distress, the researcher will explore the participants' support network and offer to supply contact details of relevant organisations, if necessary. As the participant will have been recruited from a member involvement group involved in the Neighbourhoods and Dementia Study, the researcher will liaise with gatekeeper of their respective group as appropriate. The individual would be informed of this beforehand.
6. If the participant wishes to continue with the interview, then the interview will resume. If not, the researcher will make sure the participant is stable and ensure it is appropriate to leave.

***Actions*:**

- The researcher will report the event to the Chief Investigator.
- The researcher will record the event/s via a fieldwork diary, complete with date, time and description of the occurrence.

As this study is part of the Neighbourhoods and Dementia study, the co-researchers and participants will also have access to a clinical psychologist for support via Work Programme 8, the member well-being service. Information explaining how individuals can make a referral to this support will be given at the beginning of the research group and at every interview.