The use of life story work in an age inclusive dementia service: a participatory action research study

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"For a person with dementia who is losing their memory and trying to make sense of who they are, a life story book can be an atlas, the compass, the guide to finding their self."
(Tom Kitwood 1997)

ABSTRACT

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Aim and objectives: The aim of this qualitative study was to examine how life story work can be embedded into an age-inclusive dementia service. The objectives were to: explore the cultural and organisational changes required for practitioners to internalise life story work as part of delivering high-quality dementia care; determine how the use of a life story profile can be embedded into an age-inclusive dementia service; develop a model of service redesign which facilitates the introduction of good practice in dementia care; and analyse the essential and desirable components of life story work from the perspective of the person, their carers and practitioners.

Methodology: An inter-disciplinary participatory action research group was established to reintroduce life story work. This group met on eight occasions. These meetings were audio recorded, and notes made by an independent observer on the group processes. Field notes were also compiled by the researcher. Data collection further included interviews with research group members (5), people with dementia (4) and carers (3). The data were coded using Miles and Huberman's (1994) framework.

Findings: Four themes were identified: 'Life story work is a mechanism for resolving inflexible paradigms in working practice'; 'Life story work is a means of bringing people together in a collaborative manner'; 'Life story work is a strategy for providing post-diagnostic support' and 'Life story work is a framework for managing boundaries between staff and service users'.

Conclusions: This study suggested that a new 'PIC' model (participatory action research, innovation and creativity and cultural change) is recommended to enhance the delivery of person-centred care. This model assimilates the essential LSW strategies as proposed by the informants, the positive outcomes of undertaking LSW as identified in the literature and a framework for locality-based change management. When implemented, the PIC model will result in high-quality dementia care.

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In memory of my father, Charles Fredrick Albert Wood, and my mother, Doreen Elizabeth Ellen Wood.

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Preface

The decisions regarding the terminology used, arrangement style, confidentiality and presentation of the quotes used in the production of this thesis required thoughtful deliberation on several factors. These are explained below.

Terminology

The terms used in this thesis have been carefully considered. It is acknowledged that the term ‘person or individual with dementia’ has been overused. However, it was felt essential to use this term rather than the often-used acronym ‘PWD’. Such an abbreviation removes the individuality of the person and is a form of labelling. The term ‘person or individual with dementia’ is also the terminology preferred by people who have dementia, the Alzheimer’s Society and many other charities and service user groups.

To avoid the possibility that the clinical team in which the study was conducted might be identified the term ‘the service’ is utilised to describe the research setting and the generic term ‘service manager’ rather than the specific role title. Similarly, the term ‘the Trust’ has been used to describe the location of the research project.

Confidentiality

Pseudonyms have been used for all the participants' quotations as taken from the participatory action research groups and semi-structured interviews. This ensures anonymity for their contributions to the research and confidentiality in line with ethical principles.

No formal planning meeting notes, presentations or project reports have been included to ensure managers and local staff cannot be identified.

Quotations

The words of the participants are presented verbatim within quotation marks. Primarily, the quotations used are kept to just two examples to exemplify the key points made, but on occasion, additional quotations are employed. These multiple quotations have been used because each illustrates a different position. The quotations utilised also include speech hesitations and other nuances to indicate implicit meaning and reflection on the issues being discussed.

Abbreviations / Acronyms

AD	Alzheimer’s Disease
AR	Action Research
BPS	British Psychological Society
CASP	Critical Appraisal Skills Programme
CCGs	Clinical Commissioning Group(s)
CQUIN	Commissioning for Quality & Innovation
CST	Cognitive Stimulation Therapy
DoH	UK Department of Health
GPs	General Practitioners
IRAS	Integrated Research Application System
LSW	Life Story Work
MCI	Minor Cognitive Impairment
NDS	National Dementia Strategy
NHS	National Health Service
NICE	National Institute for Health & Care Excellence
PAR	Participatory Action Research
PCNF	Person-Centred Nursing Framework
PDS	Post-diagnostic support
PEARL	The ‘Positively Enriching and Enhancing Residents Lives’ Quality Assurance Programme
PIC	A New Model to Integrate Participatory Action Research, Innovation and Creativity and Cultural Change
PCC	Person-Centred Care
RCTs	Randomised Controlled Trials
VIPS	‘Valuing, Individualised, Perspectives & Social/Psychological’ Framework

Chapter 1: Introduction

"We often provide care for people with dementia, with very little knowledge of the person we are caring for and without an understanding of who that person is or has been in the context of his or her whole life"

McKeown (2011: 01 PhD Thesis)

Written in the first person to emphasise the reflective intention of the narrative, the opening part of this chapter provides a reflexive researcher statement that describes the personal assumptions that have influenced this study. This is followed by an explanation of the link between this thesis and a concomitant project which was being undertaken within the Trust. The nature and impact of dementia for the person with dementia and their carers and the current policy context are then described to emphasise the importance of person-centred care.

The chapter further outlines the principles of Tom Kitwood's approach to person-centred dementia care and contemporary interpretations of his research. The pressures associated with working in the National Health Service (NHS) are briefly summarised, followed by an assertion that organisational and cultural difficulties can be overcome and innovative person-centred care achieved if the values that underpin the social enterprise model are utilised.

To support this contention, it is proposed that the principles of Kitwood's research, participatory action research (PAR) and a critical consideration of the culture of care can be used as a framework for innovative practice. Life story work (LSW) is then defined, accompanied by an explanation of how it forms a component of person-centred dementia care.

1.1 Reflexive statement and position as a researcher

A critical aspect of any research study is the reflexive examination of the assumptions that have influenced the researcher's orientation to the research and the stated aim and objectives. Reflexivity "refers to the systematic process of self-examination. In the reflexive analysis, the investigator examines his or her own perspective and determines how it has influenced not only what is learned but also how it is learned" (DePoy & Gitlin 2005: 229). Reflexivity has also been described by Robson (2011: 172) as "an awareness of the ways in which the researcher as an individual with particular social identity and background has an impact on the research process".

McCormack (2003) explained that an essential requirement for research that focuses on person-centred care is to ensure such strategies are an integral part of the research process. To achieve this, the researcher must have a vision for the study "from the design through to implementation and beyond" (McCormack 2003:182). Such a view requires the researcher to reflect on their ontological position or the interplay between the concepts and categories of the research and their epistemological stance which is concerned with the origins and background to the investigator's position as researcher and of the study topic. An essential consideration in this respect is the congruence of the researcher's values and the research aims and methods employed within the project and the thesis (McCormack

2003). This includes potential influences on the data collected and the researcher's role and the possible impact of these on the themes identified within the project.

I initially became interested in the project because it seemed to provide the opportunity of working directly with a clinical team and in a study that had the potential to improve the lives of people with dementia and family carers. I had worked as a mental health academic for many years and while this role provided the opportunity to undertake clinically relevant work such as practice development, service evaluations, research, supervision and supportive counselling, the chance to return to a more direct clinical role was appealing at this point in my career.

I welcomed the opportunity to help support and deliver person-centred care interventions for people with dementia and their carers. I already had a strong affinity with the underpinning concepts of person-centred care, a philosophy that had been influenced by several personal and work-related experiences.

As a newly qualified registered mental health nurse, I had worked on the type of dementia care ward that influenced Tom Kitwood in his transformational thinking about person-centred dementia care. The clinicians in this team were mostly caring but constrained by the care environment and the dominance of the medical treatment model. I recall a desire to enhance the quality of care but being unable to influence the culture of care directly owing to the above-mentioned constraints. Furthermore, as a charge nurse on an end of life care dementia ward, I struggled under the burden of managing an under-resourced team while caring for a challenging client group. The work was stressful, and I was concurrently raising a young family and studying for a diploma to further my nursing career. Therefore, it is possible I was keen to be involved in this project owing to residual dissatisfaction at being unable to deliver individualised care practices earlier in my career.

My background as a mental health nurse and academic further impacted on my interest in the project because, while undertaking the research, I was simultaneously teaching students about models of person-centred care. The mental health nursing curriculum was based on a humanistic, recovery-focused model. Occasionally this initiated a philosophical debate within the research group and sporadic disagreements with staff from different professional backgrounds. Overall though, these perspectives were quickly resolved and enriched the project.

Thus, my epistemological and ontological stance, prior experience and personal philosophy influenced the choice of methodology and the use of PAR as a framework. Reflexive engagement with the study would also have impacted on my facilitation style in the PAR group, the approaches to the semi-structured interviews, the data analysis strategies employed and the interpretation of the results.

In surfacing this biographical material, I became aware of these influences and I approached my research role with the intention of operating in a person-centred way that was congruent with the project aims and the research strategies utilised. There is no doubt that Tom Kitwood’s theories strongly resonate with my personal beliefs and that these have had a significant impact on my views about how people with dementia and their relatives and work colleagues should be supported. In this regard, I have used the term ‘person with dementia’ or ‘person who has dementia’ throughout this study because these are commonly used words that emphasise the importance of Kitwood’s notion of ‘seeing the person, not the dementia’. The use of such terms helps ensure that an individualised and personalised approach is taken to data collection. Moreover, the notion of person-centred care is a requirement of all Government health, social and dementia care policies.

The above reflective statement describes the reasons I became interested in and agreed to lead the initial Trust funded project to reintroduce LSW into an age inclusive dementia service. While both the Trust project and the research study conducted for this thesis were concerned with exploring the same research question, aim and objectives, the Trust funded study was completed, and a summary report compiled for the launch event in November 2014. At this event several notional themes were presented to the participants and further discussion and sharing of updated life stories were undertaken. This finalised the requirements for the Trust project.

This thesis then commenced from December 2014 by conducting a comprehensive literature search and review and detailed analysis and coding of the data collected. This was an extensive process that resulted in the final thesis themes being established; the process of which is outlined and described in chapters three and four. The implications of the four generated themes are discussed in chapter five.

1.2 The nature and impact of dementia

The UK population is ageing, and people are living longer (Office for National Statistics 2012, 2017). Increasing age is also a significant risk factor for the development of dementia (Alzheimer’s Society 2007, Alzheimer's Society 2014). This means that dementia rates are rising and are projected to increase further in the near future (Bamford 2010, Alzheimer’s Disease International 2011). Alzheimer’s Disease and other forms of dementia are now the leading cause of death in England and Wales, representing more than 11% of the total deaths registered; a figure that has doubled since 2010 (Office for National Statistics 2017). Whilst the Alzheimer’s Society (2012) believe the number of people with dementia will grow steadily, rather than dramatically, over the next 25 years, this scenario still presents a significant challenge for health and social care services.

There are estimated to be 821,884 people in the UK with dementia, of which women make up 66 per cent (Alzheimer’s Society 2014, Prince et al. 2014, Andrews 2015). This figure is 15 per cent higher than previously predicted and equates to one in 20 of those aged over 65 (Alzheimer’s Research Trust 2010, Bamford 2010, Alzheimer’s Disease International 2011, Alzheimer's Society 2014). These estimates include over 40,000 individuals with young-onset dementia (under 65 years old). By 2025, it is anticipated there will be over one million people with dementia in the UK, a figure that is expected to rise to over 2 million by 2051 as the population ages, by which time one in three people over the age of 65 will have some form of dementia (Alzheimer’s Society 2007, Bamford 2010, Alzheimer's Society 2014).

In 2010, global estimates showed that over 35 million people had dementia and this number was projected to more than double by 2030 and triple by 2050 (Alzheimer's Research Trust 2012, Prince et al. 2013). Approximately 8 million new cases of dementia are diagnosed each year internationally, whilst in Europe, a new instance of dementia arises every 24 seconds (Alzheimer's Disease International 2015). At 1.2 million, Germany has the highest per capita rate of dementia in Europe, although it should be borne in mind that the overall total is affected by the population size, how the population ages and their health and social status (Bamford 2010, Prince et al. 2013). These figures were updated in the World Alzheimer Report of 2016, based on an estimate that 46.8 million people worldwide had dementia in 2015. The report further predicted that this number would virtually double every 20 years, becoming 74.7 million in 2030 and 131.5 million in 2050, with significant rises in China, India, South Asia and the West Pacific (Alzheimer's Disease International 2015, LaingBuisson 2017). Additionally, there are thousands of people with a mild cognitive impairment (Petersen et al. 2014); according to the Alzheimer's Research Trust (2012), ten to 15 per cent of people diagnosed with mild cognitive impairment have an increased risk of progressing to Alzheimer's disease.

1.3 Defining dementia

Dementia is considered to be an umbrella term and has been defined as follows:

> *"Dementia is a syndrome due to disease of the brain, usually of a chronic or progressive nature in which there is a disturbance of multiple higher cortical*

> *functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgment."*
>
> *(The World Health Organisation 2012:7)*

> *"Dementia is a clinical syndrome caused by neurodegeneration (Alzheimer's disease, vascular dementia, Lewy body, and frontotemporal dementia being the most common underlying pathologies) and characterised by inexorably progressive deterioration in cognitive ability and capacity for independent living."*
>
> *(Prince et al. 2013: 64)*

As can be seen from the above definitions, dementia tends to be defined and described within a medical, disease-oriented rather than a person-centred paradigm that focuses on neuropathology and an associated decline in psychological and physical functioning. The experiences of dementia vary between individuals but commonly include short-term memory loss and personality change and an array of behaviours that could be seen as a challenge to the person or to relatives and significant others (Feast et al. 2016).

1.4 The sub-types of dementia

There are many different sub-types of dementia, of which the main ones are listed on Box 01 on the next page:

Box 01: The different sub-types of dementia

DEMENTIA SUB-TYPE	**PERCENTAGE**
Alzheimer's disease	62%
Vascular dementia	17%
Mixed dementia	10%
Dementia with Lewy bodies	4%
Fronto-temporal dementia (including Pick's)	2%
Parkinson's dementia	2%
Other dementias (including Korsakoff's syndrome, HIV & AIDS-related dementia and Creutzfeldt-Jakob disease)	3%
Source: Alzheimer's Research Trust (2012)	

1.5 The impact of dementia on the person, their relatives and care providers

It is difficult to project the cost of health and social care because diagnostic rates are poor with just 40-50% of people living with dementia receiving a diagnosis (Alzheimer’s Disease International 2015, Alzheimer’s Society 2017). Nevertheless, the personal and social effects are evident; it also has a significant economic impact and substantial financial implications for people with dementia, their families, and health and social care providers. The current financial cost to the UK economy is estimated to be more than £18 billion per annum, a figure that could treble as the number of people living with dementia increases (Alzheimer’s Society 2007, Goodchild 2009).

As people with dementia are at an increased risk of physical health problems and potentially more dependent on care services, there is also a significant effect on family carers and other relatives who provide unpaid care. In view of this, post-diagnostic support (PDS) is vital for families as well as acknowledgement of the immense responsibility they face (La Fontaine et al. 2011, Feast et al. 2016).

Nevertheless, the reality is that carers continue to be confronted with major difficulties, including financial problems, a lack of a needs assessment, inadequate access to support and information, mental and physical health challenges and social isolation (Carers UK 2016, Alzheimer’s Society 2017). The outcome of such a situation often results in the rights of carers, as defined in the Care Act (2014), not being sufficiently addressed (Carers UK 2016).

Experiences similar to the family carers are also reflected in the rapidly expanding archive of living with dementia as documented by people who have dementia. This impact has been described as a feeling of loss in respect of previous abilities, including intellect and short-term memory (Mitchell 2018) and difficulty in adjusting to change and unfamiliar environments and a corresponding need for structure (Oliver 2016). Similarly, the psychological effects of recognising the first signs of dementia, the impact of a diagnosis on those with a young family, the effect on work roles and responses of colleagues to same and requirement to re-evaluate financial considerations have been cited by Bryden (2012).

Moreover, feelings of grief, disbelief, denial and the associated emotional turmoil have been outlined by Swaffer (2016) who also cites a loss of social contacts, feeling marginalised and difficulties adjusting to a diagnosis. Whitman (2016) further mentions a need to ‘resist’ dementia but also views it as a journey of discovery, with a corresponding need for spiritual and religious guidance and desire to contribute to raising awareness and to be involved in research. Such a perspective is supported by Bryden (2012) who advocates a requirement to maintain optimism and meaningful occupation. Finally, Mitchell (2018) highlights occasional poor coordination of services, a lack of staff empathy and understanding and a need to access information about dementia.

Hence, dementia has significant implications for care providers and on the general economy and a substantial personal effect on individuals who have dementia and their relatives and friends (Alzheimer's Research Trust 2012). The challenges to health and social care providers are clear: there will be a need to deliver suitable home support and person-centred long-term care provided by specialist staff in the context of increasing financial constraints and rising numbers of people with dementia. A cure for dementia and the likelihood of any new drug treatments is potentially decades away and so there is a pressing need to focus on improving the quality of life and care for people with dementia and their family carers in the present (Barker 2014). This involves listening to the people for whom the services are being provided and developing services tailored to meet their needs. In this context, the attainment of person-centred care can be challenging to achieve, yet many approaches can be efficiently and cost-effectively utilised with considerable benefits (Kellett 2010).

1.6 UK dementia policy

In response to the needs of and the difficulties faced by people with dementia and their family carers, the UK Government has released several policy initiatives:

> The National Dementia Strategy (NDS) for England (Department of Health [DoH] 2009) and the updated version published in September 2010 (DoH

> 2010) which emphasised the need for person-centred care and identified several priorities for change.
>
> The UK Prime Minister (2012) strengthened the above strategy by establishing a three-year ‘Dementia Challenge’ in March 2012, issuing a new five-year dementia plan in February 2015 and releasing an updated version of the Challenge in 2016.

In addition to the above, the National Dementia Declaration (Dementia Action Alliance 2010) and the National Institute for Health and Clinical Excellence (NICE) Quality Standard for Dementia (2010) and updated version of this issued in April 2013, have shaped guidelines for good practice in dementia care and determined what people with dementia need from care service.

The five-year NDS for England (DoH 2009) required dementia care providers to develop local action plans for implementing the objectives contained within this strategy and to deliver according to the guidelines, as mentioned in the previous paragraph. Published in February 2009, the vision of the NDS was to ensure that people with dementia and their family were supported to ‘live well with dementia’. Several of the NDS objectives have relevance to this research study, particularly the need to improve the quality of care and provide person-centred interventions and family carer support. An updated version of the NDS was published in September 2010 (DoH 2010) and this document outlined the priorities for continuing to improve the care outcomes for individuals, including high-quality support and being treated with dignity and respect, both of which are integral to LSW.

Similarly, the NICE quality standard for dementia also promoted the need for excellent dementia care. NICE published a further standard and a commissioning guide in April 2013 (NICE 2013). The National Dementia Declaration (Dementia Action Alliance 2010) also outlines outcomes that have the potential to improve care. These include services being designed to meet personal needs. The declaration was updated in 2017 and contained new standards and rights, which are representative of what people with dementia require. These rights are endorsed by relevant health and social care legislation and include choice, acceptance and the right to early diagnosis and access to support (Alzheimer's Society 2017).

The three-year 'Dementia Challenge', launched by the Prime Minister in March 2012, aimed to enhance the lives of people and their families significantly. This initiative built on the progress of the NDS by seeking to establish three dementia challenge action groups to drive care improvements, create dementia-friendly communities and increase research (DoH 2012). The Alzheimer's Society's report of March 2012 (Dementia 2012: A National Challenge) acknowledged that there had been some improvement in this regard but noted that considerable additional work was required to ensure the aims of contemporary dementia policies were achieved. The Dementia Challenge progress report, released in May 2013, further noted improvement, including enhanced compassionate care in acute hospitals and greater quality of life for people with dementia, but it also showed that progress had been slow and that considerably more work was required to ensure that policy intentions are reflected in the experiences of individuals in all care settings. Another activity report, released in May 2014, documented increased diagnosis rates, expanding numbers of dementia-friendly communities and more research spending with further improvements planned in post-diagnostic support. In 2015 the Prime Minister's Challenge on Dementia 2020 was released. This action plan extended the NDS and the Prime Minister's Dementia Challenge (2012), placing emphasis on therapeutic activities and increasing treatment research.

Central to all the above policies and guidelines is a requirement to achieve high quality, person-centred dementia care. This can only be accomplished if the starting point for and central component of such care is the person's life story (Kitwood 1997, Brooker et al. 2009).

1.7 Tom Kitwood and person-centred dementia care

The contemporary principles of caring for a person who has dementia have been significantly influenced by the research and work of the late Tom Kitwood. His conceptual framework, the origins of which lie in spirituality and humanistic psychology and the theories of Carl Rogers, initiated a significant paradigm shift from the dominant biomedical model utilised at the time to a person-centred philosophy (Kitwood 1987, Kitwood 1990, Adams 1996, Kitwood 1997, Baldwin & Capstick 2007, Adams 2008). Kitwood challenged the culture of dementia care in the 1980s and early 1990s by highlighting the limitations of the biomedical model as a reductionist approach that focused on the disease, not the individual (Kitwood 1990, Kitwood 1997). Such a model sees the person who has dementia as having a neurodegenerative disease of the brain characterised by a progressive loss of physical, psychological and social functioning that eventually leads to complete dependence (Kitwood & Bredin 1992, Kitwood & Benson 1995).

Importantly, Kitwood also emphasised that, despite the organic changes in the brain that occur in dementia, the progress of the disease could be influenced by several other important factors (Baldwin & Capstick 2007). Therefore, he believed that to view dementia simply as a degenerative process meant that critical human issues were overlooked (Adams 1996). Kitwood argued that if dementia is understood purely as a biomedical concept, care becomes task-oriented and controlling (Kitwood 1997). In turn, interventions such as sedating medication and physical restraint become overused (Kitwood 1990, Kitwood 1997). Such a circumstance encourages labelling and the ‘warehousing’ of people with dementia in care homes and long-stay wards, a process which devalues the individuality of the person (Adams 1996, Adams 2008). The impact of this phenomenon may also have contributed to high numbers of people with dementia in England being unnecessarily prescribed anti-psychotic medication; a situation that causes approximately 1,800 deaths per year (Banerjee 2009). The review conducted in this regard outlined 11 recommendations including ensuring professional staff consider alternative therapeutic approaches and only use anti-psychotic medication when there is a clear need (Banerjee 2009).

To counteract the impact of the reductionist approach to dementia care, Kitwood (1997) proposed his ‘Enriched model of dementia care’, an approach that considered the multiplicity of factors which affect a person’s lived experience of dementia. This model views dementia as a social creation which includes integrative consideration of the interplay between a person’s neurological impairment, physical health, biography, personal experience and the social (or care) environment (Brooker 2007). He then described how these factors affect the subjective experience of the person’s dementia and presented these as an equation (D = P + B + H + NI + SP) to explain the presentation of a person with dementia and to place the neurological impairment into the context of the person’s complete experience (Kitwood & Benson 1995):

Dementia presentation =

P = Personality
B = Biography
H = Health
NI = Neurological Impairment
SP = Social Psychology

Within this person-centred framework, Bellchambers & Penning (2007) described how Kitwood also based care on the assumption that all humans have five fundamental (or a cluster of) psychological needs: Comfort, the providing of warmth and strength; Attachment, the making of specific bonds or attachments; Inclusion, being part of a group; Occupation, being involved in the process of life; and Identity, having a sense and feeling of who one is. Founded on this supposition, Kitwood undertook research into personhood which is concerned with how biography and personality influence a person's experience of dementia (Kitwood 1997). His inquiries aimed to provide a better understanding of how personhood was undermined for those individuals who were living with dementia.

Personhood is defined as “a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust” (Kitwood 1997: 8). Kitwood (1997) firmly believed that the individual should not be defined in terms of the disease but as someone in danger of losing their personhood. Therefore, he advocated that the personhood of the person with dementia be respected (Adams 1996, Baldwin & Capstick 2007, Adams 2008, Dewing 2008).

Kitwood also used the phrase ‘malignant social psychology’ to describe the undermining of personhood when negative emotions and individual needs and rights are overlooked (Kitwood 1990, Kitwood 1997). Malignant social psychology is seen as a series of behaviours adopted either consciously or unconsciously by professional or unpaid carers such as labelling, intimidation and disempowerment (there are 17 in total) which undermine personhood by producing care practices that prevent the meeting of the person’s cluster of psychological needs and rights (Brooker 2005). As previously outlined, these ‘malignant’ interactions are often not intended but result from a lack of knowledge or insight on the part of the practitioner or are due to the use of the biomedical model of care (Dewing 2008, Brooker et al. 2009). When this occurs, it becomes difficult to counteract the dehumanising care processes that exist, and so personhood is lost (Adams 2008). In such situations where clinical staff believe the person has been replaced by the dementia, this negatively influences the care given and reduces the person to a set of symptoms and care to a meaningless task. However, if the opposite view is taken, person-centred care will result (Kitwood 1990, Kitwood 1997).

To help support more positive care practices, Kitwood (1997) sought to understand how high-quality dementia care could be provided through the adoption of Dementia Care Mapping. This is an observational tool comprised of five phases: Preparation and briefing; Observation; Analysis; Feedback; and Action Planning (Chenoweth & Jeon 2007, Douglass et al. 2010). It is an approach that attempts to assume the perspective of the person with dementia by using a combination of empathy and observation, whereby coding frames are used as a focus for feedback to the care team on the interactions observed and for organisational change that includes action planning and monitoring (Kitwood 1997, Brooker 2005, Brooker 2007).

Although some theorists have highlighted a perceived lack of scientific evidence to support Tom Kitwood’s ideas (Adams 1996, Dewing 2008), there is still a considerable volume of high-quality research that reinforces the useful application of his views and the positive impact of maintaining personhood (Brooker 2005, Baldwin & Capstick 2007, Adams 2008). In addition, there are a significant number of studies that have utilised Dementia Care Mapping for evaluative and change purposes (Chenoweth & Jeon 2007, Douglass et al. 2010).

Kitwood attempted to alter the perspective of dementia to one in which 'the person comes first', meaning that people with dementia must be cared for as individuals in the context of their unique identity, sense of self and personal biography (Kitwood 1997, Dewing 2008). There can be no doubt that such a perspective initiated a transformation and significant paradigm shift in dementia care practice. Indeed, Kitwood’s model is still considered to be the ‘gold standard’ for person-centred dementia care today, the principles of which are embedded within all current dementia care policies (Brooker & Latham 2006, Loveday 2013, Andrews 2015). What also remains clear is that his enriched model provided the impetus for the development of individualised and holistic care approaches including personal biographies and the influence and sharing of the lived experience of dementia.

1.8 Contemporary perspectives of person-centred care

Tom Kitwood passed away in 1998, but, as stated, his work so significantly transformed the culture of dementia care that his philosophy continues to influence contemporary dementia policy and practice. Nonetheless, person-centred dementia care is now interpreted in a variety of ways and has progressed to encompass creative thinking about and innovative practice in dementia care. Such an approach includes adopting a critical and reflective perspective towards all aspects of dementia care practice so that new ideas evolve and are implemented by positively adapting the care environment and by initiating new approaches to interactions such as simulated presence therapy which is concerned with reducing anxiety by playing an audio recording of a relative to the person with dementia (Abraha et al. 2016) and the VERA framework that involves using a four-step process to provide compassionate communication responses (Hawkes et al. 2015). Consequently, Kitwood’s theories and ideas have been remodelled and reinterpreted with the result that person-centred dementia care now seems to convey several different meanings. The following three frameworks, of which the ‘Valuing, Individualised, Perspectives and Social/Psychological’ (VIPS) approach is the most notable, are the most popular contemporary representations of Kitwood’s work. A more comprehensive overview of the VIPS model is provided because it is most closely aligned with Kitwood’s work and is the only framework specific to dementia care.

The VIPS Framework was developed by Professor Dawn Brooker (2004) who worked with Tom Kitwood and then published further ideas on his theories in the two editions of ‘Person-Centred Dementia Care’ (Brooker & Latham 2007, Brooker &

Latham 2016). The approaches outlined in these textbooks are now internationally recognised as a context for providing individualised care and have become the most widely accepted interpretation of person-centred dementia care. The framework is multifaceted and integrates approaches derived from the theoretical perspectives of person-centred dementia care, as developed by Kitwood but underpinned by an evaluative tool (Brooker & Latham 2016). These fundamental principles provide the basis for quality dementia care. As an attempt to integrate existing evidence and to define the essential elements of individualised care, the framework acts as a contemporary summary of Kitwood's person-centred ideas by using the acronym 'VIPS' to encapsulate the defining components which it groups into four elements:

Box 02: The four elements of the VIPS framework

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 person identified needing support.
S	Providing a social environment that supports psychological needs.

The VIPS Framework Tool was conceived as a structured approach based on these elements to describe the relevance of person-centred care to practice. Accordingly, to provide care that supports the personhood of people with dementia, care providers need to attend to each of the VIPS elements (Brooker 2004, Brooker & Latham 2006, Brooker & Latham 2016). To help achieve this aim, the evaluative VIPS Framework Tool is utilised. For each VIPS element, six indicators were derived, enabling evidence gathering to support the evaluation of how efficiently person-centred dementia care is being delivered:

Box 03: The VIPS elements with the six indicators for each

The Person-Centred Care Provider – Brooker (2007)	
VALUING V1 vision V2 human resource management V3 management ethos V4 training & staff development V5 the service environments V6 quality assurance	**INDIVIDUALISED** I1 care planning I2 regular reviews I3 personal possessions I4 individual preferences I5 life history work I6 activity & occupation
PERSPECTIVE P1 communication P2 empathy & acceptable risk P3 physical environment P4 physical health needs P5 challenging behaviour P6 advocacy	**SOCIAL/PSYCHOLOGICAL** S1 inclusion S2 respect S3 warmth S4 validation S5 enabling S6 part of family & community

The six indicators for each element are integrated into a toolkit which is not only used to evaluate the care environment but also to enable care teams to compare the care provided with principles of good practice. In turn, this then guides implementation, constructive feedback and improvement. Each indicator is rated on a four-point scale known as: ‘How are we doing?’. Overall performance is rated according to 26 VIPS indicators. An example from the VIPS Framework Tool (the ‘V’ element) is reproduced overleaf (Brooker & Latham 2016):

Box 04: An example from the VIPS Framework Tool

Valuing people with dementia and those who care for them	**How are we doing?** ‘Excellent’, ‘Good’, ‘Okay’ or ‘Needs More Work’.
V1 Vision: Does everyone know what we stand for and share the vision?	
V2 Human resources: Are systems in place to ensure staff know that they are valued as a precious resource?	
V3 Management ethos: Are management practices empowering to staff delivering direct care to ensure care is person-centred?	
V4 Training and staff development: Are there systems in place to support the development of a workforce skilled in person-centred dementia care? Do staff know that supporting people living with dementia is treated as skilled and important work?	
V5 Service environments: Are there supportive and inclusive physical and social environments for people living with cognitive disability? Do our places help people?	
V6 Quality assurance: Are Continuous Quality Improvement mechanisms in place that are driven by knowing and acting upon needs and concerns of people with dementia and their supporters? Do we strive to get better all the time?	

The service evaluation conducted by using the VIPS framework is also supported by the following strategies (Brooker & Latham 2016):

- Dementia Care Mapping
- In-depth semi-structured interviews with the family carers
- Individual interviews with staff team (including bank staff members)
- Individual interviews with manager(s)
- Informal observation and conversations with clients
- Telephone and personal interviews with professionals with significant involvement with the service
- Review of care documentation, records and processes
- Consideration of previous reports including previous internal Dementia Care Mapping reports
- Attendance at team meetings
- Review of literature and policy relevant to the dementia service provision

A final report is then produced under the headings of ‘Points for action’ and ‘Overall performance’ (Brooker 2007).

The VIPS framework also emphasises the importance of the full involvement of all levels of the organisation’s management if person-centred care is to be achieved. Brooker & Latham (2016) explained that to establish the value base of person-centred care and to set standards for delivering it, the responsibility for this must rest with senior management. A further asset of the framework is claimed to be the integration of Kitwood’s principles into a workable and accessible model that continues to place the person with dementia at the centre of care processes. This is achieved by emphasising the fact that unless the organisational culture and the culture of the care environment is assessed and adapted and care teams supported, then person-centred dementia care is impossible to achieve (Brooker & Latham 2016).

As can be seen from the above summary of the process for utilising the VIPS framework, whilst the tool provides helpful feedback to the organisation on the quality of care and procedures to support it, this involves a very lengthy and potentially time-consuming process. There is a requirement to utilise a range of evidence sources and to extensively consult with a vast number of stakeholders (Brooker & Latham 2016). This is a very laudable intention, but given the current pressure on health and social care providers, it means that the framework and tool could be impractical to use.

Similarly, although the model concurrently uses Dementia Care Mapping, this has not been extensively applied because of the need to allocate sufficient time and resources to fully utilise its potential (Edvardsson & Innes 2010, Cooke & Chaudhury 2012, Barbosa et al. 2017). Indeed, only three evaluations have been completed on the VIPS framework to date. Even though positive outcomes were reported, all seem to lack research rigour. For example, Røsvik et al. (2011) undertook an evaluation, using qualitative methodology, of a nine-week pilot of the VIPS model in two nursing homes. Data were collected by conducting four focus groups, and subsequently analysed using content analysis. The themes identified explored staff roles; their knowledge acquisition; support for the facilitator; and lead nurse roles by the organisation. This study concluded that VIPS operated well in units which had a lead registered nurse who supported the facilitation role of the auxiliary nurse.

Passalacqua & Harwood (2012) also used VIPS to develop a series of workshops to improve the communication skills of care workers in a long-term care facility in the USA. Using pre- and post-evaluation, participants reported improved attitudes and expertise. Additionally, Baker (2014) described using VIPS as an organising principle for an internal quality improvement programme called ‘Positively Enriching And enhancing Residents Lives’ (PEARL) in a large private care home provider in the UK. This project positively impacted on the lives of residents and produced several benefits for people with dementia. An essential part of this project was to view LSW as a central component of the PEARL model (Baker 2014).

In addition to the above limitations and the small number of evaluative studies undertaken of the VIPS framework, the VIPS model does not seem to easily incorporate the considerable volume of contemporary ideas on person-centred dementia care that are concerned with the innovative approaches that emerge from personal biographical projects. These include schemes such as the hair and care project (Ward et al. 2016), the use of photovoice (Evans et al. 2016), the significance of clothing and dress to the person with dementia (Twigg et al. 2013) and the use of walking or neighbourhood life stories (Ward et al. 2017). These types of projects and the associated evaluative research appear to embody and exemplify the contemporary philosophy and values of person-centred care and suggest that another element i.e. 'I' to symbolise innovation and creative thinking could potentially be added to VIPS, as shown below:

Box 05: Suggested addition of 'I' for Innovation to the VIPS Framework Tool

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 person** identified needing support.
S	Providing a **social environment** that supports psychological needs.

I	Promoting and placing **innovative and creative thinking** as the essential ingredient of quality care.

Whilst not specific to dementia care, McCormack & McCance (2006, 2010) and McCormack et al. (2012) developed 'The Person-Centred Nursing Framework (PCNF)' and suggested that contemporary person-centred care should be about a collaborative, compassionate and respectful partnership between the practitioner and the person, getting to know the individual as a person, the sharing of power and responsibility, accessibility and flexibility of services, coordination and integration of care and having an environment conducive to individualised practice. The significance of the care environment or culture of care is particularly emphasised in this model. With these assertions in mind, McCormack et al. (2012) critically reviewed several published models of person-centred care with the intention of documenting the similarities and differences and exploring these in respect of the qualified nurse's role in the long-term care of older people. Three potential applications were identified, with each representing a unique view of person-centred care and each having a different theoretical perspective:

CULTURE CHANGE CONSTRUCTS AND PRACTICES driven by practice-based innovations:

- Person-centred care: Resident driven routines
- Home-like environment: Private rooms, gardens, etc.
- Close relationships: Consistency of staff, sense of community
- Staff empowerment: Active involvement in planning
- Collaborative and decentralised leadership
- Systematic quality improvement processes

PERSON-CENTRED PRACTICE which focuses on the attributes of the practitioner, the care environment and person-centred processes:

- The attributes of the nurse
- The care environment
- Person-centred processes; e.g. range of activities
- Outcomes are the results of effective person-centred care
- No distinction is made between the person, their families/significant others and care staff

RELATIONSHIP-CENTRED CARE whereby relationships are critical to positive outcomes for patients and practitioners:

- Relationships are critical to positive outcomes for patients and practitioners:
- Prerequisites
- The care environment
- Care processes

McCormack & McCance (2010) and McCormack et al. (2012) further identified a person-centred nursing framework that was comprised of four constructs:

Box 06: The four constructs of the person-centred nursing framework (McCormack et al. 2012)

PREREQUISITES	**CARE ENVIRONMENT**
• Attributes of the care worker • Being professionally competent • High level of interpersonal skills • Being committed to the job • Demonstrating clarity of beliefs and values • Knowing one's self	• Appropriate skill mix • A system that facilitates shared decision making • Effective staff relationships • Supportive organisational systems • Sharing of power • Innovation • Risk taking • Physical environment
PERSON CENTRED PROCESS	**OUTCOMES**
• Delivering care through range of activities • Working with patient's beliefs & values • Engagement • Sympathetic presence • Sharing decision making • Providing holistic care	• Satisfaction with care • Involvement with care • Feeling of well-being • Creation of a therapeutic environment

McCormack et al. (2012) concluded that their review of the literature identified that each model was unique and offered different perspectives of the person. Despite this, nevertheless, the models do not define personhood in relation to the various roles in the operation, for example, care recipient and relative (McCormack et al. 2012). They also warn that the different focus of the many models in operation raises the possibility of person-centred care moving away from its humanistic tradition. In consequence, there is an even greater need to concentrate on personhood, and the examples of good practice their framework offers (McCormack et al. 2012).

Meanwhile, Nolan et al. (2004) explained that there is now general awareness that the concept of person-centred care correlates with high-quality practice and in recognition of this, developed 'The Senses Framework'. After undertaking several literature reviews that analysed the care given to older adults with long-term conditions, the authors evaluated the theoretical perspectives that support 'person-centredness' and then proposed that a relationship-centred strategy could be the most appropriate. Taking this point into account, the dimensions of the Senses Framework are considered to be:

- Security – to feel safe within relationships
- Belonging – to feel 'part' of things
- Continuity – to experience links and consistency
- Purpose – to have a personally valuable goal or goals
- Achievement – to make progress towards a desired goal or goals
- Significance – to feel that 'you' matter

An essential part of the framework is the consideration of the relationships relevant to the individual, thereby recognising the 'interdependence' of the person, their relatives, the local community and care workers. Also, the framework has been used and evaluated in several care settings with the authors reporting positive feedback which has enabled them to enhance the central concepts (Nolan et al. 2004).

Thus, despite a significant increase in the number of 'person-centred' frameworks and models, studies published and systematic reviews undertaken, there still appears to be a lack of clarity about what person-centred care consists of and how it should be defined (Olsson et al. 2012). For example, Morgan & Yoder (2012) conducted a concept analysis and noted that different terms were being used interchangeably: 'individualised-care', 'person-centred care', 'patient-centred care', 'client-centred care', and 'resident-centred care'. Kim & Park (2017) documented how person-centred care was viewed as a holistic and integrative approach that maintained well-being and quality of life for people with dementia by including the individual, their carers and the more extensive family. This meta-analysis also claimed to provide evidence that person-centred care was effective for people with dementia and that such interventions reduced behavioural problems and depression and improved quality of life.

Nonetheless, any improvement was only short-term, and the effects varied depending on the intervention used, staff skill level and the training provided. Olsson et al. (2012) also undertook a systematic review to evaluate person-centred care as an intervention in controlled trials. They concluded that, as an intervention, it was shown to be successful in a significant number of the studies, but importantly the evidence base is at present insufficient and hence more rigorous research is required. Edvardsson & Innes (2010) further highlighted that the tools developed to measure person-centeredness had not been validated beyond the projects in which they were used, and so their validity, reliability, and applicability required further evaluation. Additionally, the views of people who have dementia have not been consistently elicited (Edvardsson & Innes 2010).

1.9 The impact of NHS organisational culture on person-centred care

As has been shown in section 1.8, the evidence base for and the effectiveness of person-centred care continues to prove problematic. Indeed, Olsson et al. (2012) outlined how methodological problems might explain the lack of quality research and Edvardsson & Innes (2010) noted that the many instruments available makes it difficult to evaluate efficacy. Furthermore, the ‘new’ person-centred care frameworks outlined above often seem too complex and time-consuming to use and, when combined with the required ‘training manual’ approach, become too lengthy and impractical to apply within contemporary health and social care practice. Additionally, there are several associated organisational and cultural problems that frequently prevent the implementation of person-centred care interventions.

Working in the contemporary NHS is exceptionally challenging and hence being expected to deliver high-quality care in this context can often feel overwhelming for clinicians (Khamisa 2015). This can provoke a feeling of operating in a ‘storm’ of competing organisational and external influences whereby professionals are constantly confronted with many situations that, in many respects, are outside of their control. Many of these problems have to be responded to simultaneously and include having to deal with staffing and resource shortages, contend with quality inspections, attain clinical targets, implement new technology and complete an increasing number of care records (Sawbridge & Hewison 2011, Travaglia et al. 2011, De Silva 2015).

To compound this scenario, the number of clinical and Government policies that practitioners must respond to continues to significantly expand, there is an expectation of caring for an increasing number of patients, and new professional body requirements have been introduced (Khamisa 2015). All these factors make it difficult for dementia care clinicians to implement person-centred interventions. A similar situation could be observed at the service in which this study took place because the contracting requirements of the local Clinical Commissioning Groups (CCGs) appeared to prevent more person-centred care approaches being delivered.

The problems associated with this context also appear to be perpetuated by the organisational model and culture in which NHS Trusts are required to operate. By way of exemplifying this point, the King’s Fund (2014) report on organisational models used in the NHS highlighted that even though other provider model options are available, the individual Foundation Trust model remains the most widely used. Under the conditions of achieving this status, Trusts are expected to operate a business framework that focuses on attaining DoH clinical targets and managing within delegated budgets to produce a surplus. Clearly, this has not been achieved within recent years, with many Trusts running fiscal deficits. Furthermore, such a model significantly impacts on the organisational culture and the manner in which it operates. These influences are also demonstrable in the ‘storm’ scenario outlined above (De Silva 2015).

Morgan (2014) explained that there are five primary organisational structures available to contemporary businesses: ‘traditional, flatter, flat, flatarchies and holacratic’, with the traditional hierarchy now considered to be outdated and unsuitable for use in modern organisations. Despite this assertion, the traditional hierarchy remains the dominant model operated by NHS Foundation Trusts even though other options are available and have been utilised, including federations, networks, joint ventures and social enterprises (King’s Fund 2014).

The use of the social enterprise organisational model has been steadily increasing in healthcare with many social enterprises now working with clinical commissioning groups (Social Enterprise UK 2017). In respect of dementia care, social enterprises have been advocated as an essential component through which to implement the innovative practices that are starting to emerge (Ógáin & Mountain 2015). The improvements in quality of care have been achieved in part by the fact that the provider organisation operates as a charity with the financial surplus generated being re-invested into direct care (Social Enterprise UK 2017). The use of life stories is viewed as a critical aspect of social enterprises because the model emphasises individualised care and partnership working as an essential focus for care delivery (Rahman & Gaughan 2014). Accordingly, it seems that the application of the values that underpin the social enterprise model are essential if innovative person-centred care is to be achieved and the cultural and organisational difficulties associated with such initiatives overcome.

1.10 Adopting an integrative approach to person-centred dementia care

In light of the discussion on the impact of NHS organisational culture on person-centred care, how can the differing perspectives on person-centred care be integrated to form a cohesive framework for practical use in contemporary dementia care?

As a starting point, the similarity to current models of person-centred care and to the concepts established by Tom Kitwood should be noted in respect of the correlation with the operating principles of social enterprises. These include the importance of an effective culture of meaningful stakeholder engagement and innovation in dementia care. To further support this point, it was suggested in the earlier critique of the VIPS framework (Brooker 2005) that creative thinking must be an essential component if high-quality care is to be achieved. Indeed, Brooker & Latham (2016) highlighted the fact that if the organisational culture is not appraised and adapted then person-centred care will not be attained.

Therefore, it is generally agreed that there needs to be a return to the core values espoused by Kitwood. As Law et al. (1995) have suggested, person-centred care is merely a philosophy that involves working in partnership with care recipients and showing respect for them as individuals. Lutz & Bowers (2000) also emphasise the importance of collaboration between service users, their family networks and friends and clinicians in the care team. Additionally, Storlie (2015) supported the value of these aspects but added the need for professionals to be compassionate and for services and the care setting to be individualised, conducive to person-centred care, well-coordinated and accessible.

Subsequently, the principles of Kitwood’s research remain relevant and appropriate and continue to be accepted as a framework and as a foundation for innovative practice. Even if only these values are adopted, a corresponding improvement in the relationship between care staff, the individual with dementia and their family will be generated (Brooker et al. 2009).

In relation to the exploration of the VIPS framework, when person-centred care includes adopting a reflective and critical perspective on all aspects of dementia care then innovative ideas evolve and become implemented. This would involve adapting the care environment and initiating new approaches to therapeutic interactions and care excellence such as dementia communities and personal biographical strategies. The person-centred frameworks reviewed in this chapter would seem to support such a suggestion, in that once the principles of person-centred care become integral to everyday practice, then the next stage is to undertake a reflective, yet critical, evaluation of the care environment. The desired outcome of such an evaluation is to develop innovative ways of delivering dementia care. This type of approach also correlates with the evolving evidence on the benefits of building dementia-friendly environments whereby even subtle environmental changes can have a significant impact on the quality of life of the person with dementia (Bray et al. 2015). Such projects are also in accordance with current dementia policy (DoH 2015).

Most models of person-centred care purport to include the person, family carers, staff, managers and organisational culture, yet only tend to suggest principles of good practice without considering the organisational context in sufficient depth. Therefore, a potentially useful way of reconceptualising person-centred dementia care is merely to accept that, owing to a lack of agreement regarding precisely what person-centred dementia care means, any evaluative research undertaken on it will be limited. Consequently, the focus should be on principles about which there is collective agreement, namely supporting clinicians to work with people who have dementia and their families in partnership and in creative and innovative ways, valuing personhood, ensuring people are involved at all stages of the care process, and by guaranteeing the individual’s life story is the starting point of and focus for the support provided. It is these values that have influenced and underpinned the approach to person-centred care that has been adopted in this study.

For LSW to be applied efficiently, all four stakeholders: the individual, the family carer, the care staff, and the organisation, need to adopt a collaborative approach (McKeown et al. 2006). Moreover, it is suggested that any intervention, treatment, therapy or service development can only be defined as a ‘person-centred care’ initiative if it has fully involved service users in the planning, delivery and evaluation of that action. Such principles are embedded in the philosophy of participatory action research (PAR), and so one way of ensuring the values that underpin person-centred care are achieved is to combine it with a suitable and correlational or complementary research framework such as PAR and a critical consideration of the culture of care.

1.11 Life story work and person-centred dementia care

Eliciting a person’s life story has been identified as the essential starting point and a crucial component if meaningful person-centred dementia care is to be achieved:

> *“For a person with dementia who is losing their memory and trying to make sense of who they are, a life story book can be an atlas, the compass, the guide to finding their self.”*
>
> *(Kitwood 1997: 103)*

Approaches to reminiscence and the use of personal biographical strategies such as LSW are the most commonly utilised non-pharmacological interventions in contemporary dementia practice (BPS 2014, Ward et al. 2017) and are often the option of choice as an evaluative approach for dementia care researchers (Keady et al. 2007, Jutlla 2014, Kindell et al. 2014). Similarly, the UK Prime Minister’s Dementia Challenge (2015) identified a requirement for further improvements in care, the use of strategies that promote positive perspectives of living with dementia and the need for effective evidence-based therapeutic interventions.

The British Psychological Society [BPS] (2014) see LSW as exemplifying the above approach by highlighting the positive consequences in the published literature which demonstrate that LSW improves care outcomes by enhancing relationships between care staff and care recipients (Clarke et al. 2003, Gibson & Carson 2010, McKeown et al. 2010). Indeed, LSW enhances personhood and promotes person-centred care because it empowers staff to engage in flexible and inclusive care practices (Keady et al. 2007).

Interest in LSW has grown because it represents a relatively inexpensive yet highly efficient means of supporting person-centred care (Clarke et al. 2003). It also correlates with contemporary models of person-centred care such as the VIPS (Brooker 2004) and Senses frameworks (Nolan et al. 2004) owing to its emphasis on the need for partnership between the person and clinicians.

McKeown et al. (2006: 238) defined life story work as:

> *“A term given to biographical approaches in health and social care that give people the opportunity to talk about their life experiences”.*

Gridley et al. (2016: v) provide the following definition:

> *"Life story work involves gathering information and artefacts about the person, their history and interests, and producing a picture book or other tangible output: the life story."*

LSW is not a new concept and dates back more than three decades. It has been used in numerous health and social situations and with many different client groups, including children in care and in transition, people with learning disabilities and older adults on medical wards (Clarke et al. 2003, McKeown et al. 2006). LSW is different from reminiscence because it utilises a broader range of materials and importantly does not just focus on memories. Instead, it develops a personal record that enhances relationships, improves the person's current situation and helps them plan for the future (McKeown et al. 2010, Gridley et al. 2016).

The techniques associated with LSW provide practical tools for people to use which aim to help family carers and clinicians to see 'the real person'. In this respect, methods of assessing and documenting personal biographies usually involve compiling a book by utilising a template that documents key life events and interests. However, based on the life journey concept, the process can also include photos, podcasts, DVDs, film, art, poetry, reminiscence artefacts, internet-based resources, computer tablet apps or memory boxes (McKeown et al. 2010, Kindell et al. 2014, Gridley et al. 2016).

In addition to Tom Kitwood's ideas on person-centred care, the philosophical influences that underpin LSW include the humanistic principles of Carl Rogers (1951) who emphasised that the most appropriate way to understand the person is by considering their unique perspective. Social constructionism, which is concerned with interactions between people and the language we use to understand our reality and narrative therapy, offers a counselling approach that focuses on the person's values and skills (Kaiser & Eley 2017). The theoretical concepts proposed by Stokes (2000) and Barker (2009) can also be seen as influencing LSW, namely the way in which individuals enact something about their life story in social interactions and how all behaviours shown by the person who has dementia can be interpreted in terms of their personal biography.

One of the primary objectives of LSW is to support and enable the person with dementia to reflect on their lives and to use the outcome of this process in a positive way (McKeown 2006). Many people approach LSW as an opportunity to leave a memoir for their family or help with the adjustment to a diagnosis of dementia (Kindell et al. 2014). The LSW book can also be a means of informing care staff about the person's life and preferences so that individualised care can be provided (Keady et al. 2007). In turn, the LSW book or material produced should accompany the person on their dementia journey to underpin person-centred care (Kindell et al. 2014). Where a more structured approach is taken to LSW, then more in-depth information will be obtained about the person's life (Keady et al. 2007). Correspondingly, there are significant benefits of using LSW because it helps promote a better understanding of the individual and improves therapeutic relationships, care planning and assessment (Kellet et al. 2010).

Thus, it can be seen that LSW is an innovative means of achieving high-quality person-centred care and is concerned with developing a personal biography to promote a better understanding of the person who has dementia (McKeown et al. 2010, Kindell et al. 2014). Additionally, Thompson (2011) described how engaging a person in LSW assures the production of a distinctive care plan, a point corroborated by The Life Story Network (2014) who stated that the use of life stories is key to delivering person-centred care because it places the individual’s biography at the centre of their care. It can also fundamentally improve dementia care and promote individualised care by enabling carers and practitioners to see beyond the diagnosis (Burstow 2014, The Life Story Network 2014).

The evidence base for LSW is steadily evolving, and there is now a considerable volume of high-quality research to demonstrate its effectiveness, the many benefits of using it in practice and the ways in which it improves outcomes for people with dementia and their carers (Clarke et al. 2003, McKeown et al. 2006, Kellet et al. 2010). Five systematic reviews on the positive use of LSW have now been completed, and these are summarised in chapter two.

1.12 Summary

Meeting the needs of the substantial number of people with dementia is challenging, and traditionally such care has often been undertaken without reference to the holistic nature of the individual (Russell & Timmons 2009). Crisis approaches to dementia care and CCG requirements also seem to take priority over more supportive measures, even though both can be simultaneously achieved. This was the case at the service in which this research was undertaken. In the earlier stages of dementia, the person and their carers usually prefer to receive care that focuses on their social needs combined with consistent contact with services. Contemporary research and practice indicate that LSW could support the delivery of individualised care (Kellet et al. 2010). To meet demand, there is a need to develop services which are flexible and responsive to people with dementia and to support them and their carers to live well with dementia. This involves listening to the people for whom the services are being provided and developing services accordingly to meet their needs.

Working in the current NHS can be very difficult because there are barriers inherent in the organisational culture that impact on the delivery of care. In this context, the attainment of person-centred care can be problematic to achieve, yet many approaches can be efficiently and cost-effectively applied with significant benefits. LSW is such an intervention and is now seen as an effective evidence-based intervention (McKeown et al. 2006, BPS 2014). The benefits of utilising LSW as a person-centred strategy also seem to correlate with the requirements of the Dementia Challenge 2020 report (DoH 2015). LSW can be combined with the values associated with person-centred care, participatory action research and organisational culture appraisal to form an integrative framework for innovative practice in dementia care.

This chapter has explored global and national perspectives in dementia care and the projected increases in diagnoses which pose significant challenges to care providers. The requirement to deliver person-centred care is embedded in all health and social policies. The pressures related to working in health and social care are considerable and testing. Nonetheless, the organisational and cultural difficulties associated with person-centred care can, in part, be overcome and innovative care attained if the values that underpin the social enterprise model are utilised. Life story work is integral to and is considered an exemplar and a central component of contemporary person-centred dementia care. The principles of Kitwood's research, participatory action research, life story work and a critical consideration of the culture of care can be used as an integrative framework for innovative dementia practice.

Chapter Two reviews and analyses the published research on the implications of undertaking dementia life story work for the organisation and the culture of care and the outcomes of dementia care studies that have utilised a participatory action research design.

Chapter Three explains the research context, outlines the research aim and objectives and describes the project background and how some initial difficulties were overcome. It also defines and explores participatory action research and how it was utilised in this study, the rationale for the research design, the process of data collection, data analysis, theme identification and ethical procedures.

Chapter Four presents the four themes that were derived from the interviews with people with dementia and their family carers, the participatory action research group meetings and the evaluative interviews with PAR group members. These groups and interviews were audio-recorded, transcribed and coded using the MAXQDA software package and Miles and Huberman's analytical process. The categories used also integrate the notes made by an independent observer on the interactive group processes and the initial reflective field notes compiled by the researcher.

Chapter Five provides a discussion of the findings in respect of the research question, aim and objectives and is structured by utilising the four themes generated from the data. All four themes provide an original and new perspective for the evidence-base and practice of LSW. Even though several organisational problems were experienced, the results further support the integrative use of PAR, innovation and creativity and the culture of care. These concepts provided the rationale for the proposed ‘PIC Model’, a framework to be used to plan, implement and evaluate person-centred dementia care initiatives.

Chapter Six outlines the methodological issues and limitations noted during this study, describes the planned project dissemination strategies and explains the conclusions. The recommendations include the assertion that person-centred dementia care can be attained by utilising the new ‘PIC’ model (participatory action research, innovation and creativity and cultural change). This model also incorporates the essential LSW strategies as proposed by the participants, the positive outcomes of undertaking LSW as described in the research on LSW and a framework for locality-based change management.

Chapter 2: Review of the research literature

2.1 Chapter overview

This chapter initially explains the rationale for structuring the literature review by utilising two themes: the research on the impact of dementia life story work on the organisational environment and the culture of care and the literature on the use of participatory action research in dementia care. This is followed by an overview of the search strategy employed for the literature review. A synopsis of the systematic reviews already undertaken on the use of life story work in dementia is then included.

The justification for the framework used to evaluate the research on the impact of LSW on the organisational environment and care culture is then provided followed by the critique of the studies relevant to this theme. Supported by a definition of PAR, the second review theme evaluating the literature on the use of participatory action research in dementia is presented. Finally, a literature review summary is included that highlights the key points derived from each theme and how these support the rationale for the study.

2.2 Rationale for the literature review structure

The justification for organising this literature review under the above-mentioned two themes is that these are integral to establishing the rationale for the research and the methodology utilised. In this regard it is important to highlight that LSW has been extensively evaluated in terms of the impact on the person, the family and care staff but not on the organisation and the culture of care (McKeown et al. 2015, Gridley et al. 2016). Consequently, there is a need to undertake a further search and critical appraisal of the LSW literature to determine the impact of it on the organisation and care culture. This new critique of the literature then adds to the evidence on the use of LSW and importantly helps to reinforce the study rationale.

The need to carefully plan and implement LSW and person-centred dementia care initiatives was determined in chapter one. A corresponding need to manage change and undertake reflective practice to improve the quality of dementia care was also identified. An effective way of achieving such an objective is by utilising PAR which is concerned with developing partnerships and establishing creative practice. Thus, it was considered essential to conduct a literature review of the PAR studies already conducted in dementia care to determine the outcomes of the research that utilised a PAR design and consider how this may inform the current study. Such a review had not previously been undertaken.

Lastly, three of the objectives of this study involved re-establishing LSW within the services offered by a community dementia team and to establish the effect of this for the organisation in terms of the culture of care impact and the use of PAR as a research framework.

2.3 Literature review search strategy overview

The specific search strategy employed for the two literature review themes is described under each section. For both themes a comprehensive electronic search was conducted using the following online databases:

- CINAHL Complete
- PubMed
- MEDLINE
- PsycARTICLES
- Google Scholar

Both Google and Google Scholar searches were used to search the ‘grey’ literature for potential research papers. Manual and reference list searches were also conducted to identify any papers that might have been overlooked in the electronic database searches.

Boolean logic, example truncation (*) was applied to broaden the keyword search. Also (‘or’, ‘and’) were used to combine and limit the search.

2.4 Systematic reviews already undertaken on the use of life story work in dementia care

Five systematic reviews have now been conducted on the use of LSW in dementia care (McKeown et al. 2006, Moos & Bjorn 2006, Kindell et al. 2014, Gridley et al. 2016, Grøndahl et al. 2017).

McKeown et al. (2006) analysed the literature on the utilisation of LSW in health and social care. This revealed over 1,000 publications, but after using judiciously constructed inclusion criteria, 14 papers were selected for review. It was noted that a range of methodological approaches had been adopted to explore the use of LSW with no one methodology predominating. It was also observed that LSW might help to challenge ageism, be used to initiate individualised care, improve assessment, assist when moving between different care environments and enhance relationships between practitioners and family carers.

Moos & Bjorn (2006) analysed 28 papers that evaluated the use of LSW with people in institutional settings. This review utilised three categories to highlight the purpose of the LSW approaches used, namely: to raise self-esteem and self-integration; to improve life quality, and to change behaviour. Moos & Bjorn (2006) also suggested that as LSW is concerned with providing individualised support, qualitative research should be more widely used to evaluate its usefulness.

Meanwhile, Kindell et al. (2014) analysed 11 resources to identify areas of commonality and divergence concerning the LSW materials. The authors concluded it was unclear if LSW is primarily a formal staff intervention or if people with dementia and their family carers should undertake it as an informal activity. There was a similar lack of clarity about the way in which the LSW resources and topics should be organised. The four reasons for undertaking LSW were identified as emotional connections; interactional connections; building new connections, and practical care connections. Additionally, it was mentioned that guidance on how to undertake LSW was limited. The authors concluded that further development work was required.

As the first part of a larger scale evaluation of LSW, Gridley et al. (2016) included 55 publications on LSW in dementia care (not research specific), with 47 being used to identify good practice ‘learning points’ in LSW. 18 papers supported theories of change. This review also identified areas where LSW might improve quality of life, including enhancing the care environment, improving well-being and carer coping and reducing challenging behaviour.

Finally, Grøndahl et al. (2017) undertook a systematic mixed studies review that aimed to outline the utilisation of LSW with people living with dementia in nursing homes. Three quantitative and two qualitative studies were included in the review. Grøndahl et al. (2017) concluded that LSW usually had a positive influence on the individuals who have dementia, their family and the staff. Life stories also have the potential to offer a perspective on the whole person, but potential problems include relatives providing their version of the individual’s life, staff finding it challenging to deal with disclosed personal information and uncertainty regarding how best to help the person recall their story. The scarcity of quality research was also mentioned, and so evaluation using randomised controlled trials (RCTs) was recommended to measure the impact of LSW.

2.5 Research on the impact of dementia life story work on the organisational environment and the culture of care

It can be seen from the above systematic reviews that the evidence base for the use of LSW as an intervention has been extensively evaluated in terms of the positive outcomes and benefits for people with dementia, their relatives and carers and staff.

However, these reviews also indicate that the impact of LSW on the organisation in respect of acting as a change precursor, the need to prepare the clinical environment for LSW, the requirement to provide organisational support for implementation and the need to evaluate the impact of the study outcomes on the organisational culture have not been comprehensively analysed. Therefore, the focus for this section of the literature review is to determine the impact of dementia life story work on the organisational environment and the culture of care, by using the following search question: what is the impact of dementia life story work on the organisational environment and the culture of care?

To provide the structure for the evaluation of the research papers included in this section of the literature review, the principles developed by Brooker & Latham (2016) have been utilised. These are suitable and appropriate owing to the emphasis on the importance of nurturing the quality of the organisation and culture of care for person-centred care and hence for high-quality LSW to be achieved. These principles were initially formulated for use in the evaluative study undertaken in residential care homes and were more recently translated into features to be considered by organisations for attaining person-centred dementia care (Brooker & Latham 2016). These principles are concerned with establishing if:

1: There is a practical, shared purpose in providing person-centred care.
2: There is connectedness and community between all involved in the organisation.
3: Staff are empowered to take responsibility for the well-being of people

receiving care and are supported to do so through active management processes.

4: Management mediates the impact of external factors on frontline care delivery.

5: There is ongoing and gradual change for the benefit of people receiving care.

6: The environment is being used for the benefit of people receiving care.

7: Meaningful engagement and activity are considered integral to providing care and support.

A table demonstrating how the seven principles were used to guide the critique of the studies is included in Appendix one.

To meet the inclusion criteria, the studies must have demonstrated that the care environment and the culture of the organisation had been considered and senior management support elicited before LSW was introduced. The studies could have utilised any research paradigm but must have reported on either preparing the care environment, care culture and the organisation and/or outcomes relating to the aforementioned aspects.

The starting point for this part of the literature review is the implementation of the National Dementia Strategy (NDS) in February 2009 because this policy initiated significant reform in the requirement of health and social care organisations to deliver person-centred dementia care, of which LSW is a central component. Additionally, all of the systematic reviews completed so far have included research undertaken before the NDS, and so the published evidence has already been analysed in depth. Furthermore, while the benefits of and growing interest in LSW are increasingly being identified, there have been implementation difficulties, and these include a lack of good practice in preparing a suitable organisational context (Gridley at al. 2016).

The keywords used to search the databases in the title and abstract were: ‘Dementia’ or ‘Alzheimer's’ or ‘Life Story’ or ‘Biography’.

Box 07: Inclusion and exclusion criteria for organisational & culture literature review

Inclusion criteria	Exclusion criteria
• Published from 2009 • Peer-reviewed • Primary research that evaluates the use of LSW or personal biography in dementia care • Studies that report on preparing the care environment, care culture and the organisation and/or the outcomes for the same • English language	• Published before 2009 • Not peer reviewed • Opinion piece, not research

A total of 50 studies were identified based on the inclusion criteria. 12 studies were considered suitable for inclusion:

PUBMED (26) – 17 papers did not meet inclusion criteria

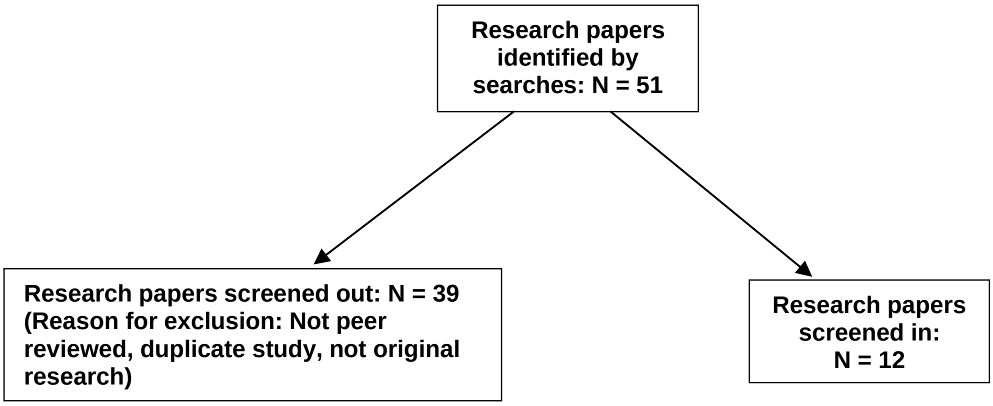
PSYCHINFO (10) - 8 were either duplicates or did not fulfil inclusion criteria

MEDLINE AND CINAHL using EBSCO (13) - 9 were either duplicates or did not satisfy inclusion criteria

HAND SEARCH OF YORK STUDY (1) - (Damianakis et al. 2010)

HAND SEARCH OF GRØNDAHL ET AL. SYSTEMATIC REVIEW (1) - (Buron 2010)

Figure 2.0: Prisma diagram showing published research study screening process (1):



Appendix two includes Critical Appraisal Skills Programme (CASP) style summaries of all 12 research studies. These studies are also listed in Table 01 on the next page.

Table 01: Studies included in the literature review (Part 1): Research on the impact of dementia life story work on the organisational environment and the culture of care

Studies included in the literature review (Part 1): Research on the impact of dementia life story work on the organisational environment and the culture of care			
Author	**Date**	**Title**	**Journal/Report**
Berendonk & Caine	2016	‘Life story work with persons with dementia in nursing homes: a grounded theory study of the perspectives of care staff’	Dementia
Buron	2010	‘Life history collages: effects on nursing home staff caring for residents with dementia’	Journal of Gerontological Nursing
Cooney & O’Shea	2018	‘The impact of life story work on person-centred care for people with dementia living in long-stay care settings in Ireland’	Dementia
Damianakis et al.	2010	‘The psychosocial impacts of multimedia biographies on persons with cognitive impairments’	Gerontologist
Doyle	2014	‘An exploration of the experiences of formal carers who participate in life story work with people with dementia in the residential care setting’	Irish Journal of Medical Science
Gridley et al.	2016	‘Improving care for people with dementia: development & initial feasibility study for evaluation of life story work in dementia care’	National Institute for Health Research
Ingersoll-Dayton et al.	2013	‘The couple’s life story approach: a dyadic intervention for dementia’	Journal of Gerontological Social Work
Kellett et al.	2010	‘Life stories & biography: a means of connecting family & staff to people with dementia’	Journal of Clinical Nursing
McKeown et al.	2010	‘The use of life story work with people with dementia to enhance person-centred care’	International Journal of Older People Nursing
McKeown et al.	2015	'You have to be mindful of whose story it is': the challenges of undertaking life story work with people with dementia & their family carers’	Dementia
Subramaniam et al.	2014	‘Life review & life story books for people with mild to moderate dementia: a randomised controlled trial’	Aging & Mental Health
Subramaniam & Woods	2012	‘The impact of individual reminiscence therapy for people with dementia: systematic review’	Expert Review of Neurotherapeutics

Overview of the studies

In the studies analysed, the research settings were quite diverse, with seven being completed in the UK (McKeown et al. 2005, McKeown et al. 2010, Doyle 2014, Subramaniam et al. 2014, Gridley et al. 2016, Subramaniam & Woods 2016, Cooney & O'Shea 2018), two in the USA (Buron 2010, Damianakis et al. 2010), one each in Germany (Berendonk & Caine 2016) and Australia (Kellett et al. 2010) and one study was concurrently conducted in the USA and Japan (Ingersoll-Dayton et al. 2013). Most studies (8) were carried out in either nursing or residential homes (Buron 2010, Damianakis et al. 2010, Kellett et al. 2010, Doyle 2014, Subramaniam 2014 et al., Berendonk & Caine 2016, Subramaniam & Woods 2016, Cooney & O'Shea 2018), four of the projects were completed in the community or home settings (McKeown et al. 2010, Ingersoll-Dayton et al. 2013, McKeown et al. 2015, Gridley et al. 2016), and three were undertaken within inpatient units (McKeown et al. 2005, McKeown et al. 2010, Gridley et al. 2016). All the environments were specific to dementia care, and three of the studies were completed in a mixture of settings (McKeown et al. 2005, McKeown et al. 2010, Gridley et al. 2016). It is encouraging to note the multiplicity of care environments that LSW has been conducted in, which would also seem to indicate a modest cross-cultural awareness of the value of LSW.

Only seven of the 12 studies included people with dementia in the research sample. Four of the projects exclusively collected data from care staff while one of the seven studies also included staff and family carers. Six projects in total involved family carers, with the largest sample (23) of people with dementia featuring in a study conducted by Subramaniam et al. (2014) and the smallest (4) in a study by

McKeown et al. (2010, 2015), although the latter used an in-depth case study approach, which helps to account for the small sample. The relatively low sampling of individuals with dementia is surprising given the inclusive intentions of LSW. In this respect, it could be countered that most of the investigations were conducted in settings that supported people in the late stages of dementia where obtaining consent can be difficult. Nevertheless, the research by Subramaniam et al. (2014) was undertaken in such a setting and had the largest sample. Indeed, given that people in the late stages of dementia are particularly vulnerable, it would seem even more important to involve them in research. In this regard, many innovative and creative approaches have been utilised (Kindell et al. 2014, Ward et al. 2017). The most representative sample was provided by Gridley et al. (2016) who included ten people with dementia, 12 family carers and 20 care staff. They further attained a response rate of 57% to their survey with 288 care providers giving feedback on their use of LSW.

Two of the studies reviewed utilised an exclusively quantitative methodology, namely a randomised control trial. Although the sampling for such a trial was quite small - 36 participants by Buron (2010) and 23 by Subramaniam et al. (2014) - this design seemed to have been used in response to recent criticisms about a perceived lack of research rigour in LSW evaluations. Given the difficulties associated with achieving a large representative sample of people in the late stages of dementia, the sample sizes attained here seem to be commendable. Two studies used mixed methodologies: Gridley et al. (2016) conducted in-depth interviews, focus groups and a survey; and Subramaniam & Woods (2016) used multiple single-case approaches. Overall, the prevailing paradigm was qualitative, with eight studies using this design, consisting mainly of semi-structured interviews, focus groups and field notes, followed by thematic analysis. However, Damianakis et al. (2010) also examined video data, and Ingersoll-Dayton et al. (2013) conducted ‘an analysis of cases’. There was no evidence of the direct involvement of people with dementia or family carers in the research design or the setting of the project aim in any of the studies although seven projects adopted a very collaborative approach to the introduction and evaluation of the LSW (Damianakis et al. 2010, Kellett et al. 2010, McKeown et al. 2010, Subramaniam et al. 2014, McKeown et al. 2015, Gridley et al. 2016, Subramaniam & Woods 2016).

As would be expected, the majority (8) of the studies used a book or template to compile the person’s life story although some adopted quite creative or innovative approaches to the task by utilising the following: life history collages (Buron 2010); a couples life story book (Ingersoll-Dayton et al. 2013); and a family biography workshop (Kellett et al. 2010); while Damianakis et al. (2010) used digital video technology to construct DVD-based personalised multimedia biographies and Subramaniam & Woods (2016) utilised multimedia digital life story books. The proposed LSW approaches were integrated mainly within the study aims, with most of the studies either being exploratory in nature or seeking the views of the participants and therefore reflecting the research methodology adopted. A slight variation to this was demonstrable in the following pieces of research: Gridley et al. (2016) who aimed to establish if full evaluation of LSW was feasible; McKeown et al. (2010) who conducted a critical appraisal of the challenges that may be faced in LSW practice; and Subramaniam & Woods (2016) who attempted to establish an evidence base for the efficacy of using multimedia digital life story books.

Four critical requirements were identified for LSW to be successfully established within organisations in the five systematic reviews already conducted on LSW (McKeown et al. 2006, Moos & Bjorn 2006, Kindell et al. 2014, Gridley et al. 2016, Grøndahl et al. 2017). These were: preparation for the study, the ongoing support provided during the project, the positive outcomes regarding the organisational culture and problematic study outcomes for the organisation. These organisational requirements were also critical to the aim and objectives of this study and so have been used to structure this part of the literature review.

Preparation for the study

The project undertaken by Gridley et al. (2016) suggested that, based on an analysis of the published literature, there should be several important considerations for the organisation in terms of assessing and preparing the care environment and culture for LSW. However, pre-project assessment and preparation regarding establishing person-centred care and LSW were not apparent in any of the studies evaluated for this literature review. Subramaniam & Woods (2016) did use participatory design in their project to ensure participants were actively involved in the LSW decision-making process and in designing, creating and directing their life story movie.

Nevertheless, such a level of involvement was not apparent at the planning stage. In regard to empowering staff to take responsibility for the well-being of the person by using supportive and active management processes, Subramaniam et al. (2014) and Subramaniam & Woods (2016) initially consulted care home managers but not the care staff. Similarly, McKeown et al. (2010; 2015) applied a practice development approach to the LSW intervention, and this included working with the senior management team and all participants before the study commenced. Active management support to ensure that staff are enabled to undertake the LSW by planning staff time accordingly, combined with the allocation of resources such as access to suitable technology, was not apparent as a preliminary consideration in any of studies reviewed. Furthermore, it is generally agreed that gradual and strategic change management is necessary. However, there was little evidence of any initial staff training being undertaken (only information sharing) in the studies reviewed, or consideration of the need to ensure that meaningful engagement and activity is embedded within the care work undertaken before the commencement of the various projects.

All the initial assessment and planning considerations included in this section are integral to the success of the research (Gridley et al. 2016), yet the lack of widespread attention to this aspect was largely absent from the studies. A factor that is of particular importance is the requirement to establish a person-centred culture of care before commencing the project to ensure LSW becomes embedded in this culture of care.

Ongoing support provided during the project

It was evident that LSW became a regular part of the service and was integrated within the care culture in all of the research reviewed while the LSW project was in progress. This ensured that a person-centred philosophy became embedded in the environment resulting in an enhanced quality of life for both the person with dementia and their family carer. Moreover, Subramaniam & Woods (2016) explained how a positive sense of community was engendered using a participatory design which ensured that the participants were actively involved in the LSW decision-making process. Similarly, the research undertaken by Doyle (2014) and Cooney & O'Shea 2018, seemed to demonstrate that the care staff were empowered by actively seeking their views on the use of LSW, with many positive perspectives being noted in this respect.

Regarding senior management support, there was evidence of notional but not always explicit support during the research period. This seemed to be the case in all studies with no real signs of planned change management in any of the projects reviewed. However, McKeown et al. (2010, 2015); Subramaniam et al. (2014) and Subramaniam & Woods (2016) appeared to provide ongoing support and facilitation to the care staff, delivered by either the researcher or the research team. Indeed, Subramaniam (2014) et al. explained how the family carers were supported by a Clinical Psychologist, Kellett et al. (2010) outlined how the researcher worked collaboratively with family carers and care staff in a series of support sessions, and Ingersoll-Dayton et al. (2013) explained how the practitioner supported the couples in their own home or the home of a family member or a care facility. Other than these examples, ongoing training for the staff was not explicitly mentioned in any of the studies.

The resourcing of LSW projects indicates a pertinent point because it appeared that in the project undertaken by Subramaniam (2014) et al. the researcher personally delivered the LSW sessions and the ongoing support. This raises the issue that if this level of assistance had not been provided, then perhaps the project would not have been so successful (the research was undertaken as part of the author’s PhD thesis).

Positive outcomes regarding the organisational culture

A number of positive results in respect of an enhanced quality of care for individuals who have dementia and their families were reported by Damianakis et al. (2010), McKeown et al. (2010) and Cooney & O’Shea (2018), with Gridley et al. (2016) measuring this improvement by using a ‘Quality of Life’ assessment tool. In addition, Subramaniam et al. (2014) noted that care staff knowledge of the residents increased as a result of their study of attitudes towards dementia. Similarly, Buron (2010) described how staff awareness of residents’ family members also improved. Subramaniam & Woods (2016) further explained that staff considered the digital life story books to be useful and that communication and interaction were consequently enhanced. Subramaniam et al. (2014) and Subramaniam & Woods (2016) observed that, by providing new information and knowledge about residents, the life story books appeared to have had a significant impact on the care homes by improving communication, with some homes developing new life story books for other residents and also integrating LSW into the home’s care programme. Partnership working between care staff, people with dementia and family carers also showed evidence of improvement (Buron 2010, Berendonk & Caine 2016).

An interesting point was raised by Berendonk & Caine (2016) who explained that public authorities in Germany require care homes to include residents’ life stories in

care documentation; this is then reviewed by the authorities, and so all homes embed some form of LSW in their care processes. However, making this compulsory entails the risk that in some homes LSW becomes merely a ‘tick-box’ exercise.
In their LSW project, Kellett et al. (2010) explained the phenomenon of ‘Complementing the organisation’ which is concerned with promoting a sense of community. LSW can make a valuable contribution in this respect because it encourages positive communication between staff, family and the person who has dementia (Doyle 2014) and improves partnership working between staff, the individual and the family, with staff and carers collaborating on LSW projects, both in the care home and in the person’s own home (Kellett et al. 2010, Ingersoll-Dayton et al. 2013). Kellett et al. (2010) explained that, following the LSW research project, care staff felt empowered to engage in inclusive care practices, while Gridley et al. (2016) examined staff burnout and attitudes, and found that staff attitudes significantly improved following their study.

While McKeown et al. (2010) emphasised the importance of taking a practice development approach to ensure LSW can be implemented sensitively and sustained in practice, it has been difficult to determine whether active management support was apparent in the studies reviewed. As potential strategies, Doyle (2014) emphasised the importance of staff continuity, while Kellett et al. (2010) recommended that staff should start collecting information about the person while they are still home, as well as offering staff training on life stories and linking the families of new residents with a specific staff member. McKeown et al. (2015) also advocated a planned approach to implementation and viewed facilitation, education and supervision as essential. McKeown et al. (2010), Subramaniam et al. (2014), Gridley et al. (2016) and Cooney & O'Shea (2018), all highlighted the importance of training and supervision.

Problematic study outcomes for the organisation

Gridley et al. (2016) explained how challenges within an organisation can potentially prevent meaningful outcomes being attained in LSW because an individualised context for implementation is essential for person-centred care to succeed. One such challenge for staff is that if care is essentially task-driven, it restricts the amount of time they can spend with residents (Berendonk and Caine 2016). Other organisational challenges include the observation that some families will not be ready to undertake LSW until they acknowledge the changes in the person that dementia brings. Indeed, some relatives never reach this level of acceptance (Kellett et al. 2010). McKeown et al. (2015) also pointed out that, in some cases, staff were unaware of the existence of the life story books, and so consequently, these were not used with residents. Conversely, McKeown et al. (2015) also noted there was potential for life story books to be 'over-used', and hence there is a need to find the 'correct' balance in this regard.

In the study conducted by Buron (2010) it was documented that there was no real evidence of staff working in partnership with people with dementia and their carers and that staff perceptions of person-centred care did not improve. Meanwhile Berendonk and Caine (2016) observed that some staff members did not involve residents in the compilation of their life stories. Regarding active management support, while the LSW project was being undertaken, Gridley et al. (2016) indicated that full evaluation of LSW could only be achieved if staffing levels were increased. Both Kellett et al. (2010) and Doyle (2014) emphasised the need to include LSW in care planning and that the person’s care plan must be written within the first month of admission (a time of multiple form filling), otherwise the opportunity to integrate the individual’s life story will be lost. While such an assertion can be questioned because care planning should be a continuous, rather than a one-off, process it is nonetheless a significant concern. Indeed, Doyle (2014) proposed that LSW should commence before admission. Finally, Gridley et al. (2016) drew attention to some potentially problematic organisational implications for researchers, namely that the time pressures on staff can result in the investigator’s time being wasted, while staff fatigue can contribute to a lack of data being collected. To help offset this problem, but also to support positive project outcomes, Gridley et al. (2016) suggested that researchers need to be based at or in close proximity to the project setting.

2.6 The literature on the use of participatory action research in dementia care

As previously mentioned, LSW has been extensively evaluated in terms of the impact for the person who has dementia, their unpaid carer and care staff, but its effect has not been as widely assessed in terms of the implications for, and effects on, clinical teams, organisations or the culture of care. The number of people with dementia will continue to increase and no new effective treatments are likely to be available in the next few years. Therefore, the immediate focus needs to be on improving the quality of dementia care. To achieve this objective, there needs to be an emphasis on planned change, working in partnership, innovative and creative practice and research that aims to promote excellence in relation to care. With this point in mind, an important objective of this study involved transforming teams and bringing about organisational change by using PAR as a research strategy. Accordingly, the focus of this section of the literature review is to determine the changes achieved by utilising participatory action research in dementia care, based on the following literature search question: What are the outcomes of dementia care studies that utilised a participatory action research design?

To provide context for this literature review PAR is defined as:

> *“a philosophical approach to research that recognizes the need for persons being studied to participate in the design and conduct of all phases of any research that affects them.”*
>
> *(Vollman et al. 2004: 129)*

A more detailed definition and overview of PAR is provided in chapter three but it is important to note there are many parallels between Action Research (AR) and PAR, in particular, a focus on change and reflective practice. However PAR has a unique philosophy in that it views participants as stakeholders in the study (Rahman 1993) and emphasises the need for high levels of collaboration and participation (Fine et al. 2000, Greenwood & Levin 2007).

PAR studies were only included if a genuinely participatory approach was adopted and if the research conformed to PAR principles. An open time frame for inclusion was used, in order to ensure sufficient PAR papers were included, as it was only possible to find a relatively small number of studies relevant to dementia.

Box 08: Inclusion and exclusion criteria for participatory action research use

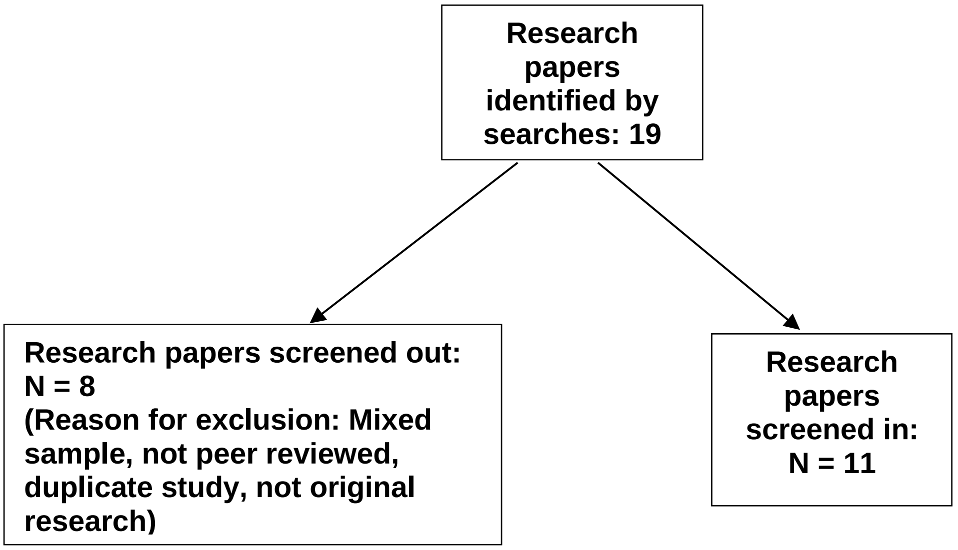
Inclusion criteria	Exclusion criteria
• All years • Peer reviewed • Primary research • Participatory action research in dementia care • English language	• Not peer reviewed • Opinion piece, not research • Mixed diagnoses in sample, i.e. not dementia exclusive

The keywords used to search the databases in the title and abstract were: ‘Dementia’ or ‘Alzheimer's’ or ‘cognitive impairment’ or ‘memory loss and participatory action research’.

A total of 19 studies were identified based on the inclusion criteria. 11 studies were considered suitable for inclusion.

There was only one research article from the UK. Correspondingly, recommendations are made with caution as the studies may be influenced by other extraneous variables that are not present in the UK or vice versa.

Figure 2.1: Prisma diagram showing published research study screening process (2):



Appendix three includes CASP style summaries of all 11 studies. These studies are also listed in Table 02 on the following page.

Table 02: Studies included in the literature review (Part 2): Research on the use of participatory action research in dementia care

Studies included in the literature review (Part 2): Research on the use of participatory action research in dementia care			
Author	**Date**	**Title**	**Journal/Report**
Caine	2013	'Is music the best medicine?'	CRFR/IRISS (Scotland)
Chenoweth and Kilstoff	1998	'Facilitating positive changes in community dementia management through participatory action research'	International Journal of Nursing Practice
Clancy	2015	'Practice model for a dementia outreach service in rural Australia'	The Australian Journal of Rural Health
Dupuisa et al.	2012	'Theoretical foundations guiding culture change: The work of the Partnerships in Dementia Care Alliance'	Dementia
Goeman et al.	2016a	'Development of a model of dementia support & pathway for culturally & linguistically diverse communities using co-creation & participatory action research'	British Medical Journal
Goeman et al.	2016b	'Partnering with consumers to develop & evaluate a Vietnamese dementia talking-book to support low health literacy: a qualitative study incorporating co-design & participatory action research'	British Medical Journal
Hanson et al.	2007	'Working together with persons with early stage dementia & their family members to design a user-friendly technology based support service'	Dementia
Keatinge et al.	2000	'The manifestation & nursing management of agitation in institutionalised residents with dementia'	International Journal of Nursing Practice
Nomura et al.	2009	'Empowering older people with early dementia & family caregivers: a participatory action research study'	International Journal of Nursing Studies
Vikström et al.	2015	'A model for implementing guidelines for person-centered care in a nursing home setting'	International Psychogeriatrics
Wiersma et al.	2016	'Creating space for citizenship: The impact of group structure on validating the voices of people with dementia'	Dementia

A thematic analysis of the 11 research papers considered suitable for inclusion was undertaken. Three themes were identified: study context, research methods and project outcomes. These topics have been used to structure this part of the literature review.

Study context

The research studies included in this review were concerned with implementing new services, guidelines, models or interventions for people with dementia. The studies were conducted in five different countries, and so there is an international context to the research, albeit a limited one. The majority of the projects (five) were carried out in Australia (Chenoweth & Kilstoff 1998, Keatinge et al. 2000, Clancy 2015, Goeman et al. 2016a, Goeman et al. 2016b), two were conducted in Canada (Dupuis et al. 2012, Wiersma et al. 2016), two in Sweden (Hanson et al. 2007, Vikström et al. 2015), and one each in Japan (Nomura et al. 2009) and Scotland (Caine 2013). The settings for the research were similarly diverse (see Appendix three) and included nursing or care teams in community services (seven), a Dementia Café and an outreach scheme. The remaining four studies were set in a project group environment.

The largest overall sample was utilised by Dupuis et al. (2012) who surveyed 215 participants (people with dementia, carers and professional staff). The breakdown of subjects into these groups was not declared. A broad cross-section was also achieved by Vikström et al. (2015) who involved 200 participants in their study. In this case the sample consisted of 170 nurse aides, 25 professionals (RNs and physical & OTs) and five managers. However, people who had dementia or family carers were not included. In Goeman et al.’s (2016a) study, 62 people were sampled, of which 47 were people with dementia who were receiving support from Specialist Dementia Nurses and 15 were relatives. 13 expert stakeholders were also involved in the study. Goeman et al. (2016b) used a convenience sample of 59 people from the Vietnamese community, although only one person had dementia. Additionally, 11 stakeholders were involved in the PAR process.

The remaining seven research studies consisted of relatively small samples; Wiersma et al. (2016) utilised three advisory groups which consisted of 20 people with dementia, 13 care partners, and 3 service providers. Caine (2013) recruited five couples to take part, with the participants being in the early to moderate stages of dementia. Nomura et al. (2009) studied 37 people living at home with early or mild dementia and 31 family carers. Six researchers and eleven clinicians also contributed to the PAR process. Keatinge et al. (2000) recruited ten nursing home residents to participate in their research. The investigation conducted by Chenoweth & Kilstoff (1998) required day care staff (8) and family carers (16) to consult with people with dementia (16). Clancy (2015) assembled a group of 22 participants comprised of staff who worked for a dementia service, representatives of the community dementia service, and other clinical staff who had experience in dementia care. Hanson et al. (2007) included seven people with dementia in total and one family carer. Therefore, the largest sample of people with dementia was 47 (Goeman et al. 2016a), and the lowest was five (Caine 2013).

There were significant variations in the study length (see Appendix three), ranging from five years (Nomura et al. 2009) to just six months (Caine 2013). This is a considerable difference which makes it difficult to compare the overall study outcomes in any meaningful way. Given that most PAR studies are seeking to establish quite major changes, it would seem that longitudinal studies are more likely to achieve this aim.

The importance of the principles of co-design and partnership was espoused by all of the studies, yet only three projects included people with dementia at all stages (Hanson et al. 2007, Dupuis et al. 2012, Wiersma et al. 2016). This is particularly surprising given that most of the study samples involved people who were at an early stage of dementia and so would have been able to contribute to the project actively. Similarly, family carers were only fully consulted in two of the studies (Chenoweth & Kilstoff 1998, Dupuis et al. 2012). Thus, while the importance of an empowering, ‘bottom-up’ approach was mentioned in the initial design of all projects, such a principle was not extended to people with dementia and their family carers. In this respect, the option taken was often local advocacy group involvement.

Research methods

Owing to small sample sizes and a lack of academic rigour, e.g. weak data analysis strategies, none of the studies would be considered suitable for inclusion in a systematic review.

Ethical approval and informed consent appeared to have been obtained in all studies, although the process followed in this respect when seeking consent from individuals who had dementia was often difficult to determine and only mentioned quite briefly.

All of the research reports were presented in different styles: some used a spiral, cycle or phased approach; and six papers broadly followed a ‘classic’ research report format (Chenoweth & Kilstoff 1998, Nomura et al. 2009, Clancy 2015, Goeman et al. 2016a, Goeman et al. 2016b, Wiersma et al. 2016). This caused difficulty when attempting to extract, summarise and compare the key themes from the published reports. All the studies cited the use of a PAR framework, but each study utilised a different structure to plan and deliver the project. All had some degree of ‘cyclical’ activity, but only two used a recognised framework: Vikström et al. (2015) utilised Taylor’s (2004) 6 step PAR empowering model; and Hanson et al. (2007) used the ‘Action’ design process comprising the three phases of identifying user needs, early programme development and testing and refining. Appreciative inquiry was suggested as a change management strategy appropriate for use in PAR by Dupuis et al. (2012).

All 11 studies used qualitative methodologies to achieve the PAR project aims while two further utilised SPSS to record participant characteristics (Keatinge et al. 2000, Goeman et al. 2016b). The research methods used in the studies reviewed are summarised in Appendix three, but essentially these were semi-structured interviews, field or researcher notes and focus groups (or slight variations of these) followed by thematic feedback to the main project groups. In terms of data analysis, coding and identification of themes, Dupuis et al. (2012) were guided by hermeneutic phenomenology, Goeman et al. (2016b) continued conducting interviews until data saturation was reached, Clancy (2015) and Wiersma et al. (2016) followed an iterative process, while the codes identified by Chenoweth & Kilstoff (1998) were based on the guidelines produced by Morse & Field (1996). Both Keatinge et al. (2000) and Vikström et al. (2015) extracted data by qualitative content analysis, and Caine (2013) used grounded theory.

Project outcomes

Some more recently published papers have exemplified principles of partnership and innovative thinking about the nature of dementia care. The diverse and creative nature of the projects undertaken is summarised in Appendix three and include: Goeman et al's (2016a) inclusive model of culturally sensitive support; Wiersma et al's (2016) self-management programme; Nomura et al's (2009) empowering programme of cognitive rehabilitation for the person with dementia and carers; Chenoweth & Kilstoff's (1998) alternative therapies programme; Clancy's (2015) person-centred service model for a dementia outreach service; and Hanson et al.'s (2007) telematics interventions support service. Even these reports seemed to lack research internal rigour and validity and wider generalisability. For example, wide-ranging benefits of the projects were often cited, but such positive outcomes were not supported by the project outcomes or evaluation measures used. Indeed, while it was commendable that a critical view was taken of current practice or that a project was undertaken with an intention to improve the quality of life of a community, none of the studies verified the immediate or long-term impact of the change. All that could be stated about the outcome was that the project had the potential to improve the quality of life or care for the people with dementia and their carers. Of course, such an outcome might well be sufficient in itself but it seems equally important to evaluate the longer-term impact of a project. However, in most cases it was hard to determine what happened next regarding further evaluation of the ‘new’ practice implemented.

The approaches cited as being used for project evaluation were wide-ranging but largely unstructured and opportunistic. Two studies claimed a measured increase in activities (Goeman et al. 2016a) or referral rates (Nomura et al. 2009), but this was not followed up in the long term. Others used participant feedback such as positive statements about the intervention, including this being positively received and an example of good practice combined with increased knowledge (Chenoweth & Kilstoff 1998, Nomura et al. 2009, Dupuis et al. 2012, Caine 2013, Clancy 2015, Goeman et al. 2016b). Other evaluative approaches included the project group highlighting a successful guideline implementation (Vikström et al. 2015), a new programme evaluated as useful by participants (Wiersma et al. 2016), and the researchers documenting their project as empowering for people with dementia and carers (Nomura et al. 2009), or providing an evidence base for nursing practice (Keatinge et al. 2000). One study by Hanson et al. (2007), claimed that the project constituted a significant service development yet the small sample would seem to contradict this.

None of the studies planned any further longitudinal follow-up, but two studies did suggest their work could be replicated with different client groups or in different settings: the model could be adopted at a national level (Goeman et al. 2016a); and the talking-book could be used with the various conditions as an example of good practice (Goeman et al. 2016b). Two papers suggested further research on the intervention or rating scales was needed (Keatinge et al. 2000, Caine 2013). Nomura et al. (2009) recommended that further research should focus on changes in carers, staff experiences of PAR and the impact of empowering people with dementia. Hanson et al. (2007) indicated research should be targeted at families of people with dementia and Wiersma et al. (2006) claimed research was required in respect of enabling appropriate group membership and facilitating citizenship. Regarding research methodologies, Goeman et al. (2016b) recommended further research using RCTs and Vikström et al. (2015) suggested the PAR approach used could be a model of good practice.

While only one study specifically identified the impact of the initiative on the clinical team (Chenoweth & Kilstoff 1998), all the research papers were analysed for examples of the effect on the clinical or project team resulting from the use of PAR as a framework. The outcomes were difficult to quantify in any significant way, but the main themes included new ways of working, the impact on a group or team dynamics, the need for an effective stakeholder group and managerial support regarding resource allocation.

In terms of new ways of working, Goeman et al. (2016a) indicated that the new model of good practice developed would have required the home nursing service to work to new delivery patterns, Nomura et al (2009) highlighted the finding that team members became students of individuals with dementia and also identified the need for staff to assume responsibility for PAR, Dupuis et al. (2012) emphasised the importance of team members recognising the potential of authentic partnership and personal growth, while Keatinge et al. (2000) cited the opportunity for the team to engage in meaningful research and enhanced care practices. Chenoweth & Kilstoff (1998) found that the staff enjoyed the closer interaction with carers and people with dementia which in turn produced a calmer care environment, and Clancy (2015) documented that the specialist skills of the MDT were widely valued.

With regard to group dynamics, Wiersma et al. (2016) explored stakeholder group formation, and Vikström et al. (2015) indicated that a small number of staff were resistant to the change but further emphasised that effective staff empowerment could be achieved by using a ‘bottom-up’ approach. Caine (2013) stated that care cultures could be enhanced by effective team working, Nomura et al. (2009) asserted that positive attitudes among staff were essential to develop empowering care practices and to form collaborative partnerships, and Chenoweth & Kilstoff (1998) outlined how the team worked to overcome communication barriers. Similarly, stakeholder groups collaborated in an efficient and co-operative way in the projects undertaken by Hanson et al. (2007) and Goeman et al. (2016b). A lack of time was cited by staff as a major barrier to implementing new initiatives according to Vikström et al. (2015).

The majority of published papers that evaluated the impact of new initiatives in dementia care tended to focus on the quality of care for the person, carers and staff. The studies selected for this literature review were similarly searched for examples of an organisational impact because of the use of PAR as a framework. Again, it is hard to quantify the outcomes but they seemed to include changes to service delivery, the need for project resource allocation and the success of multi-stakeholder groups.

The organisational changes to care delivery required the overall service to adapt to a new model of good practice (Goeman et al. 2016a). However, this impact was not evaluated. The success of some of the projects were highlighted as having a broader impact on the host organisation but also more widely, for example, Caine (2013) and Clancy (2015) emphasised the importance of person-centred care initiatives for all organisations delivering dementia care, Nomura et al. (2009) and Dupuis et al. (2012) mentioned that the PAR and partnership models used could be applicable to a wider dementia care context and Chenoweth & Kilstoff (1998) and Hanson et al. (2007) outlined how the PAR model, as an example of good practice, could be replicated to change a negative situation into a positive one.

The need for effective organisational support with resource allocation was mentioned by Goeman et al. (2016a) who stated that resources, specialist staff, training and debriefs were required to support new models of care delivery. Vikström et al. (2015) required all 24 units in the care home to participate and gave staff the opportunity to do so. Both Goeman et al. (2016b) and Wiersma et al. (2016) highlighted the success of the multi-stakeholder project groups which were successful regarding cooperation and the involvement of people with dementia.

2.7 Literature review summary

The key points relevant to the implications of undertaking dementia life story work for the organisation and the culture of care are identifiable in the research of Subramaniam et al. (2014) and Subramaniam & Woods (2016), whose study exemplifies good practice in LSW research by incorporating several innovative and fundamental principles into the project design: a partnership approach, innovative LSW, multiple data collection methods and the creative use of technology and multimedia. Furthermore, the research papers analysed in this part of the literature review showed that to deliver LSW in a more sustainable way, the research sample must include all stakeholders, namely people with dementia, care staff and family carers. Additionally, these stakeholders must be directly involved in a research design that uses creative or innovative approaches to collating the person’s life story. Lastly, the studies reviewed here all demonstrated that for positive outcomes to be reached for the participants the care environment must be assessed and adjustments made and active organisational and management support attained prior to commencing the project.

There is considerable synergy when comparing the significant factors relevant to the outcomes of dementia care studies that utilised a participatory action research design. The weaknesses of all the reviewed papers have been noted throughout this review and include a small sample size, a lack of internal validity, inconsistency regarding the PAR frameworks adopted, methodological flaws and a lack of outcome measurement. However, the strongest papers that seemed to produce the best outcomes for people with dementia, even if they were not directly involved in all stages of the project, were the ones that adopted a longitudinal approach and meaningful stakeholder involvement. The positive features of the project design in this regard were co-production, empowerment of a minority group, innovative and creative practice and improved access to services. These aspects seem to represent the major strengths of utilising a PAR approach.

The prevailing paradigm utilised in all of the studies reviewed in both parts of the literature review was qualitative. This methodology seems most suitable for LSW owing to the need for partnership and wide-ranging participant involvement. It is often thought that RCTs are the most appropriate methodology with which to evaluate therapeutic interventions but such methods are often viewed by participants as being based on a biomedical model. For example, participants often fear that if they decline to participate, treatment or therapy might be withheld.

Accordingly, the application of PAR as a research framework combined with the utilisation of qualitative methodologies are considered to provide the most suitable strategy for achieving the aim and objectives of this study. LSW is still at a comparatively early stage of development (Subramaniam & Woods 2016), and so qualitative research would seem to be more appropriate because it can provide invaluable data that challenges residual biomedical approaches that are often still evident in dementia care and is more suitable for the required levels of collaborative practice (Moniz-Cook et al. 2006, Cahill et al. 2014).

Chapter 3: Research methodology

3.1. Overview of the research methodology

Drawing on the findings of the literature review in relation to methods, this chapter will firstly provide a brief explanation of the purpose of the project with the research question, aim and objectives then outlined. The ontological and epistemological position of the researcher and the rationale for utilising participatory action research as the research framework and qualitative research for the methodology is subsequently described.

The chapter further gives an overview of the methodology, the nature of action research and participatory action research, the research setting, the background and study context, the sampling processes, the recruitment strategy and how access to the participants was obtained. The data collection process, data trustworthiness considerations, the ethical procedures followed, the data analysis strategies utilised, including the data transcription process and use of the Computer Assisted Qualitative Data Analysis (CAQDAS) Software MAXQDA and the stages of coding the data are then described. Finally, a chapter summary is provided.

Initially, the chapter is presented from a third person perspective but moves to the first person in section 3.6.4, before returning to the third person subsequently. This approach has been specifically chosen to explain how some of the original problems were, to an extent, overcome. In addition, the reflective and narrative style used in 3.6.4 correlates with the expectations of PAR and the associated problem-solving cycle. Such an approach enables a largely objective stance to be taken, thereby explaining the decisions taken from the start of the project regarding the choices made about the research framework and methodologies employed.

3.2. Purpose of the study

This participatory action research study utilised a relativist perspective from which to explore the experiences of people with dementia, their carers and dementia care clinicians of developing and delivering life story work in an age-inclusive dementia service.

Research question:

How can life story work be embedded into an age-inclusive dementia service?

The study aimed to:

Examine how life story work can be embedded into an age-inclusive dementia service.

The study objectives were to:

1. Explore the cultural and organisational changes required for practitioners to internalise life story work as part of delivering high-quality dementia care.
2. Determine how the use of a life story profile can be embedded into an age-inclusive dementia service.

3. Develop a model of service redesign which facilitates the introduction of good practice in dementia care.
4. Analyse the essential and desirable components of life story work from the perspective of the person with dementia, their carers and practitioners.

3.3. Ontological and epistemological position

To appreciate the processes that underpinned the judgements made in the design of this study and how it was operationalised, the researcher's philosophical assumptions are explained in the following section.

Research paradigms can be "characterised by the way in which the proponents respond to three basic questions" (Guba 1990: 18). These three questions are: ontological or 'what is the nature of reality?'; epistemological or 'how do you know something?'; and methodological or 'how do you go about finding out knowledge?' (Guba 1990). Therefore, ontology is concerned with studying the nature of the world, epistemology encompasses how we come to know about our world, and methodology involves selecting strategies that aim to solve the stated problem; questions and dilemmas that academics and philosophers have been concerned with for decades (DePoy & Gitlin 2005).

Ontologies evolve from realist belief systems such as positivism which aims to produce research outcomes that are generalisable to other settings. This is achieved by testing hypotheses utilising experimental methodologies (Robson 2011). In contrast, relativist perspectives like social constructionism assert that reality is socially constructed and so such studies describe the participants’ views on their experiences which the researcher then interprets (DePoy & Gitlin 2005). Qualitative studies of this type are usually only relevant to the research context, and so generalisability can be viewed as setting specific. Epistemology is a division of philosophy and is involved with the way in which knowledge is attained and what is considered to be meaningful knowledge (Kothari 2004). There is a range of epistemological assumptions that move from the assertion that knowledge is entirely objective to the perspective that knowledge is subjective (DePoy & Gitlin 2005).

The three dominant research paradigms are: Firstly, positivism or objectivism, which is more commonly used in the natural sciences and follows the belief there is a single reality, which can be measured and known (Kothari 2004). The positivist paradigm mainly uses quantitative methods to measure this reality. The second paradigm is constructivism or interpretivism which is associated more with the social sciences. This adopts a belief system whereby there is no single reality or truth; individuals create their own subjective perspectives of the world, and so the many realities must be interpreted, with qualitative methods being utilised to elicit these (Hinshaw et al. 1999, DePoy & Gitlin 2005). Finally, pragmatists assume the stance that reality is perpetually analysed and interpreted, with the research method (usually mixed) being determined by the nature of the problem (Hinshaw et al. 1999, Kothari 2004, DePoy & Gitlin 2005).

Ontological and epistemological perspectives will impact on the design of a research project and the methodologies utilised (Robson 2011), and for this study, the researcher takes the view that multiple realities exist, and so reality is subjective. For example, some professionals believe that the presentation of dementia solely results from the degenerative changes that occur in the brain, while many clinicians take the view that other influences play a part such as social and psychological factors. Therefore, the research paradigm that this research concurs with is the social constructivist or relativist approach. This perspective asserts that knowledge is developed from social interactions (Hinshaw et al. 1999). Thus, personal experiences are an interpretation that is affected by the person’s language, culture, background and biography (Robson 2011).

3.4. Rationale for the research design and method

The design of this research study involved selecting the most appropriate means of addressing the research question, aim and objectives. The researcher’s epistemological standpoint combined with contextual factors such as the research environment and project resources also influenced the design.

PAR was chosen as the research framework for the study because of the need to re-establish the use of LSW at the dementia service in a more sustainable way. Given the problems documented in section 3.6.4 of this chapter, a collaborative approach was needed that considered the culture and operating philosophy of the dementia service. Dupuis et al. (2016) pointed out that the best way to achieve cultural and organisational change in dementia care is to utilise a multi-stakeholder and partnership approach. In this context, PAR has been shown to be the most appropriate research framework to facilitate partnership and to effect positive change (Chenoweth & Kilstoff 1998, Day et al. 2009). Furthermore, the use of PAR in dementia care has demonstrated positive outcomes when a longitudinal design and participant involvement approach has been utilised (Day et al. 2009, O’Sullivan 2012).

PAR has also been utilised in many different health, and social care, settings and has been shown to be an efficient way of supporting change management in these situations (Koch & Kralik 2006). Similarly, the literature review conducted in Chapter Two on the use of PAR highlighted its value in bringing about significant and long-term change in practice through its use of partnership work (Chenoweth & Kilstoff 1998, Day et al. 2009, O’Sullivan 2012). Additionally, the research on the use of LSW has successfully utilised a practice development approach to deliver LSW, for example through the establishment of multi-stakeholder project groups which is a central part of PAR (McKeown 2010). In turn, the use of PAR then involves participants at all stages of the research process and so has the potential to empower them. Recent research that uses innovative approaches to LSW has also adopted a participatory design and multiple data collection methods (Subramaniam et al. 2014, Subramaniam & Woods 2016). Such principles are integral to the intentions of this study and so have influenced the choice of PAR as the guiding research framework.

As explained above, essentially PAR is a framework for research rather than a paradigm. This means that quantitative, qualitative or, indeed, mixed methods can potentially be used to address the research question. Qualitative and quantitative research strategies are the most widely known research paradigms: “quantitative research is concerned with objectivity, tight controls over the research situation, and the ability to generalize findings", whereas "qualitative research is concerned with the subjective meaning of experiences to individuals" (Nieswiadomy 2012 :6).

In addition, "quantitative research is based on the measurement of quantity or amount. It is applicable to phenomena that can be expressed in terms of quantity. Qualitative research, on the other hand, is concerned with the qualitative phenomenon, i.e., phenomena relating to or involving quality or kind. For instance, when we are interested in investigating the reasons for human behaviour" (Kothari 2004 :3). Data is generated in quantitative research using randomised control trials, questionnaires or surveys, whereas the qualitative approach generally uses focus groups, field notes, observation and interviews (Nieswiadomy 2012).

Combined with the use of PAR, this study has utilised a qualitative methodology. Such an approach was adopted not only because of the appropriateness of PAR to the research context but also because qualitative research seeks to elicit the views and perspectives of people involved in a social situation (Kothari 2004). The usefulness of these two strategies in respect of obtaining the opinions and experiences of people who have dementia, carers and the clinicians in the PAR group was also significant. McCormack & McCance (2010) emphasise the irony that considerable research into person-centred care does not assume a person-centred approach to the research process. Thus, the qualitative strategy of interpretative phenomenology was explicitly utilised for data collection and analysis to ensure a person-centred method was achieved. Phenomenology has moved from being merely a description of the person's experiences, known as descriptive phenomenology, to an interpretative approach whereby the contextual aspects are studied to provide a more in-depth understanding of an individual’s experience (Matua & Van der Wal 2015). Again, this feature was integral to the decisions taken in respect of the approaches selected.

Whilst randomised control trials are frequently considered to be the method of choice to study the efficacy of psychosocial interventions, these are often thought to be inappropriate by service users owing to their similarity to the medical model of care (Cahill et al. 2014). This was one of the reasons that quantitative approaches were not chosen for this research, but also because the study was concerned with exploring the multiple views, perspectives and experiences of the participants undertaking LSW, with a view to utilising these to bring about a change in the culture of care. It was felt that the only way to achieve such an objective was to adopt the collaborative and exploratory approaches associated with qualitative methodologies (Robson 2011).

In addition, the literature review noted that research into the organisational aspects of LSW is lacking, and so as qualitative approaches were the most frequently utilised method in research on LSW, they were considered the most appropriate for this project because of the need for collaborative working. Moreover, despite the significant number of systematic reviews, the research on LSW is in many ways still at an early stage of maturity (Subramaniam & Woods 2016). Therefore, qualitative methods are more appropriate because of the need to continue to challenge the biomedical model and the attitudes that underpin it (Moniz-Cook et al. 2006, Cahill et al. 2014). Qualitative research has been criticised for its lack of generalisability and sample representation, yet the way in which qualitative data is obtained and presented is intended to challenge attitudes towards and perceptions of a problem (Kothari 2004). With this point in mind, Booth (2016) emphasised that, in order to improve care, qualitative methods must generate research that is provocative and thought-provoking, an observation that exemplified the intentions of this study. Additionally, the seven factors relevant to the care culture outlined as part of the literature review such as meaningful engagement, are considered essential in creating an appropriate culture for person-centred care (Brooker & Latham 2016). These factors are similar to sound practice principles in LSW (Gridley et al. 2016) and a participatory approach to the implementation of these.

3.5. Data collection strategies

The research question, aim and objectives, overall design, and the principles outlined in the above exploration of the rationale for the research design and method, determined the data collection strategies to be used in this study. These are explained in more detail in sections 3.6 and 3.7 of this chapter but can be summarised as follows:

- An inter-professional PAR group was established to develop and implement a new approach to LSW. The eight PAR group meetings were audio recorded, transcribed, analysed and coded.
- Notes were compiled on the interactive PAR group processes by an independent observer.
- Reflective field notes were maintained by the researcher in the early stages of the project to inform the topic list for each PAR group meeting, the first PAR

cycle (Figure 3.1) and the reflective observations made in sub-section 3.6.4 (background and study context).

- Semi-structured interviews with PAR group members (5), people with dementia (4) and family carers (3).

3.6 Method

3.6.1 Methodology overview

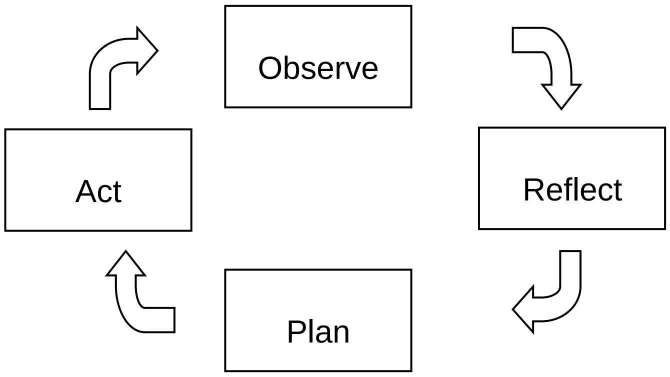
For this study, participatory action research was used as the research framework and qualitative methods, namely interpretative phenomenology, were utilised for data collection and analysis.

3.6.2 Action research and participatory action research

AR has been described as “a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview. It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities." (Reason & Bradbury 2001:1). According to Nieswiadomy (2012:142), “action research is a type of qualitative research that seeks action to improve practice and study the effects of the action that was taken”. AR has also been defined by Gillis & Jackson (2002: 264) as the “systematic collection and analysis of data for the purpose of taking action and making change". Nieswiadomy (2012) further explained that AR does not aim to generalise the study outcomes; instead the intention is to apply resolutions to problems as these are identified immediately.

The roots of AR can be traced to the action research framework as postulated by Kurt Lewin in the 1940s (Gillis & Jackson 2002, Nieswiadomy 2012). Lewin initially used his theory of AR to support social workers in enhancing their clinical work but further gained prominence for his ideas on change theory, i.e. 'Force Field Analysis' (Nieswiadomy 2012). Lewin's approach continues to influence researchers to organise their inquiries around a series of logical and sequential steps, the aim of which is to bring about change by using a spiral of action (change, improvement) and research (understanding, knowledge); this spiral can be commenced at any point and repeated as new evaluative data emerges (Koshy 2010). This spiral or the action research cycle has been represented by O'Leary (2004) as shown in the diagram below:

Figure 3.0: Action research cycle as represented by O'Leary (2004)



While closely allied to AR and Lewin’s concepts, the origins of PAR have also been associated with Paulo Freire, a Brazilian philosopher, who thought that analytical reflection was essential to achieve social change (McIntyre 2008). Thus it can be seen that PAR has its roots in AR but is uniquely considered to be “a special kind of community-based research in which there is collaboration between the study participants and the researcher in all steps of the study, determining the problem, the research methods to use, the analysis of data, and how the study results will be used” (Nieswiadomy 2012:140). Similarly, PAR has been defined as “a philosophical approach to research that recognizes the need for persons being studied to participate in the design and conduct of all phases of any research that affects them” (Vollman et al. 2004: 129). Greenwood & Levin (2007) further explained how, through PAR, the individuals affected by the change become directly involved in the research and collaborate to establish mutual understanding followed by action. Additionally, Rahman (1993) and Fine et al. (2000) emphasised the uniqueness of PAR in seeing participants as ‘collaborative stakeholders’ who drive the research, resulting in practice improvements.

While there are similarities between AR and PAR, there are also significant differences, both philosophically and methodologically (Greenwood & Levin 2007). For example, while AR is associated with less direct involvement by the researcher(s) and clinical team, PAR researchers add the word ‘participatory’ to demonstrate their commitment to a collaborative process (Rahman 1993, Reason & Bradbury 2001). Taylor et al. (2004) suggested that PAR is more focused on learning and eliciting the views of participants, whereas AR is more concerned with social change and policy reform. Fine et al. (2000: 108) further asserted that, “PAR is distinct because it is driven by participants (a group of people who have a stake in the issue being researched) rather than an outside researcher, academic or manager because this assures democracy, ensures personal knowledge is utilised and is collaborative at every stage”.

From the above definitions and descriptions, it can be seen PAR’s uniqueness lies in the fact that it incorporates several essential characteristics: the use of different research methods; a cycle of action; active reflection on a specific environmental context; a collective desire to bring about change and to develop knowledge; and full participant involvement in the research process through a collaborative process (Kindon et al. 2007, McIntyre 2008). Regarding data collection strategies, Gillis & Jackson (2002) explained how several different approaches have been utilised, with project team members working together to select the most suitable strategies. The most widely used methods are qualitative in nature, such as semi-structured interviews, field notes and diaries, focus groups and observational schedules (Greenwood & Levin 2007). Multiple data collection approaches should also be adopted to provide triangulation of data, which has been demonstrated to be the most efficient way to address the research question (Streubert & Carpenter 1995).

The use of participatory action research in this study has been adapted from the action research cycle outlined in Figure 3.0 and the work of Zina O'Leary (2004). Figure 3.1, on the next page, has been included to illustrate how the cyclical process was used to initially reflect on and then develop an action plan with which to implement the required new approach to LSW. This is followed by Figure 3.2 which represents the process followed in the second PAR stage to demonstrate how the different forms of evidence collected were analysed and then integrated to support the study recommendations. This was still a cyclical process, and thus the PAR cycle has also been used in this diagram to show how the problem-solving stages correlate with the analysis of evidence.

Figure 3.1: Application of the participatory action research cycle

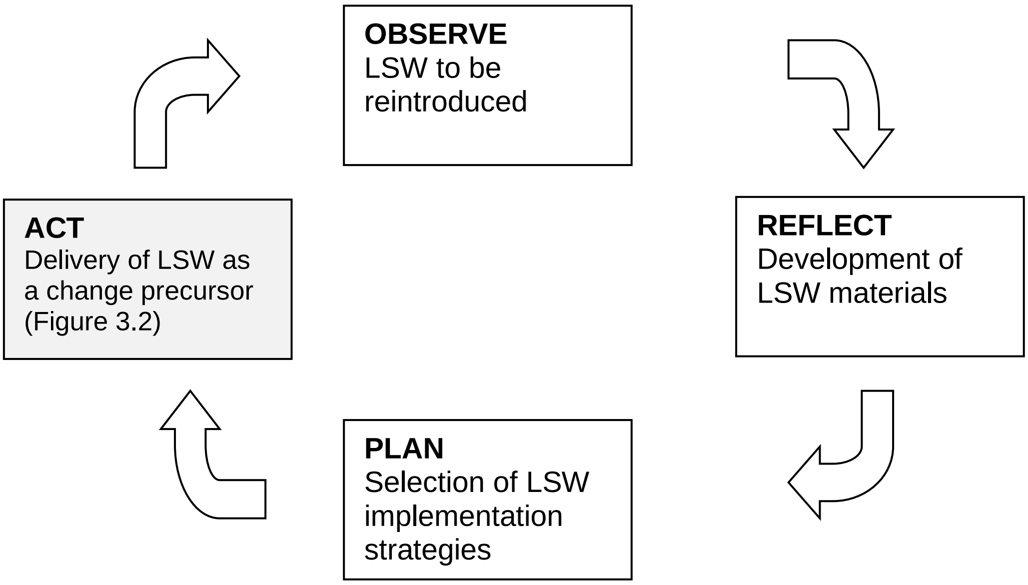
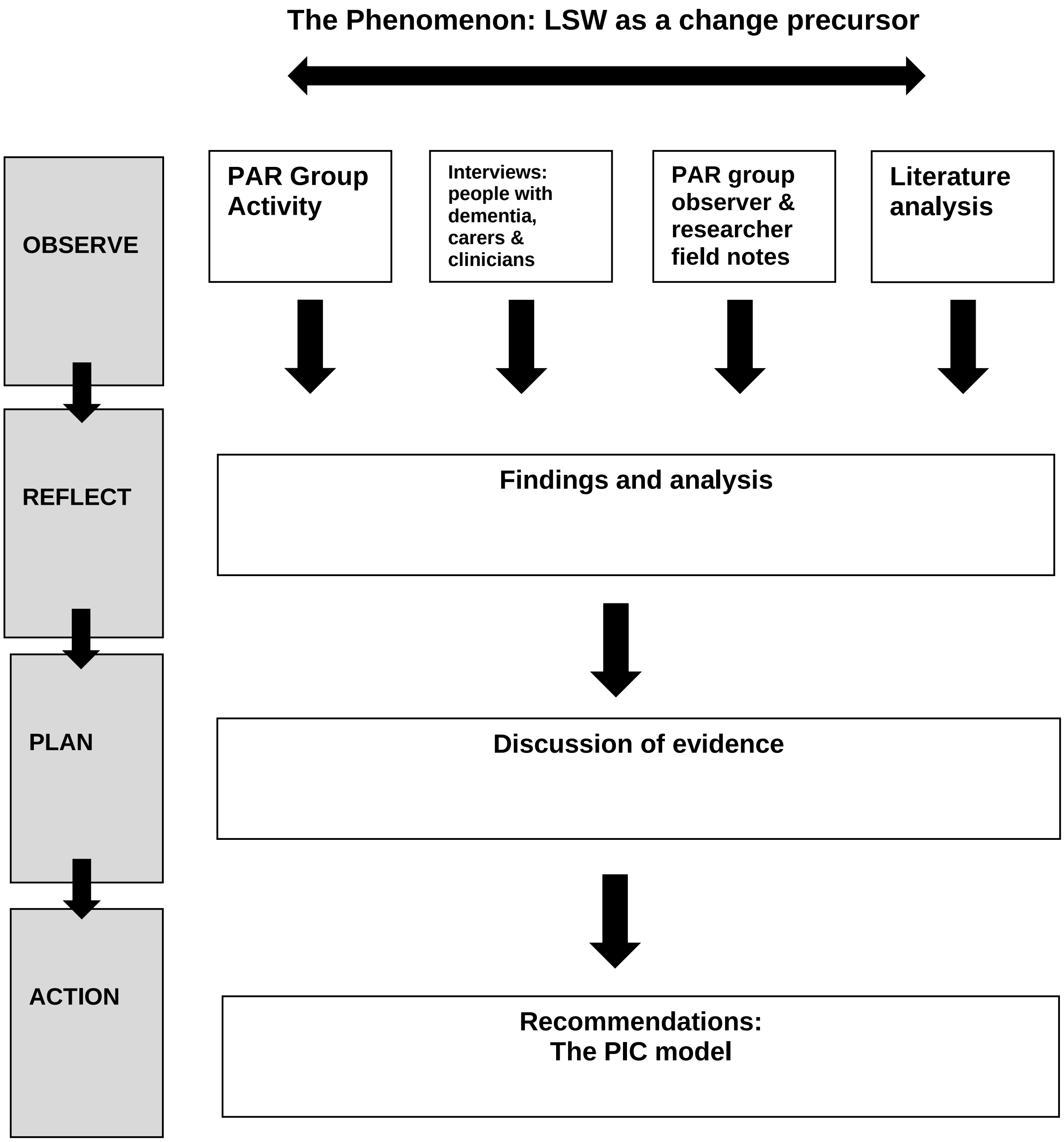


Figure 3.2: Overview of the phenomenon: LSW as a change precursor



3.6.3 The research setting

The researcher was appointed by a large Mental Health NHS Foundation Trust (the Trust) to undertake the role of researcher for a project that had already attained Trust funding.

The study gained ethical approval in November 2013, was commenced in January 2014 and data collection was completed in December 2014.

This project was undertaken in a local age-inclusive specialist dementia team, and the focus of this service was concerned with providing high-quality care and community support to people with dementia and their family carers. Its primary aim was to carry out assessments of people who were experiencing memory difficulties and who were potentially in the initial stages of dementia. The multi-professional team consisted of mental health nurses, associate practitioners, healthcare assistants, psychologists, social workers, occupational therapists and medical practitioners. The services offered included memory assessment and monitoring, home treatment, crisis support, CST, carer education groups and care coordination as required by the Care Programme Approach. Referrals to the service were usually made by General Practitioners (GPs). An essential feature of this new service was to be ‘age-inclusive’, i.e. to provide support to people with dementia and their relatives, regardless of age.

3.6.4 Background and study context

After being appointed as researcher to the project, several operational problems became apparent. The following section is based on the researcher's field notes and reflections on this process and explains how a resolution was reached. This is written in the first person, as documented in my field notes, to emphasise the reflective process undertaken.

As I reviewed the study protocol, I became aware that the research project had previously been submitted for potential funding to a national organisation. This bid had not been successful hence the second application for Trust financial support. I took the opportunity to read through the original research proposal and background information and noted the many positive comments from the peer reviewers and subject experts. Four critical elements of the proposal impressed me: the use of a person-centred approach to LSW; the application of LSW within an age-inclusive dementia service; the evaluation of LSW by seeking the views of people with dementia; and the analysis of care plans for evidence of the use of person-centred LSW. These aspects correlated with my philosophy and personal interest in dementia care. I also assumed all the key components of the project were already embedded into the dementia service (which had been operational for about 18 months). Therefore, on my appointment as researcher to the project, I began entering the proposal details into the Integrated Research Application System (IRAS) database. I undertook this task immediately because, after reviewing the research proposal, I had concluded the plan was of high-quality and supposed that all the preliminaries had been completed, i.e. checks the clinical team supported the proposal and that LSW was being implemented as outlined in the documentation. However, concurrent to completing the research ethics committee documentation, the project supervisors and I met with the dementia service team and also attended other meetings to discuss the research project plans. A critical outcome of these meetings was that I was informed that LSW was now being delivered differently to that reported during preparation of the initial research protocol. The reasons put forward by the team for this included the pressure of work, higher than anticipated referral rates, competing priorities such as delivering therapeutic groups, and time spent documenting care events.

Clearly, service priorities will evolve and change and have become quite common in the NHS and so dynamic leadership is required. In this regard, The King’s Fund (2013) has released a series of reports that outline strategies that aim to improve clinical management in the NHS. However, effective change management and clinical leadership would seem to be only part of the solution; what is actually required is more direct verification. These questions are considered, analysed and expanded on in chapters four and five.

When the dementia service was established in 2012, LSW was considered integral to the services offered and the service’s operational model. A reflective analysis seemed to suggest other factors also played a significant part in the resistance to setting up the project. From conversations with some of the clinicians and specialists involved in the initial establishment of the dementia service, a number of additional influencing factors emerged. It was highlighted that the provision started in an unstructured way; for example, the notion of an ‘age-inclusive service’ was considered to be a critical component for the development of a new dementia team at this time, a factor that was subsumed in all dementia care policies and guidance. Therefore, as part of the contracting process with the local CCG, it was agreed that the new dementia service would be founded on this principle. However, during the planning stage and early operationalisation of the team, there was considerable resistance to the age-inclusive concept, particularly from some of the psychiatrists but also from various other professionals. When the researcher joined the team, his observation was that this ‘age-inclusive’ problem was mostly unresolved and this aspect received only notional support from the team; a difficulty that might have impacted on the diversity of the sample. Additionally, there seemed to be a lack of professional confidence within the team, compounded by the medical clinicians having different line management arrangements.

Thus, the new service started in an uncertain way with considerable resistance to the operational plans emerging, which resulted in ambiguity regarding roles and a lack of clarity about the strategic direction the team should take. Furthermore, shortly after the service commenced, the process of applying for ‘Practice Development Unit’ status was initiated. As part of the assessment and accreditation procedure, the aforementioned problems were further highlighted and reinforced. A critical point emphasised in this regard was the lack of service user and carer involvement at the planning stage and direct participation in the delivery of the therapies and interventions on offer. This observation was exemplified in the use of information meetings which give a considerable volume of material about dementia to the person and their relative(s), information that was seldom used or acted upon. This observation is analysed in chapter five. It was further noted that the care priorities for the team were driven by the contractual requirements place on them by the CCG.

Any emergent service will involve appointing new team members and will thereby generate new team dynamics and a requirement to work on these in a positive and meaningful way. It appeared to the researcher that when the project commenced, such undercurrents had not been addressed and so the inter-professional team were still engaged in the ‘storming’ or conflict phase, as described by Tuckman (1965) in his seminal work on team formation and stages of group development. Therefore, this scenario provided the backdrop to the project and helps to explain and rationalise some of the difficulties experienced prior to and during the LSW implementation stage. There are numerous barriers to executing research on person-centred dementia care or improving clinical services, as documented in many recently published papers, and so the problems encountered are not unique to this project. Nevertheless, the issues relevant to the need to develop and foster a positive culture and organisational care environment to achieve person-centred care are a central component of this thesis and are considered, explored and used as a frame of reference in every chapter.

However, given the problems outlined above, there was still a need to work within the current cultural and organisational structures in the service and thus to reframe the project and develop a revised implementation plan. Given the strong evidence base for LSW, the team were keen to re-establish its use but in a more meaningful and sustainable way. As part of this process, it was agreed that the most appropriate framework to support the implementation and evaluation of LSW within the identified care culture would be participatory action research.

PAR was chosen because there are examples of it being successfully applied in similar healthcare situations and specifically in dementia and older adult care contexts. PAR would also facilitate open dialogue regarding the problems associated with establishing a new service. Accordingly, following a series of meetings with managers, clinicians, the researcher and project supervisors, a revised research proposal started to emerge. The investigator then held two preliminary meetings with prospective research group members, and after the second meeting and a literature search, a revised plan for implementing LSW was formulated. This involved the development of a new LSW template, combined with person-centred support sessions to help people with dementia compile their life story profiles. Moreover, a steering group consisting of the project / academic supervisors, core team members and two senior local managers was established to help ensure the study achieved its objectives.

The principles of collaborative involvement were adhered to as far as reasonably possible in this study by using collegiate strategies and the sharing of information with project team members such as drafts of the research outcomes. Importantly, the original research proposal was developed in consultation with people with dementia and family carers through initial stakeholder meetings with representatives from the local Alzheimer’s Society. The revised research protocol is included in Appendix four. A scientific summary of the initial study outcomes was also discussed with and presented to all the people with dementia and their relatives at a Trust-wide launch event held in November 2014. This successful event provided the opportunity for all participants to give feedback on the initial findings and provide an update on their life story books.

3.6.5 Sample and participants

Marshall (1996) explained that the sample for qualitative research must be sufficient to enable the research question to be addressed. Thus, as the study develops and data is collected, the appropriate sample size becomes clear. In qualitative research, there are three main approaches to non-probability sampling: Convenience sampling “is one that is simply available to the researcher by virtue of its accessibility” (Bryman 2004: 201). While it is the least costly in terms of research resources, convenience sampling can adversely affect data value and reliability. Judgement sampling, which is also known as purposeful, selective or subjective sampling, is the most prevalent approach used whereby a sample is developed that represents what seems most appropriate to the researcher to provide a solution to the research question (Marshall 1996, Bryman 2004). A more extensive range of sample variables is developed that extends beyond demographic principles and so may include differing levels of experience, professional qualifications or the holding of certain attitudes. Theoretical sampling is utilised with grounded theory whereby new samples are selected as the data is analysed and themes emerge, with the overall aim of attaining data saturation (Marshall 1996).

For this project, the sample for the interviews with people who had dementia and their family carers was mainly one of convenience but was also, where possible, age-inclusive, representative of the client group and consisted of people from different social backgrounds. Judgement sampling was used for the PAR clinician group because the staff were allocated to this group by a team leader. It was anticipated that the clinicians assigned would be either delivering the LSW or undertaking a support role in its re-introduction.

Sample sizes used in this study are comparable to other major LSW studies such as those conducted by McKeown (2011) and Gridley et al. (2016). The difficulties in obtaining larger samples for research into LSW have been outlined in the literature review, and these include the capacity to give consent, and the need for long-term commitment to the study. Similarly, such sampling difficulties are acknowledged in qualitative research whereby, in respect of smaller scale studies, the sample could be fewer than ten participants, whereas for more multifaceted research questions a larger sample would be required and possibly combined with different sampling approaches (Marshall 1996).

For the sample selection of the people with dementia and their family carers, the following inclusion criteria were adhered to:

- Age inclusive, i.e. the sample included people who had young-onset dementia, and so the sample was drawn from as broad an age range as possible
- The person was newly referred to the dementia service following diagnosis and assessment by the memory assessment service

- The Trust profiling data was utilised by the key workers to ensure the sample was representative by including people who had different types of dementia and who had differing social profiles
- The individual was able and willing to give informed consent
- Both male and female participants were recruited.

The exclusion criteria were:

- People assessed by the memory clinic, but who did not access the dementia service on a regular basis
- People with behaviours that challenge and who require inpatient or residential care (it would be unethical and possibly ineffective to engage with a group who are currently in distress)
- People with more advanced dementia (similarly, it could be unethical or distressing for the person).

To be eligible for inclusion in the study, the person had to be recently diagnosed with dementia, be under the care of a Consultant Psychiatrist and be able to give informed consent. All of the people with dementia who were interviewed had an ICD-10 diagnosis of Alzheimer’s disease or vascular dementia and were receiving support from the dementia service. Four people were identified as meeting the inclusion criteria for the interviews, and all agreed to take part. This part of the sample consisted of two women and two men diagnosed with dementia aged between 59 and 81 years. Most of the individuals interviewed had retired and so were not in employment. The family carers of these people with dementia were also asked to participate in the semi-structured interviews, and three agreed.

During 2012 the Trust recruited around 25 staff to operate the dementia service. This staff group was comprised of multi-professional and support staff, and the range of professions included nursing, occupational therapy, social work, psychology, medicine and associate practitioners. The PAR group utilised for this study consisted of six members from the multi-disciplinary team, namely a clinical psychologist, two healthcare assistants, two mental health nurses and an occupational therapist. Group members were selected who had a particular interest in LSW or who were tasked with delivering the LSW as planned. Additionally, the researcher and PAR group observer attended all meetings and contributed to the group discussions. For this group, the following inclusion criteria adhered to:

- Employment specifically within the dementia service
- Had undertaken in-house preparation for working in the dementia service including person-centred care
- Both male and female staff
- Age range from 20-65.

The exclusion criteria were:

- Temporary, bank or agency staff
- Staff who were unable to commit to attending all of the PAR groups.

An essential point noted in chapter two regarding the use of PAR in dementia care is that the project outcomes seem more likely to be sustained if stakeholder co-design, involvement and collaboration is attained at every stage of the study (Hanson et al. 2007, Dupuis et al. 2012, Wiersma et al. 2016). The project management group for this study were aware of the significance of this principle but took the decision not to involve people with dementia and family carers within the PAR group. The reasons for this were that it was the clinical staff who were planning and implementing the LSW and as a consequence of the use of PAR, the culture of care at the dementia service would be the focus for critical examination. Indeed, such scrutiny was a requirement of three of the study objectives, which were concerned with analysing the use of LSW on the organisational culture at the service.

To support this viewpoint, Brandon (1991) explains how clinicians often hold a completely different perspective on care priorities to those espoused by service users and how it is these professional standpoints that are frequently prioritised above the stated needs of patients because of the prevailing power of professionals and pervading influence of the organisational priorities. This phenomenon is further exemplified in the concepts advocated by Kurt Lewin and his notion of ‘Force field analysis’ whereby numerous resisting organisational and professional ‘forces’ have to be mitigated to bring about change (Lewin & Gold 1999). Contemporary examples of these concepts are described in chapter five, for example, carer education groups being provided by the dementia service as opposed to the required post-diagnostic support. Therefore, it was felt that as people with dementia and their relatives were only attending the service for appointments or short-term therapies, they would not experience the internal organisational culture that operated and so would not be able to contribute to this perspective.

However, it is important to mention the work of the PAR group was just one component of the overall data collection strategy and that this study did extensively involve people with dementia, their relatives and Alzheimer's Society representatives in the design, protocol development and final generation of all research themes. Additionally, one of the objectives was to document the experiences of people with dementia, and their carers' of undertaking LSW with opportunities provided for discussion, feedback and sharing of their LSW books. Thus, meaningful collaboration was achieved by utilising a number of co-operative approaches including potential participant meetings and the publication and discussion of a summary report on the emerging themes.

Such strategies correlate with the PAR principles as used by Dupuis et al. (2012), Vikström et al. (2015), Goeman et al. (2016a) and Wiersma et al. (2016) and their approaches to stakeholder involvement in dementia research. That said, the initial planning stages for this study were undertaken in 2012 and so several key decisions, including the principles used for PAR group membership, took place at this time. Since 2012, there has been a considerable shift in the values that underpin collaborative involvement and engagement of people with dementia and carers in research. There are numerous published examples of guidance and application of service user led research in this regard (Di Lorito et al. 2016, Novek & Wilkinson 2017). As well, there is a burgeoning volume of reports, policies and evaluative research that demonstrate the activism of individuals with dementia (Bartlett 2012, Swaffer 2014, the Dementia Engagement & Empowerment Project 2018). The importance of ensuring people with dementia are either actively involved or lead research and the principles that underpin the activism movement are acknowledged and responded to in the study limitations section within chapter six.

3.6.6 Recruitment strategy and access

Information sheets about the research study were left with the service staff who were delivering LSW, and they discussed the project with prospective couples who met the inclusion criteria. As mentioned, four people with dementia and three family carers gave permission for the researcher to contact them and all agreed to participate in the research.

It was anticipated that a small group of staff would be delivering the LSW or supporting its re-introduction and so clinicians were allocated to the PAR group by a team leader.

3.7 Data collection

Following a series of meetings between the researcher and managers and practitioners from the clinical team, a new approach to LSW that involved choice for people with dementia about how their life story could be captured was developed. This consisted of two books: one containing information and chapters on LSW; the other with pockets to allow the insertion of information, photos, and other media (colour coded so that people could choose which sections to use). The concept of

LSW was to be introduced to people recently diagnosed with dementia and their family carers by an experienced practitioner in a two-hour group meeting. They would then be provided with three further one-hour individual support sessions in their own homes.

The methods used to collect this qualitative data included audio-recorded, evaluative, semi-structured interviews with people with dementia (n=4), and their family carers (n=3). These aimed to reflect the uniqueness of each experience and to be exploratory in nature about the use of LSW and the support received. The interview schedules used to carry out these interviews are included in chapter four.

An inter-disciplinary staff PAR group with eight members (including the investigator and observer) was established to develop a strategic vision and to manage the operational processes associated with implementing LSW. The PAR group met on eight occasions over a seven-month period and these meetings were audio recorded, transcribed, analysed and coded as part of the study.

These groups were also observed regarding their interactive processes, with notes compiled by an independent observer, who was an experienced academic and therapeutic group facilitator. The role of the observer was to observe, document and then feedback on the interpersonal interactions within the group and the development process to help the group become a cohesive and effective project team. This feedback was audio recorded in the PAR groups and so as well being used to help with group formation, was also utilised as part of the data collected.

Additionally, individual interviews were conducted with PAR team members and reflective notes on the initial PAR process were collected by the lead researcher and used to inform the evaluative stages. The PAR group meetings were mostly exploratory and based on themes and issues that emerged from the previous session. The semi-structured evaluative interviews conducted with PAR group members were also largely exploratory but based on the following themes and questions:

- Your reflections on the project; before and after; what has been achieved?
- How could LSW at the service be enhanced?
- How could the achievements be sustained?
- Has the aim of ‘embedding LSW’ been achieved? What does embedding mean to you?
- Why has the service chosen to deliver the menu of services on offer?
- Any other thoughts on LSW?

Semi-structured interviews are a central means of collecting data in qualitative research and have been defined as follows:

> *“In semi-structured interviews, interviewers are generally required to ask a certain number of specific questions, but additional probes are allowed or even encouraged. Both closed-ended and open-ended questions are included in a semi-structured interview. In this type of interview, data are gathered that*

> *can be compared across all respondents in the study. In addition, individualized data may be gathered that will provide depth and richness to the findings." (Nieswiadomy 2012: 188)*

The above definition accurately reflects the approaches utilised in the semi-structured interviews conducted for this study. This style of interviewing was selected because it is the most common data collection method used in qualitative research (Hinshaw et al. 1999, Kothari 2004, DePoy & Gitlin 2005). Semi-structured approaches also correspond closely with the researcher's epistemological standpoint and so represent an invaluable method of eliciting participant perspectives and views on their experiences and the associated research topic. Alternative approaches to interviewing such as structured or unstructured interviews, and qualitative data collection methods such as observation, can also be utilised (Nieswiadomy 2012). However, these were not considered appropriate because the questions posed needed to be designed to reflect the study objectives. Furthermore, the participants' views were unique to their experiences of either undertaking LSW or planning and delivering it, and could thus only be obtained through the use of semi-structured interviews.

3.8 Trustworthiness

A well-documented difficulty associated with justifying the reliability and validity of qualitative research is that these projects tend to be appraised by using the same criterion as quantitative studies (Golafshani 2003, Robson 2011). For example, study replication is a critical component of quantitative approaches, and consequently the former could be viewed as more objective than qualitative research that is usually context specific (Seale 1999, Yin 2009, Yin 2010). Moreover, it is often suggested that qualitative projects cannot be generalised to the extent that quantitative studies can, owing to the case specificity of the research (Kothari 2004). Despite these problems, it is essential that all researchers take measures to assure the credibility of their study outcomes and thus, given the significant differences in the two paradigms outlined earlier in this chapter, it seems more pertinent to focus on reliability and validity in terms of the uniqueness of qualitative research (Golafshani 2003, Yin 2010, Nieswiadomy 2012).

According to Seale (1999), reliability and validity in qualitative research can only be assured by examining the trustworthiness of the data collected, with the following four criteria being utilised to evaluate it in each study: transferability, dependability, credibility and confirmability (Lincoln and Guba 1985, Seale 1999). More detail on these criteria is included in Table 03, on the next page, combined with examples of how these were achieved in this project. Overall, trustworthiness is attained by emphasising the importance of the project outcomes, the distinctiveness of each setting, the notion of the participants as the experts on the topic under investigation, and how the longitudinal aspects, multiple sources, data volume and verification of data increase the reliability and validity of the study outcomes (Kothari 2004, Nieswiadomy 2012).

The following strategies in Table 03 were used in this study to assure the reliability and validity of the data collected. These have been explained in more detail elsewhere in the chapter and so are only summarised here. Additionally, an overview of the data analysis processes undertaken using Miles & Huberman's (1994) three-stage analytical structure is included in Appendix five.

Table 03: Strategies used in this study to establish trustworthiness

Trustworthiness criteria	**Description of criteria**	**Techniques for establishing the criteria as proposed by Lincoln and Guba (1985)**	**Approaches used in this study to establish trustworthiness**
Transferability	Provision of sufficient information to demonstrate study outcomes are relevant to other contexts	• Purposeful sampling • Thick description	• Sampling process explained and justified • Comprehensive description of findings supported by multiple quotations
Dependability	Demonstration that the decisions taken about the methods are appropriate	• External audit	• Project management group • Project plan agreed with Alzheimer's Society • Methodology rationale • Trust Research & Development audit • Multiple project seminars/presentations
Credibility	Evidence that the findings are authentic	• Prolonged Engagement • Triangulation • Peer debriefing • Negative case analysis • Member-checking	• Bryman's coding process combined with Miles & Huberman's analytical structure • Researcher immersion in thematic process • Quotations presented verbatim • Project supervision • Longitudinal project • Critical reading of research reports • Project launch event

Confirmability	Confidence that the results have not been influenced by the researcher's views	- Audit trail - Triangulation - Reflexivity	- Data coding and theme identification using MAXQDA - Themes verified by all participants at launch event and in PAR groups (topics for group) - Themes analysed with the project supervisors - Early emerging themes modified in line with project objectives - Multiple data sources used - Analysis of potential researcher influence - Researcher reflexivity

3.9 Ethical considerations

3.9.1 The ethical approval process for people with dementia and their family carers

Addressing ethical principles and informed consent requirements when involving people with dementia in research presented the investigator with several challenges. These included: how to obtain meaningful, continuous consent from the respondents; how to ensure a positive research outcome for them; and how to prevent personal distress or risk. Dementia can be a lonely and isolating experience (Alzheimer's Society 2013), and so it is critical that research helps to counterbalance this feeling of social exclusion by ensuring the person is involved in studies that document their perception of care processes. This project sought to uphold this principle by obtaining the views of people while they were using LSW. However, to plan for this many ethical tenets had to be considered, mainly because of the memory and cognitive difficulties associated with dementia. To alleviate such problems, research of similar design has adopted a multi-process, reflexive and layered approach, combined with person-centred strategies and process consent to establish principles of good ethical practice (Dewing 2002, Reid et al. 2011, Ellins et al. 2012).

Therefore, this study reflected such a philosophy by utilising the following ethical principles and strategies with the person who has dementia and their family carers who agreed to participate:

- The letter circulated to the potential participants included written information about the study and explained why it was being conducted (Appendices six and seven). Potential participants were asked to return an expression of interest form (Appendices eight and nine) to the researcher who made contact by phone with the person and their carer to explain the purpose of the research and to decide on a date for the interview.
- A further explanation was given and written consent (Appendix ten and 11) obtained just before the interview commenced (family carers were present during this process). Participants were informed of their right to withdraw from the study at any time, without having to provide a reason and without this affecting their care or treatment. Verbal consent was also recorded at the beginning of each interview. A consent process chart is included in Appendix 12.

- Each interview was recorded and lasted approximately one hour. With one exception, people using the services at the service were interviewed with their carers. The decision to interview them conjointly reflected the reality of their shared experiences because some of those using the dementia service may have needed support during the research process. The investigator also adopted an approach of ‘memory difficulties’ rather than a diagnosis of dementia (unless the person was fully aware of their diagnosis) to the interviews. Participants were given assurances that their confidentiality, privacy and anonymity would be protected. They were also advised that the data would be kept on a Trust computer which would be password protected and could only be accessed by the researcher and Project Supervisor and that once the research report was completed the data would be erased. Assurances were also given that they would not be identifiable in the report and a summary of the research report (or the full report if requested) would be sent in the post.

- Representatives from the Alzheimer’s Society and family carers have acted as advisors to this project by providing advice, guidance and support to the project team. The local Alzheimer’s Society could also be contacted by participants for independent advice, thus ensuring that the rights of the person have been protected through independent advice and guidance. This ethical framework has also been peer reviewed and scrutinised by experienced research colleagues and clinical experts.

3.9.2 Ethical approval process for clinical staff participants

A similar approach to the ethical process used for people with dementia and family carers was followed with the clinical staff participating in the study as members of the PAR group:

- The clinical team manager helped identify suitable participants for the project and circulated a letter of invitation to the practitioners (who met the inclusion criteria). The letter included written information about the study and explained the purpose (Appendix 13). Potential participants were asked to return an expression of interest form (Appendix 14) to the investigator who made contact by phone to explain the purpose of the research and to agree on dates for group attendance.
- A further explanation was given and written consent (Appendix 15) obtained before the PAR groups commenced. Participants were informed of their right to withdraw from the study at any time, without having to provide a reason and without it affecting their role or status. Verbal consent was also recorded at the beginning of the PAR groups.
- Each PAR group was recorded and lasted approximately one hour. The agenda for each PAR meeting was set by the group but included discussion on the person and carer involvement in LSW and the strategies used for service development. The PAR group was facilitated, and the service lead for LSW assumed group leadership.
- The PAR group participants were given assurances that their confidentiality, privacy and anonymity would be protected. They were also asked to respect

the confidentiality of anything that took place in the group. The respondents were further advised that the data would be kept on a Trust computer and could only be accessed by the researcher and project supervisor and that once the research report was completed the data would be erased. Assurances were also given that no individual could be identifiable in the report and that all respondents would be sent a summary of the research report (or the full report if requested).

In addition to the general ethical principles, the following consent processes were adopted with the person and carers and practitioners:

- The research process and hence ethical principles were monitored by the project steering group and six-monthly progress reports compiled.
- The researcher's professional background in mental health nursing, dementia care and training, and role as a mental health academic assisted in sensitively facilitating the interviews and dealing with any problems the research caused. The investigator was the sole researcher, and as such was a continuous point of contact for all participants for the duration of the study. He had previously undertaken qualitative research that utilised semi-structured interviews and focus groups (including interviewing carers and older adults) and was experienced in principles of informed consent and in maintaining confidentiality.
- The researcher was supervised by two experienced academics and a clinical expert. A model of 'ongoing consent' was adopted by utilising regular discussion, debriefs and reflection on the research process. Although no

issues presented, the investigator could have discussed any consent issues that arose from the PAR groups within the supervisory process.

- The research information sheet, letter of invitation and consent forms (Appendices 6-11 and 13-15) were written in plain language and a large font. The information in these documents was kept to a minimum but it was ensured that all essential information was provided.
- The investigator had been appointed as researcher for the project and so was not concurrently undertaking a clinical role. Thus, no professional role conflicts were anticipated or presented.

Approval was gained from the NRES Committee East of England - Cambridge South (Reference no 13/EE/0306) (Appendix 16 & 17) and the University of Essex (Appendix 18 & 19) in November 2013 and approval was obtained from the Trust's Research and Development group in December 2013 (Appendix 20). The NRES 'End of study acknowledgement' is included in Appendix 21

3.10 Data analysis

3.10.1 Data transcription

The PAR group meetings, semi-structured interviews with people with dementia and carers and clinicians, were all audio recorded and then transcribed by a professional transcribing service in a verbatim style. The service assured confidentiality and compliance with other ethical aspects as part of their contractual conditions. The transcribed notes included all non-verbal communication such as quiet time taken for reflection, laughter and words such as “um”. A summary of the data coding procedure followed is outlined in Appendix five. And the schedule used for the semi-structured interviews with individuals with dementia and their carers is included in Appendix 22.

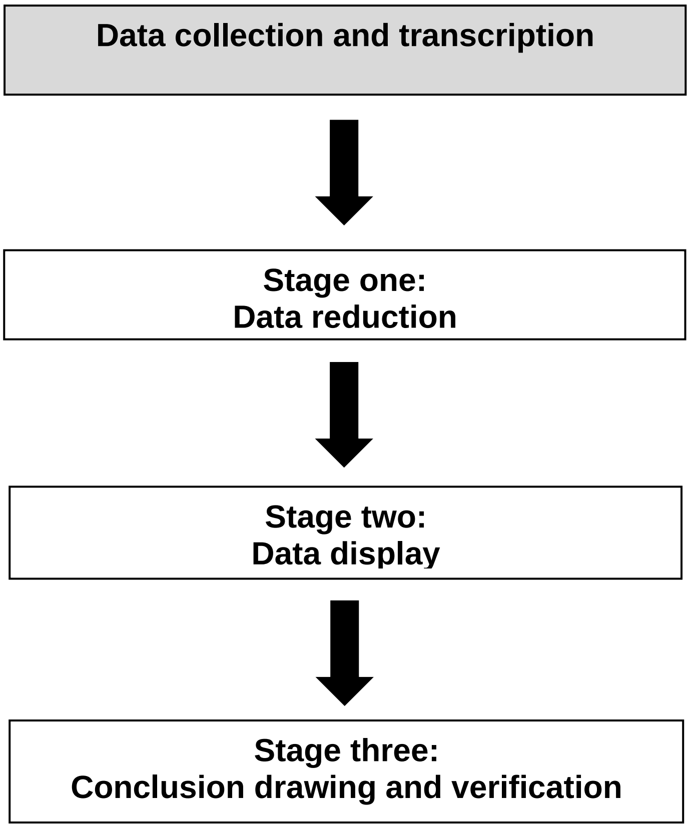
3.10.2 Computer Assisted Qualitative Data Analysis (CAQDAS) Software MAXQDA

For this project, the MAXQDA-11 software package was used to code and analyse the data. Initial themes were generated by using the study objectives but, owing to the large volume of data, sub codes were then utilised. Overall the researcher found the coding and thematic identification process to be an extremely lengthy but rigorous process that must be worked through to identify the themes. Other positive aspects of using this software included the presentation of the data in windows that then enabled integrative analysis of the findings, being able to export the themes in a Word format that then facilitated further theme identification and the use of memos or notes, so the investigator could immediately resume the coding process at the following session.

3.10.3 Stages of coding the data

Miles & Huberman’s (1994) three-stage analytical structure of data reduction, data display, conclusion drawing, and verification was used to analyse and code the data collected. This can be represented as shown on the next page:

Figure 3.3: Miles & Huberman's (1994) three-stage analytical structure of data reduction



The reason for choosing this data analysis framework was because after considering alternatives, it seemed to be the most appropriate with which to address the study objectives and the data obtained. Furthermore, it adopts an interpretive phenomenological approach that enables a holistic perspective of the data collected to be adopted which then provides a comprehensive presentation of the experience of the participants. Also, the framework has been widely used to interpret qualitative data and, in particular, has been utilised in research that seeks to be collaborative and person-centred. All of these characteristics were central to the overall aim of this study. Moreover, to provide detailed descriptions of all of the stages of data analysis undertaken in the study, the four stages of qualitative analysis described by Bryman

(2004) were used to give detail about each stage and exemplify the actions taken in this project. Figure 3.4, on the next page, outlines Bryman's stages and Table 04 relates both processes to the specific actions taken in this project. Finally, the worked through coding process is included in Appendix five.

Figure 3.4: The four stages of qualitative analysis (Bryman 2004)

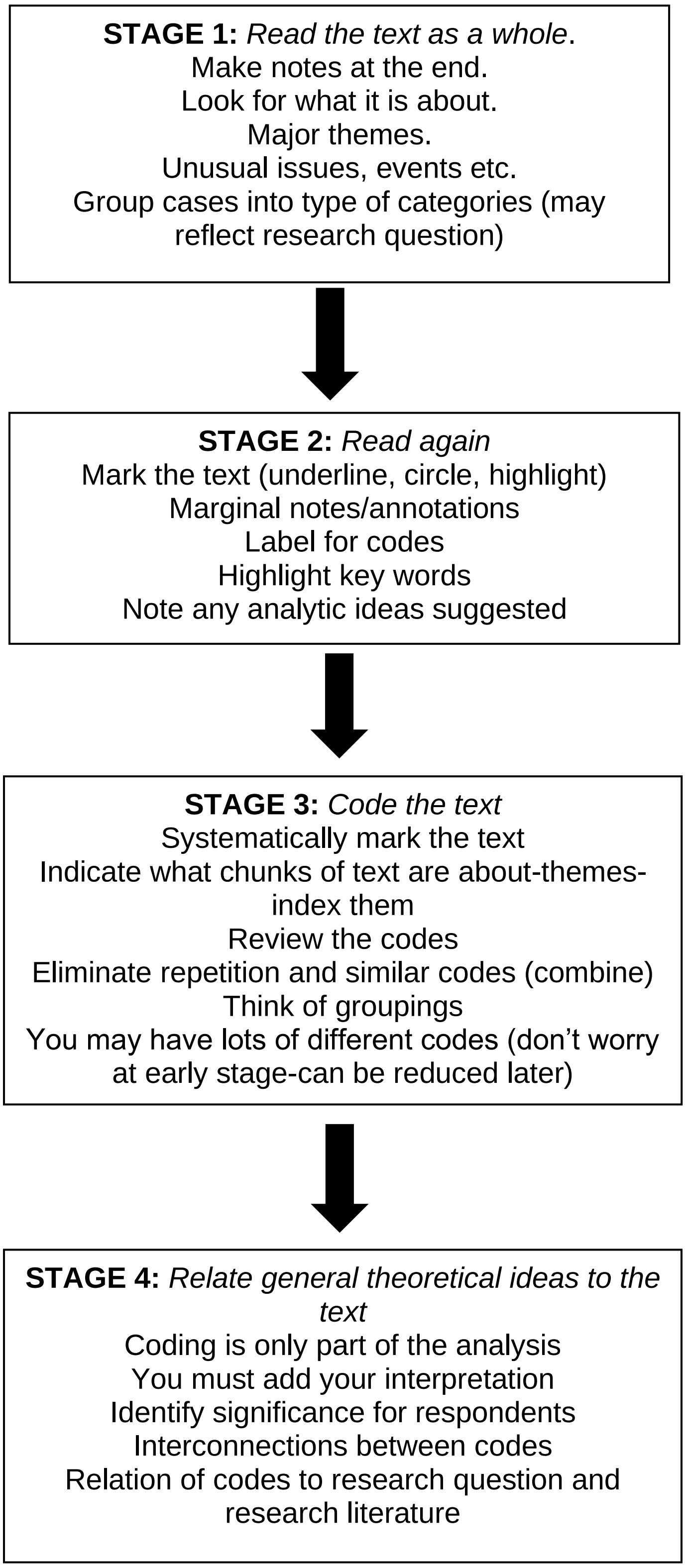


Table 04: Integrative presentation of the data analysis processes undertaken

Miles & Huberman's (1994) three stages	Miles & Huberman's (1994) three stages-corresponding processes	Bryman's four Stages of qualitative analysis (2004)	Project Actions
Data reduction	Data collection completed Data transcription Data inputted into MAXQDA Initial coding based on project objectives Identify emergent themes	Stages 1 & 2	Transcribed data from the semi-structured interviews and the PAR groups was inputted into the software qualitative data analysis programme, MAXQDA. Analysis commenced only when all of the data had been collected. Emergent themes were identified from the data by using a coding process.
Data display	Theme expansion	Stages 3 & 4	Data was reported with reference to the informants' accounts through which the veracity of the emergent themes was demonstrated. Each theme was expanded and made complete. Data has been displayed in a manner that is readable and comprehensible to both professional and lay audiences and has accurately reported the findings in context.
Conclusion drawing and verification	Credibility		The informants were invited to comment on the data analysis and emergent themes. This was undertaken in the PAR groups and at the project launch.
	Confirmability		The sources of data were repeatedly sampled during the research and from various sources.
	Meaning-in-context		The data has not been reported without reference to the context from which it emerged.

	Recurrent patterning		The themes have only been considered viable when they have been observable within different data sets.
	Saturation		Owing to the project time deadlines, it was not possible to achieve complete saturation. However, given the richness of the documented themes, the researcher is confident the data is fully representative of the participants' experiences and views.
	Transferability		The richness of the meaning-in-context data elicited will enable the research to be transferred to a similar location or dementia service. Some of the findings, particularly LSW tools, will be utilisable in a broader range of locations.

An important final point to mention in respect of the data analysis processes utilised relates to the notion that if person-centred principles were fully adhered to in this study, it could be suggested that the person with dementia and the family carers should have been fully involved in the data analysis and identification of the themes. Additionally, one of the critical issues identified in the literature review was the importance of service users being fully participating members of the PAR project team. The researcher was fully aware of these principles at the outset of the project, but after careful reflection and discussion with the project supervisors, the decision was taken not to involve people with dementia and family carers at the initial data analysis and theme identification stage. The reason for this is the fact that it was the clinicians who were planning and driving the change and the implementation of LSW.

Moreover, three of the primary objectives were, to different levels, concerned with evaluating the impact of LSW on the service’s and, to an extent, the Trust’s organisational culture which people with dementia and carers would not necessarily be able to contribute to. One of the four project themes was to elicit the experiences of people with dementia, and their carers’ experiences of undertaking LSW and these perspectives were verified by the participants at the Trust project launch, with opportunities provided for discussion, further feedback and sharing of their LSW. Following the final project launch, further analysis, coding and theme identification was undertaken. People with dementia and their carers were also involved at other key points in the project such as protocol development and study design.

3.11 Chapter Summary

This chapter has described the study purpose, the research question, aim and objectives and the ontological and epistemological position of the researcher. The rationale for utilising participatory action research as the research framework and qualitative strategies for the methodology and the nature of action research and participatory action research was then outlined. Furthermore, the study context has been explored in respect of several organisational and culture of care difficulties experienced, as well as outlining how some of these problems were overcome. The study research methods and the sampling processes, the data collection and the data analysis strategies were also provided. Finally, the ethical procedures, the theme identification and coding approaches considerations were described.

Chapter 4: Findings

4.1 Introduction

This chapter presents the four themes that were derived from the data collected from the interviews with people with dementia (n=4) and their family carers (n=3), the participatory action research (PAR) group meetings (n=8), and the evaluative interviews with PAR group members (n=5). These groups and interviews were audio-recorded, transcribed and coded using the MAXQDA software package and Miles & Huberman's analytical process. The themes also integrate the notes made by an independent observer on the interactive group processes and the reflective field notes compiled by the researcher. The investigator's reflections on the pre-project stage were outlined in chapter three (3.6.4) to support the rationale for using PAR as the research framework and to explain the study background which included the culture of care and organisational context.

Four themes were generated from the data, namely:

- 'Life story work is a mechanism for resolving inflexible paradigms in working practice'
- 'Life story work is a means of bringing people together in a collaborative manner'
- 'Life story work is a strategy for providing post-diagnostic support'
- 'Life story work is a framework for managing boundaries between staff and service users'.

4.2 Thematic Overview

The four themes identified are summarised in Box 09. A brief overview of each theme is also included, these explanations have been used as sub-headings and cross-referenced.

Box 09: Thematic overview

LIFE STORY WORK IS A:			
4.3 MECHANISM FOR RESOLVING INFLEXIBLE PARADIGMS IN WORKING PRACTICE	4.4 MEANS OF BRINGING PEOPLE TOGETHER IN A COLLABORATIVE MANNER	4.5. STRATEGY FOR PROVIDING POST-DIAGNOSTIC SUPPORT	4.6 FRAMEWORK FOR MANAGING BOUNDARIES BETWEEN STAFF AND SERVICE USERS
4.3.1 LSW enables the person who has dementia, their carer and clinicians to think differently about dementia. 4.3.2 LSW prompts clinicians to reconsider how LSW could be used and how it impacts on the person and their care. 4.3.3 LSW empowers the team to bring about change that has a broader organisational impact.	4.4.1 LSW has different meanings for all involved in the process. 4.4.2 LSW enables this complexity to be overcome through enhanced collaborative and reciprocal communication between diverse individuals.	4.5.1 LSW as part of a post-diagnostic strategy prompts the individual with dementia, their carers, clinical staff and the organisation to reflect on the support needed and the associated challenges. 4.5.2 LSW enables all parties to overcome these challenges by working with a shared set of values.	4.6.1 LSW facilitates recognition of the importance of personal, professional, organisational and structural boundaries. 4.6.2 LSW enables the individual with dementia, their carers, clinical staff and the organisation to manage these boundaries by evolving innovative strategies.

4.3 Life story work is a mechanism for resolving inflexible paradigms in working practice

“We’re, kind of, sometimes looking in a mirror, aren’t we, potentially, and (the) difficult work that’s asked of us or you to accompany patients on quite an uncertain journey” (PA-PAR Meeting 7)

This theme outlines how the functional paradigm in the dementia service was developed and how the biomedical model of dementia care still operated when this study commenced. Examples of this paradigm include how resource limitations and changes to referral patterns resulted in therapies such as home treatment and CST taking priority over LSW. Despite the fact that LSW was valued by the clinicians, it became perceived as an additional burden. Many of the interventions being used, such as information meetings, appeared to adopt a biomedical approach. Potential solutions to this situation were offered by the clinicians, but these did not seem to reflect the experiences of people with dementia or their carers, and neither did they appear to take a person-centred approach. Changes to the beliefs and values of the individual with dementia, their carers and the clinicians after the re-introduction of LSW included carers and staff having a greater appreciation of the person’s life and skills which, in turn, enhanced the support given.

LSW also helped the person to appreciate living in the present more, and seemed to reactivate skills and attributes that were thought to be lost and helped to plan longer-term care needs. Some staff experienced professional dissonance as a result of facilitating LSW such as the potential incongruence of the living well with dementia philosophy. But, after personal reflection, new communication skills were developed. After the re-introduction of LSW, changes to the operating systems used by the clinical team and the organisation occurred, including the development of a more person-centred care culture, the empowerment of staff to bring about change, new operating structures in respect of innovative practice and the utilisation of LSW principles in Trust-wide working groups.

4.3.1 LSW enables the person who has dementia, their carer and clinicians to think differently about dementia

The perspectives and experiences of the people with dementia and the carers who encountered what appeared to be a largely biomedical style at the dementia service are primarily dealt with through the theme: ‘Life story work is a strategy for providing post-diagnostic support’. For example, the clinicians often assumed that relatives were ready to undertake a caring role, and a lack of continuing support was identified. However, inferences to, and the operationalisation of, this same approach can also be seen in some of the other feedback obtained, including delivering therapies in quick succession and being given too much information, the aim of which seemed to be to demonstrate that the staff were ‘doing something to help’ rather than addressing individual needs:

> *“And then we get the carers course and then her cognitive stimulation started after my carers (course). And I thought, no, we need a bit of time to come to terms with the diagnosis. So we’ve had that time, and now we’re ready to start” (Interview 2)*
>
> *“I think we were totally bombarded with paperwork. R (her husband) probably hasn’t looked at it again. I have a file upstairs that thick, and I’ve highlighted, and it’ll be easy for me to explain to R but also to remind me there’s the Council, there’s the NHS, there’s the dementia, there’s this person, that person” (Interview 1)*

New services are often given a relatively ‘free hand’ in terms of determining the type of care provision to be offered. This is often considered an empowering approach by the organisation and one which can foster effective team working. The service was founded on such a principle and, initially, LSW, short-term interventions, memory monitoring and crisis support seemed to co-exist comfortably. However, over a period of eighteen months, the increased volume of new referrals for memory assessment from GPs, combined with managing and documenting care events, resulted in memory assessment, home treatment, carer education and CST becoming the focus for the service. Thus, owing to a perceived lack of staffing resources combined with competing demands, these therapies were given priority in terms of clinician time allocation:

> *"Lack of staff, lack of staff. Because it wasn't lack of interest. Lack of staff and time. Because home treatment just got big, CST is big, carers' ed now is getting bigger. It just seems lack of time and persons to do it" (X6-interview)*
>
> *"Fundamentally within the team, we need to have a think about how what we as a team might use life story information within the services that we provide" (PA-PAR Meeting 6)*

The organisational concerns that seem to have influenced the operations of and priorities for the team and clinicians, such as a focus on contractual requirements, memory assessments, quality inspections, 'crisis' work and responding to increasing referrals, can be seen in the feedback provided and type of language used by two core team members in one of the PAR group meetings. The clear priority for the team is the interventions that are perceived to represent the 'acute' aspects of dementia care in preference to more person-centred approaches. This observation is significant in terms of the operating paradigm, given that these members of staff have clinical guidance roles:

> *"Well, in terms of what the service offers at the moment, we've pulled in memory monitoring into that as well, which, the trajectory for that is 20% increase in the next year. In terms of memory assessment, we're practically up to capacity with memory assessment nurses. So, I guess it's going to be about us having those conversations with the commissioners. I think what will happen is, you know, the crisis work's increased, I think we are going to have to look at increasing our home treatment, you know, the sort of sharper end, you know, more acute end of things as well" (IE2-PAR meeting 8)*

> *"I think it is a workable model (the LSW approach used for the project). But I also think that you know, with the manager's hat on you have to think about, you know, the resources that you're putting into that, you've got to know, enough people attending to make it viable. But when the evening session was set up, nobody came" (IV-PAR Meeting 8)*

The re-introduction of LSW, as required by this project, appeared to challenge the move from utilising LSW and other person-centred approaches as a central part of the operational model of the service. Therefore, even though LSW was valued by the clinicians, it was seen as an additional burden or as being in competition with the other services being delivered, and so it became difficult to offer this to individuals with dementia in a consistent way or to enable staff to become involved:

> *"There wasn't quite the full group participation. But granted some of that is due to the other demands of the service and everything" (X4-interview)*
>
> *"I've found it quite hard to get people interested in it (LSW)" (X6-PAR Meeting 2)*

As a result of these fluctuating priorities, many of the care services and therapies on offer at the service when the study commenced seemed more closely allied to the traditional biomedical of dementia care rather than a person-centred framework. While the interventions on offer, such as CST and home treatment, were presented by the clinicians as 'person-centred', these did not seem to conform to current conceptions of individualised care. For example, the high rates of referral from GPs for memory assessment appear to have shifted the focus from therapeutic care to a screening service. In this context, the very structured strategy required for such evaluations means that a medicalised approach is adopted owing to the requirement to use the associated battery of psychological tests, scans and diagnostic criteria that are set out in the commissioning guidelines. In such a scenario, memory assessment takes priority over more therapeutic options, leading to staff roles being re-defined, as exemplified by the use of terms such as ‘memory assessment nurses’. Thus, crisis and similar types of clinical work become more important than LSW:

> *“I’m not saying life story is not routine, but actually it’s not something that you go, oh, yes, emergency, I’ll go and do something, it’s on his life story, he’s not (in crisis), you know, it’s the routine elements of the work is much easier to…” (UM-PAR Meeting 8)*
>
> *“Just as an example, I know that this month we’ve had 140 referrals to the dementia service. Just in one month. It is quite massive really” (X7-interview)*

Therefore, the team appeared to be operating under the understanding that the interventions being utilised in preference to LSW and other more person-centred therapies were innovative and constituted what people with dementia and their carers required from a dementia service. A further example of this involved the person and their relatives being invited to a follow-up ‘information meeting’ at the service with an experienced member of the clinical team, shortly after a diagnosis of dementia. This session focuses on giving the person who has dementia and their family a range of information (often in paper format and in a folder) that aims to enable them to contact local sources of support, read about the nature of dementia and access resources, and thereby help them adjust to the diagnosis:

> *“I think, that we generally see people for information meetings after diagnosis to support them and guide them in what’s available out there” (IE1-PAR Meeting 8)*
>
> *“I think they just say; We’ve got life story, and we look into their past, write the book and stuff. If they [the clinicians conducting the information meetings] had a better understanding, I think it could be explained in a better way” (X3-interview)*

It is clear from the above statements that the need for and the importance of the information meetings seems to be taken for granted, even though such consultations are not necessarily common practice within dementia care. Concern about the volume of information and how this will be covered is also evident. The brevity of the diagnosis follow-up meeting with the Consultant Psychiatrist appears to further exemplify a task-focused approach whereby only a limited amount of time is allocated for any discussion. This aspect is then left to the nurse or occupational therapist to respond to at the information meeting:

> *“Because obviously, after their initial meeting with the consultant, which is very, very brief and they come and have an information meeting with us, and we have so much stuff to cover, like, within the space of, let’s say, an hour; everything that we do as well as their diagnosis and any questions they have and any difficulties they’re having and everything, within an hour, which is just and then that’s it, kind of, potentially, at that point” (PA-PAR Meeting 6)*
>
> *“I’ve got to say, life story work at that point (in information meetings) is a little bit of an afterthought, I’m afraid” (UM-PAR Meeting 8)*

As can be seen from the above excerpts, the re-introduction of LSW, whilst prompting reflection on the therapies currently on offer, was perceived by the clinicians as an additional burden for them in terms of caseload and therapeutic interventions, particularly given that they had to deliver the other priorities already outlined, such as CST and carers’ education. This resulted in avoidance (of the LSW project) on the part of other team members. While the clinicians could see the value of LSW, the additional workload and the ‘competing interests’ scenario described above, combined with the components of the prevailing biomedical paradigm, seemed to have an adverse effect on the commitment of staff who were required to explain LSW and seek out potential participants:

> *“I wonder if there’s a way of making it seem less of a chore on top of everything else that’s going on or whether there’s a way to make that easier” (F1-PAR Meeting 3)*
>
> *“I don’t really want to commit myself to actually being involved (in LSW)” (X6-PAR Meeting 2)*
>
> *“To be quite honest I think the team is so busy that actually, they’re quite happy just leaving this (LSW) going on at the side-line” (F3-PAR Meeting 3)*

Reluctance among the clinicians to raise awareness of the availability of LSW to individuals with dementia was also partly due to the view that LSW was not seen as a routine intervention. This is surprising given the principles that underpin LSW, with staff seemingly not acknowledging its person-centred aspects, an observation that seems to manifest as a rationalisation for the use of CST and the other interventions:

> *“That would be the issue because we do spend an awful lot of time recruiting for CST and carers’ education, you know. I mean a lot of time, and, you know, when you consider the amount of people that are actually saying, yes, and then get a proper invitation (to LSW) because we’ve checked up and they’ve changed their mind, and then actually turn up on the day, numbers do tend to dwindle” (IE1-PAR Meeting 8)*
>
> *“I think we need to keep reiterating it (LSW) at team meetings because it gets mentioned and then it gets lost. We certainly need to keep saying that it’s still going on and this is where we’re at, and actually maybe giving them a bit of a rundown of where we’re at and talking about any difficulties that occur to them” (X2-PAR Meeting 4)*

Solutions were offered by the broader clinical team for the resulting poor uptake of LSW such as delivering it differently or adding it to other therapies, but such approaches would still have resulted in the more biomedical interventions continuing to take priority. In this regard, the conciliatory offer seemed to be a concession that would simply have maintained the status quo:

> *“I think it’s going to be very difficult to have the life story work as an individual thing on its own. Which is why I’m saying if it’s embedded in with a (CST) group. Because otherwise, it’s going to be probably the first thing to go when the cuts all come in” (X4-interview)*
>
> *“All I’m thinking is if you want life story to be workable into this, probably the quick and easiest way might be to tag on to something that’s already working, rather than try and set up something completely separately, which might be hard work” (IE1-PAR Meeting 8)*

The prevailing paradigm utilised at the service seemed to be the biomedical model, and this was strongly represented in the operational processes, such as responding to referrals and the use of information meetings, and in therapies like CST and crisis support. Even though the principles that underpin LSW were acknowledged as useful by the staff and challenged the rationale for the therapies being used, LSW was no longer a care priority. Additionally, the interventions on offer did not seem to adopt a service user perspective.

4.3.2 LSW prompts clinicians to reconsider how LSW could be used and how it impacts on the person and their care

One of the outcomes of reintroducing LSW was that all involved in supporting the individual with dementia now had an enhanced understanding of the person in the context of their life story: ‘this now makes sense’. Dementia can cause communication difficulties and a loss of capacity, but it was noted that LSW helped in this respect by promoting awareness of individual differences and knowledge of the person, their personhood and achievements. This, in turn, enabled relatives and staff to see their personal identity more clearly, thus assisting with care planning and the use of appropriate interventions:

> *"With respect to people living with dementia because as they go along, they can't communicate these special bits of their life, the experiences that they've had. It's really important that we find out about them so that we can still know them as people. Without knowing them (their life experiences), we can't know them (as individuals) and then support them as best we can" (X5-interview)*

> *"Because this particular lady has got no support system in place whatsoever. There is no carers, no family so there will be no information about this lady when she loses her capacity and awareness, so that is why I have pushed for LSW" (XX-PAR Group 0)*

In a similar way, LSW also seemed to help explain behaviours observed in and communications made by the person with dementia in the context of their life. The awareness developed as a result changed the clinicians' perspective and understanding of the actions of the person with dementia, and so the quality of the interaction and, correspondingly, the care provided was enhanced. In this regard, LSW was considered to be a person-centred and evidence-based way of evaluating interventions and thus further helped with interaction:

> *"We went to see a gentleman at a care home, and he was just moving the furniture around all the time. They put him down like he was aggressive, but I sort of looked at the sense of the life story thing, and it turned out that he was a builder and he was used to moving things. Once you sort of bring that it just all sort of made sense to them. It gives you a completely different perspective" (F2-PAR Meeting 3)*

> *"I think that out of all the other methodologies (LSW use combined with PAR); it's probably the best one to use for people with dementia and their loved ones. It was less intrusive and less 'you will go through this paper and answer all the questions and tick all the boxes, this feels like it's a much more person-centred kind of way of doing research" (UM-PAR Meeting 8)*

Furthermore, the approach used for LSW prompted the clinicians to reconsider how LSW could be used and how it impacts on the person and their care and the way in which care is organised. In this way, it appeared to enable positive memories to be documented and the dissemination of the person's life achievements to a broader family by acting as a memento and continuing record. Also, approaching LSW as a personal document provided renewed purpose and structure:

> *"I've decided that the day that I go, my granddaughters will have this, because my granddaughters live abroad and I don't have a lot of contact with them, and this way they will know more about me. And that's why I wanted to put it like that, a lively book; I don't want it to be a solemn book because I am not like that. I mean, I don't want to have the book and have it put away because I say that this is a never-ending book" (Interview 4)*
>
> *"It was amazing what he really did. And he felt like he'd gone back to his old self" (X3-PAR Group 2)*

In view of this newly developed understanding of the person-centred aspects of LSW, the approaches selected by the person were all very different and seemed to reflect their personal story, personality and life skills. The uniqueness of these strategies also enabled the family to (re)appreciate the skills the person with dementia had developed over their lifetime. Indeed, the very bespoke nature of the approaches used by the individuals with dementia for LSW and the personal attributes associated with these also seemed to surprise the family and carers alike:

> *"For me, it was more like a photo album, and I didn't want that; I wanted my book to be more explicit" (Interview 4)*
>
> *"So, you have really got a structure in terms of going almost year by year, haven't you?" (Interview 1)*

Being diagnosed with dementia and undertaking LSW enabled individuals to re-evaluate their life and, consequently, place a higher value on their life achievements and important relationships and appreciate living in the present more. Such reflection and reappraisal also led to the conclusion that 'dementia has given me a new lease of life' or 'I've been given a different life'. In this regard, people seemed to become more contemplative and introspective, and even develop new skills. This is a significant observation because having dementia appears to open up social opportunities and relationships that did not exist before diagnosis. In addition, it is interesting to note that LSW can help initiate personal adjustment:

> *“Having dementia has given me another life, a life that I didn't know; it's opened my eyes to these things. That is wonderful because it is wonderful that's happening to people who are diagnosed” (Interview 4)*
>
> *“When I read it, it makes me smile. It makes me laugh, it makes me cry, for me, it's a joy, and I don't feel like I'm reading my story, I feel like I'm reading a book of somebody else, and it's making me smile, it brings me that smile every day” (Interview 4)*

Similarly, LSW prompted the individual with dementia to review their life and see having dementia in a more insightful, different and reflective way. In turn, this led them to retrieve and recall significant life events and achievements that had previously been forgotten. This process then enabled a couple (or family members) to reflect on these moments in a meaningful and positive way in the present:

> *“All the good things that are coming up, because of one thing, something else comes up” (Interview 4)*
>
> *“Or that, because that (computer) is always on, my husband leaves it on for me, and I go onto the (computer) files, and I open them, and I read them, and I feel like, ooh, I want to put something in there, so I get paper, and I write it down for my husband to do it for me (type into the computer file), you know” (Interview 4)*

The clinicians involved in delivering LSW were experienced in dementia care and so were fully aware of what might happen to the person in the future, in respect of the dementia becoming more progressive, and thereby impacting on their life and personal care abilities. Yet, the use of LSW enabled everyone to focus on the present and living as well as possible with dementia. Such a perspective was also apparent within other interactions and therapies, for example, the staff provided support and guidance in a person-centred way:

> *“I think that he was at the point where he thought that he didn’t have a future and that this was his last point. But obviously, I just put a lot of reinforcement in that he can live well with dementia and it may limit some things, but it isn’t going to stop him living his life” (X3-PAR Meeting 2)*
>
> *“I suppose because we know a lot about the future, don’t we, in a certain aspect, not to the point where individually we know what’s going to happen, but we see what can happen. I try not to bring that in too much” (F2-PAR Meeting 3)*

Not only did LSW promote the recall of memories and events that otherwise might have been forgotten or lost, it gave further motivation, and a new purpose, as well as re-enabling skills and attributes learnt during the person’s lifetime to be retrieved and used in a meaningful way once again. The individual LSW support sessions provided also seemed to be helpful in attaining significant outcomes in this regard. Additionally, it was documented how LSW informs the person’s care journey in the present and in respect of planning their longer-term care needs. Furthermore, if crisis support is needed, LSW can enhance this because the clinical team will have access to detailed information about the person with dementia. This perspective is shared by people with dementia, and their relatives, who indicated that such awareness would also influence end of life care and the care preferences of the individual at this life stage:

> *“In a sense, life story work being completed potentially could prevent some of those crisis situations, or more urgent situations developing. If you know someone very, very well and you can see ways of working with them and things that would help to calm the situations” (X7-interview)*
>
> *“Oh, what I want at my funeral, I've put it here as well, you know, even though I've got a will. But for me, I've said to go by this (the life story book), because I've changed a few things” (Interview 4)*

In a similar way to the potential for clinicians to utilise the enhanced knowledge of the person gleaned from LSW, from the perspective of the person with dementia and their carer, this information was going to be used to plan ahead in terms of their own care and in the documentation of their wishes. LSW also further prompts staff to reappraise the overall data collected about the person and how this might be used to support innovative practice and influence their care in other ways. In this regard, consideration of the use of care formulation or LSW personal profiles for use within team or case conferences were considered to be potential options:

> *"It just got me thinking maybe, once the person's done their life story, we need to take the key information somewhere and maybe build it up, for formulation or a profile of some sort" (MO-PAR Meeting 6)*
>
> *"That the information that we're using is used for a very specific purpose rather than it just being information that we're gathering" (X2-PAR Group 2)*

Undertaking LSW also enabled reflection on the part of carers about the range and quality of the services accessed, who might provide assistance with primary care and the inherent value of all these potential support options. This process seemed to develop carers' awareness of local services and thus they became more likely to access and utilise these. Such consideration further seemed to support the research aspect of the LSW project, mainly by helping others who might be starting on the same care journey:

> *"I think they also spent a bit of time reflecting on the journey through the services and how helpful and supportive they'd found services" (X2-PAR Meeting 2)*
>
> *"It's usually the doctors and the nurses" (in the GP surgeries who gave further support with LSW) (Interview 2)*

In line with the personal concerns expressed by the individual with dementia, LSW also prompted staff to reflect on the professional, and in some respects personal, discomfort caused by implementing LSW and the implications of using it to explore what the future might hold for the person. The dissonance created needs to be analysed and evaluated by the clinicians to ensure it is utilised constructively and that both practice and inter-personal communication are enhanced:

> *"I worry about going on about the future too much and scaring them. That's my biggest worry" (F2-PAR Meeting 3)*
>
> *"Also courage as well, we're, kind of, sometimes looking in a mirror, aren't we, potentially, and (the) difficult work that's asked of us or you to accompany patients on quite an uncertain journey, which has been contained in here, actually, because you could easily say, oh, God, this is really awful, we don't know what we're doing, and it could all just fall apart, but somehow this group has managed to contain that" (PA-PAR Meeting 7)*

In this regard, critical reflection on the part of the staff seemed to evolve into an awareness of personal skill deficits whereby staff became worried about whether they possess the necessary skills to deal with the emotional issues that develop. Such collaborative working on LSW and the empathy developed also required all parties to reflect on their own roles, skills and experience and the nature of the interactions and then modify these accordingly and/or reconstruct new communication patterns:

> *"How the age of the facilitator and then questions from patients about their ability to, sort of, empathise with them. But maybe once they've got to know you and they know you can empathise with them" (PA-PAR Meeting 7)*
>
> *"As they go along on their journey, pictorial things and objects are really, really important visual prompts for people to be able to share with you their thoughts and feelings. Even if they can't express it verbally and with the words they want to use" (X5-interview)*

In consideration of this point, service users seemed to appreciate that the LSW facilitator had developed new skills as a result of using the techniques of LSW. These skills included the use of multiple reminiscence methods, inter-generational awareness, historical searching and empathy building. Thus, LSW becomes a psychotherapeutic and skilled process, and so staff need additional training and clinical supervision to facilitate LSW effectively. The abilities required in this regard include individualised planning, interpersonal skills, resourcefulness and competence in using information technology:

> *“X. helped us. She went into Google and got some photographs of ‘L’ town in the 1940s” (Interview 2)*
>
> *“You're going to get me started on reminiscing; I’ll go on” (Interview 2)*
>
> *“If I'm honest, X was much more helpful than reading anything or doing anything, because she was very practical about it all” (Interview 3)*

Therefore, many changes to the beliefs and values of the person with dementia, their carers and the clinicians became apparent after the re-introduction of LSW. These changes included improved awareness of the person with dementia’s existing skills and life achievements. Following personal reflective analysis, the clinicians also seemed to develop new skills in delivering LSW that were appreciated by people who have dementia and their relatives. LSW further seemed to help everyone involved to understand the importance of living in the present, but at the same time, it also enabled people to consider their longer-term care needs.

4.3.3 LSW empowers the team to bring about change that has a broader organisational impact

Some of the professional staff openly welcomed the opportunity to use LSW to implement a new therapeutic approach. Therefore, one of the outcomes of using LSW on the part of the clinicians was that it seemed to empower them to bring about changes in the broader team and within the Trust in respect of the new positive practice principles gleaned from the project. This came about because the staff had developed new knowledge, skills and professional confidence which was founded on the use of evidence-based and reflective practice. The outcome of this situation was that the clinicians felt that the power balance had shifted in their favour and this awareness then impacted on the organisational structures and systems within which they worked. Correspondingly, LSW helped the staff to explain the problems they encountered in practice to the local managers which, in turn, enabled the managers to appreciate these difficulties and support the LSW facilitators in implementing change:

> *"We're not the people who have the power to say yes or no as to whether it actually goes ahead or not. But the power should shift a bit because you've now got more knowledge, haven't you? You've been doing it, so you can actually go back and tell, this is our experience, this is what needs to change, and you've got research to back it up" (PA-PAR Meeting 7)*
>
> *"I think it helps the link-up (with the project management team), the processes, and I think from that meeting, I actually felt that there was a greater understanding within the steering group of some of the challenges that we were facing and where the blocks were coming from, and I think actually if that's there earlier, then the support that they're giving, you know, it's coming from a place of understanding" (PA-PAR Meeting 7)*

In addition, LSW appeared to encourage the clinical team to undertake critical reflection on current practice, which, in turn, further facilitated organisational change, i.e. the enhanced use of LSW and person-centred care. This also brought about new and innovative ways of working within the team and organisation, including LSW special interest groups. This aspect is important because of the competing pressures within clinical practice and the need for the team to continually adapt and implement new processes:

> *"I think with a constantly evolving team there is the danger that things get lost. I think it's really important to spend a bit of time to think about how we embed it so that it becomes fundamental to the work that we do, both here and in the wards or some of the other services that they're also using" (F1-PAR Meeting 3)*
>
> *"It feels like the research project having happened, has driven things forward within the Trust as well, because I know you were saying about the (Trust) LSW group that X attends" (X7-interview)*

It was documented in section 4.3.1 of this theme that the therapies offered at the service were primarily determined by contractual requirements and that these were influenced by referral rates, memory monitoring and crisis work. All of these factors seemed to have the effect of making staff feel disempowered and not in control, owing to the resource implications and lack of staff time. Consequently, new therapies such as LSW were resisted even though there was an acknowledgement of their potential for enhancing practice. However, the use of LSW in this context did provide the impetus for improved person-centred care and helped to overcome labelling because the person with dementia was viewed in a more individualised way by the clinical team. The benefits were evident in care meetings and resulted in enhanced care plans for the service users:

> *"So you're discussing the person in a more therapeutic way. Because sometimes the language gets used, 'agitated, aggressive,' you get all these dominant words that get used. By sitting down and discussing the person's overall care plan and having a visual prompt on the (shift handover) board, I think it would be more person-centred in that way" (X5-interview)*

> *"It's allowed us that space to sort of explore what we can do and to create something. That in itself is quite empowering within the team" (X4-interview)*

One of the difficulties encountered within the broader team when implementing LSW was the suggestion that the project would have been more successful if it had been delivered in a different setting, such as in-patient care. This observation seemed to represent a tactic of resistance to change by 'shifting the responsibility' away from the people delivering it. Such a phenomenon appeared to miss the point or central aim of the LSW project, which was to deliver it soon after diagnosis in a community setting and in a way that permeated all aspects of care. Thus, team dynamics further influenced the situation by misconstruing LSW 'as a non-routine intervention' when it should have been the first approach utilised in any care situation. Similarly, the PAR group members were concerned about the sustainability of LSW after the planned stages of the project had been completed. This concern stemmed from the impact of these 'restricting' factors such as service demands being seen as in opposition to person-centred care. However, this awareness seemed to encourage the clinical team to initiate action to ensure the good practice principles of LSW were shared with a broader audience within the organisation. Therefore, they saw it as their responsibility to 'sell' LSW to the wider team and, beyond that, the Trust, by developing strategies such as Trust-wide seminars and LSW working groups:

> *"I guess our worries were that (if) actually it (LSW) does grind to a halt and stop, so I think we wanted to get something in there quickly so that it carries on, but actually I think we also need to combine that with getting other people involved and obviously the findings of the research and how people are experiencing it, because I guess we get little bits from the people we've been working with, but they're probably going to feel much more free to talk about how they've experienced things with you (the researcher) because you're not directly involved" (PA-PAR Meeting 7)*

> *“I know that that was an issue with the research project, because I think if we could have done some of that work in the in-patient wards, you’d probably had a lot more feedback by now” (IE1-PAR Meeting 8)*

As will be discussed later, under the theme: ‘Life story work is a strategy for providing post-diagnostic support’, the original operating intention of the dementia service was to provide a named and continuing contact to support the person with dementia and their carer throughout their service journey. However, owing to new and competing demands, this aspect was lost as the team evolved. The provision of LSW delivered through this project was then used for this purpose, which seemed to challenge the clinicians to rethink the focus of the provision being offered and consider whether it was suitable:

> *“That’s exactly what we said when the dementia service initially, came into fruition. They would have a named nurse that would remain with them for their whole journey, that type of an image, and of course, that’s not been sustainable” (PA-PAR Meeting 6)*

> *“I aim to have a first (support) session and no more than two weeks after, like, their first (introductory) session. To give them just a bit of time to go away and think about what they want and gather some bits that perhaps we could start working on and developing. Not leaving it too long and not too soon” (X3-PAR Meeting 2)*

As can be seen from the above excerpts, LSW also enhanced the way in which service users engaged with the Trust and the service by combining LSW and PDS. It further generated a new research culture at the service, which service users played a significant part in developing and maintaining. The use of PAR in this context also seemed to foster a more collegiate and empowering approach to research, the outcome of which was that LSW and person-centred care became a central component of the interventions being offered:

> *"It had kind of got to the point where we weren't really doing life story at that time. Then with the research project, it's been like a massive drive for it to be recommenced. So, we were kind of at a point where it wasn't really happening at all, and now it is. There's a new system with the groups, that's something different we didn't have before, as well" (X7-interview)*
>
> *"No, I mean, CST really has come out of NICE guidance, yes. Carers' education, the dementia strategy, really, you know, that carers need to be supported and, you know, life story is part of that" (IE2-PAR Meeting 8)*

The critical service review of current practice prompted by the use of LSW for PDS further resulted in several learning points for the clinical team. Of particular importance was an acknowledgement that, as LSW is a complex and intensive process, it is essential to take time for critical reflection on how the ideas generated might be utilised by the team and how they might be discussed and actioned more widely by the organisation:

> *"It was all a bit overwhelming to start with, wasn't it? Because there were so many ideas" (X7-PAR Meeting 2)*
>
> *"I think when we started, it felt like we all had different ideas and it was quite interesting, because I think we all collectively came to a realisation that this is actually quite big, and it can be anything, and I think it was quite nice that through that we were, kind of, throwing lots of ideas around, and it became clearer, so I think that was really nice" (PA-PAR Meeting 7)*

The impact of the 'information meeting' has also been addressed in section 4.3.1, but a critical evaluation further prompted other ways of organising the meeting, not just for the team but also more widely within the Trust. Examples included questioning whether all the material covered was actually needed and if it could be delivered in a more person-centred way in line with the principles that underpin LSW:

> *"It is a very heavy-going meeting. There is an awful lot there, and in a way, it's a case of, I'll explain about it, but then the numbers are on here, give us a call, or I give them opportunity to discuss it, but it's a case of come back to us if…" (F3-PAR Meeting 3)*

> *“In my experience, people are still absorbing and still don’t really understand, so, you know, I have to continually explain what it is (LSW) again” (IE1-PAR Meeting 8)*

The detailed information gathered about the person with dementia by using LSW, also needs to be carefully considered and reflected on by all parties and by the broader team in terms of its potential usefulness, particularly in respect of influencing the person’s care plan and its overall impact on the service user’s therapeutic programme. This also has implications for the Trust because LSW challenges the way in which personal data is collected and recorded using electronic care systems. In this respect consideration needs to be given to the embedding of LSW outcomes within personal records:

> *“There needs to be a more cohesive plan about what we use that information for, and how it then influences someone’s care and how we’re interpreting that information” (PA-PAR Group 6)*
>
> *“I think it’s important that that’s (LSW) introduced at the information meetings and given that opportunity, but it needs to be part of every other thing as well that’s done. That there is that opportunity to create a life story and be involved in the research” (X8-PAR Meeting 1)*

Additionally, the data obtained by undertaking LSW informs and helps staff to deliver other therapeutic interventions such as home treatment and crisis care. In this way, the value of conducting LSW with other couples, combined with the support and professionalism and skilled, focused practice and assessment on the part of the LSW facilitators and other staff, both at the service and in the home, was considered essential and had a significant impact on the broader processes that operated within the team:

> *"If they come onto home treatment for any reason, you can build a rapport more quickly with someone. Say you had someone living on their own and you needed to go in to see whether they were looking after themselves if you know a little bit about them and you can get a conversation going, even if it's through the letterbox. Because if you're going up and you haven't got anything to work with, you're almost stuck straight away, aren't you?" (X5-interview)*

Thus, after the re-introduction of LSW, a number of changes to the processes followed by the dementia team were documented, and the outcome of the LSW project also impacted on procedures used more widely within the Trust. While the prevailing paradigm utilised at the service was founded on the biomedical model, the use of LSW brought about several changes in the beliefs of the people with dementia and their carers who used the service, as well as in the values held by the staff, clinical team and the organisation as a whole. These changes included service users playing a significant part in developing an individualised culture of care at the service, empowering staff and equipping them with the necessary skills to implement change within the wider team and the Trust itself, thereby enabling new and innovative ways of working and reducing staff resistance to change. Furthermore, the team viewed the person with dementia in a more individualised way, and LSW also challenged the way in which personal data was collected and recorded. Lastly, the importance of critical reflection was emphasised, which prompted the clinicians to rethink the focus of the provision being delivered and consider whether the information meeting could be structured in a more person-centred way.

4.4 Life story work is a means of bringing people together in a collaborative manner

"I just envision them sitting on the sofa together, going through it together, thinking, oh do you remember that day?" (xx-interview)

This theme initially outlines some of the complexities associated with undertaking LSW, including its use for diverse purposes, the need for people to be prepared to conduct it, and the requirement for clinical staff to be aware of the need for creative and innovative practice. However, even though LSW can be a complicated activity to participate in, these difficulties can be overcome and might ultimately bring the staff, the person with dementia, their carers, and the organisation together in a co-operative and collegiate way. In this regard it was noted that LSW enables all family and friends to contribute to the person's life story, is enhanced if carried out in the home environment, requires peer support, and improves relationships by promoting meaningful activities.

Additionally, as therapeutic and reciprocal relationships develop, a sense of sharing and collaboration evolves, and this can influence the organisation as a whole and associated strategies. LSW took on different meanings for all involved, and these encompassed the positive aspects of reminiscence, helping someone to live well with dementia, improving quality of life, the regeneration of dormant skills, informing future care, and the recognition of LSW as a psychotherapeutic activity. Also, the clinicians noticed that it enhanced their knowledge and therapeutic skills, which in turn led to improved individualised care. Moreover, it should be noted that the benefits of LSW need to be thoughtfully outlined to those involved before embarking on the process.

4.4.1 LSW has different meanings for all involved in the process

Bringing people together was explored by informants through three distinct, but interrelated, narrative strands. Firstly, how LSW is used for many different purposes by different people; secondly, how people needed to be in the right place to undertake LSW and thirdly, the importance of practitioners being flexible when facilitating LSW. One example of this is how individuals with dementia used LSW for many different purposes, including: to remember the person after they've passed away; to reflect on the importance of relationships; and to aid reminiscence:

> *"A lot of people want to create a life story for their family members after they're not there, as a kind of reminiscence tool, if you like" (PA-PAR Group 6)*
>
> *"And I speak about my husband as well, in significant relationships. The only thing is he's near the end because he's my second marriage. But I think he's the one, apart from my children, he's the one I speak the most of" (Interview 4)*

People with dementia will all utilise different approaches to LSW, such as computer-based strategies, making notes and annotating photographs. It will also be undertaken in differing sequences by employing various methods. Such individualised approaches are entirely understandable given the wide-ranging criteria available. These personalised strategies can be used to enrich the LSW process and improve the outcomes:

> *"Actually it doesn't matter how you start doing it, it doesn't have to go in sequence. That bit can be organised later" (X4-PAR Group 2)*

> *"Well, what we did, we sat together, and I actually wrote it in handwriting, wrote everything out, because it was easier than doing a set-up, where you go to the computer, all that. It was easier just to sit together, and sometimes I could get a story or something that happened, and I'd say, oh, tell me about that, and then I'd write it in handwriting. And I did the whole thing in handwriting – when I say that, it's a fairly précised-down life story, but that's how we did it, and then I intended to type it up at the end. We sorted out photographs, and then what I did, I just put the handwriting into the pages, and then the photographs that went with each page, ready to type it up at the end" (Interview 3)*

Secondly, it was noted that individuals with dementia have to be 'in the right place' emotionally to undertake LSW. Therefore the preparation of people to undertake LSW requires careful consideration and planning on the part of the LSW facilitators. The initial provision of information is critical to enable individuals to consider both the benefits and potential difficulties. Of similar importance were the supportive LSW sessions that were delivered because of these facilitated explorations of the feelings and emotions associated with the memories being recalled:

> *"It's got to be right for them at the right time; they've got to have done a substantial part of the life story work, they've got to have been through all three sessions" (X9 in S-interview)*
>
> *"I've done one home visit. That went really well. That's probably the best experience I've had so far. I think it was because they were in the comfort of their own home. They just had everything there to hand to them" (X3-PAR Meeting 2)*

In light of the two issues described above, the professionals supporting the person with dementia to undertake LSW need to adopt flexible strategies and innovative ways of thinking. This is a critical element for the success of LSW. However, not all of the clinicians appeared to appreciate the need for such awareness, particularly in respect of the descriptions used and activities associated with the information meetings held at the service following a diagnosis:

> *“We used the first session as kind of an introduction and beginning to think about how you could do it. I think some people initially really wanted a more structured, ‘This is what you do’ but when we started exploring it and explaining that actually, having a more flexible approach meant that it would reflect who we are better. I think that’s just a different perspective” (X2-PAR Group Meeting 1)*
>
> *“We look into their past, write the book and stuff. If they (the clinicians) had a better understanding, I think it could be explained in a better way” (X3-interview)*

Despite these complexities, the potential difficulties associated with undertaking LSW can usually be overcome by reflective and careful planning. If this is done, then LSW seems to bring people together in a collaborative way and results in new and enhanced interpersonal relationships. One example of this is the way in which LSW enables families and friends to positively reflect on pleasant memories and life events which, in turn, promotes new modes of communication, fostered by various creative activities. It was further noted how LSW brought extended family members together and so allowed everyone to contribute to the person’s life story. Furthermore, it provides an activity for carers to undertake with their spouse or partner. Such collegiality can be achieved by allowing family members to express their hidden feelings, an opportunity which might not otherwise be created.

The events reflected on in LSW also recreated important memories and shared moments, as well as encouraging positive new reflections on these and on key relationships in the person’s life. This, in turn, has a favourable emotional impact on the person with dementia. Thus LSW was described by informants as the basis of everyday interactions and appears to have a proactive effect on those involved:

> *"I got friends (and family) to write things about me, and my daughter has written things about me. I'm still waiting for my son to do it, and my sister and they said they would, but at the same time I know what they think about me, you know, that it's there – not that I don't forget, but the day that it's not there, I can read it and. Yes, my daughter, she's written that letter. That made me cry because I didn't realise at the time how she felt, because like I said, she doesn't show her emotions" (Interview 4)*

> *"I think the idea of having a recorder if you have that close by when you're doing other things; we sit there, especially around the table (with family), we have our meal, and we just sit around the table chatting don't we. We did nearly till one o'clock the other day, didn't we? (these conversations were recorded)" (Interview 2)*

As well as family and friends, the responsibility for uncovering critical facts about the individual's life further rests with the clinicians because the person may find it difficult to communicate these things. This also enhances the collective efforts of all parties and results in an improved collaborative process. In this way, staff improve their personal knowledge not only of the person and their family, but also of other generations of the family, a process that then enriches reminiscence and life story activities. This aspect may be crucial because it may assist the family in supporting the person to develop their life story. Potentially, it results in a detailed record of the individual's life for both the person and their family to reflect on and use to support the individual's dementia journey. Additionally, a great deal of information is collected about the person during the assessment and diagnostic process, which could also be used to inform the person's life story book. Thus, LSW enables staff to work with and find out more about the person who has dementia and their life, and such knowledge assists in care delivery and is particularly useful in terms of providing individualised care:

> *"One of the strongest points of life story work that we've thrown up so far really is how it (the book) does inform the person's journey all the way through the dementia process really" (UM-PAR Group 5)*

> *“That's how it's intended to be used, really. As M said to X the other day, he said, oh, if anybody asks me now about my life, I'll just give them that book and say, there you are” (Interview 3)*

4.4.2 LSW enables this complexity to be overcome through enhanced collaborative and reciprocal communication between diverse individuals

As has been shown, LSW is a good starting point for building rapport between the person, their family and clinical staff, as well as developing new connections and enhancing friendships. The collaborative processes seem to be notably improved for all involved by undertaking LSW in the person’s own home. A number of reasons for this were suggested, including familiarity with and availability of mementoes and personal artefacts, and feeling more relaxed:

> *“It was decided that they would come to the house, they asked us what we would want, and I think it was unanimous that they would come to each of our houses. And that's what happened. And having her to yourself, it was like a one-to-one thing then, so it was easier really, and she helped, and looked at what we'd done, and said, all right, do this. As I said, she took it away, and then she helped me” (Interview 3)*
>
> *“It was nice to have X visit the house because you didn’t really want to go anywhere. We’d have been willing to, but it was nice to have her come to the house” (Interview 1)*

LSW further seemed to bring couples together and enhance relationships by providing meaningful activities they could undertake. Such activities ranged from the use of information technology to photographs to creative personal strategies. Indeed, it was noted that the family would have been unlikely to work together on new activities if the person was not undertaking LSW:

> *“The kids come over, and they dive through this bowl of photographs. We’ve got a couple of albums, haven’t we? They like looking through them, don’t they? They’re really interested because we’re going back before they were born” (Interview 2)*

> *“I had the box of photographs, but I never sat down and looked at them, and this gave me the opportunity to bring up all my pictures” (Interview 4)*

Peer support when undertaking LSW was also seen as helpful, with all participants valuing the meetings that were arranged by the LSW facilitators, combined with the unscheduled encounters at the dementia café with other people who had dementia and the mutual help and support generated. This type of support seems particularly valuable because it provides differing perspectives and views on the LSW process, even more so if the couples grew up in similar generations or neighbourhoods:

> *“At the service, yes that was with two other couples. So when we went there, we started off doing it, three couples together. Yes, it's a wonderful thing for that. Yes, that's where it started, a couple of other couples had put their names down and said they'd do it, and we discussed it together. The other thing is that whilst we were doing it, we would say to each other, have you done any more on your life story, can we talk about it, you know?” (Interview 3)*

> *“The dementia café actually helped, because they allow other people there, and it seems to be a good place to start it off” (Interview 3)*

One of the clinicians explained how people regularly re-enact aspects of their lives in everyday interactions, and thus LSW is a natural process in terms of personal communication. Promoting this type of communication is one of the main aims of LSW. Indeed, LSW was seen as meaningful in this regard, allowing deeper reciprocal relationships to develop between staff and person, friends, carers and family. In turn, this helps promote the more in-depth and personalised aspects of LSW:

> *"It's (LSW) something that's natural anyway in life isn't it? To form relationships, whether they be friends, family, working together as colleagues, or just acquaintances, you get to know a little bit about each other, to support those relationships" (X5-interview)*
>
> *"It's (LSW) almost one of those things that should just be happening almost naturally" (X4-interview)*

As a result of these more therapeutic and reciprocal relationships that develop between all involved in LSW, individualised practices and person-centred care are enhanced. This further seems to generate creative thinking on the part of all involved about which LSW strategies could be utilised that reflect personal preferences and that work best for the individual:

> *"And having her to yourself, it was like a one-to-one thing then, so it was easier really, and she helped, and looked at what we'd done, and said, all right, do this. As I said, she took it away, and then she helped me" (Interview 3)*
>
> *"She told me to do it whichever way I felt was the right way. And I thought, this is the right way for me, you know, a little book is not good enough for me" (Interview 4)*

In a similar way, LSW was considered to be a critical component of interpersonal communication and so is a good starting point for 'getting to know' each other, initiating conversations and building new relationships. Furthermore, the person, carer and staff all worked together in a reciprocal way to develop the person's life story. This seemed to manifest as a collaborative effort that was able to overcome any boundaries that existed between the practitioner and service user roles:

> *"Without life story, even in day-to-day living, we wouldn't be able to manage and communicate with each other, would we? Without knowing about each other" (X5-interview)*
>
> *"But then X (LSW facilitator) came round to see us, and she also put all the photographs in properly, on green backing paper. And I must say, that was*

> *wonderful because she helped me. I've still got to label up the photographs of what they are, we still intend to put some extra photographs in with it, and perhaps add to it in the future, but at least it's there if it's needed now, so I don't feel pressured into doing the rest of it, I can just do it when I want to" (Interview 3)*

Additionally, LSW was highly valued by the PAR group members, and this initiated a sense of sharing and collaboration within the group and a focus on re-introducing it in line with the original operating philosophy at the service. This seems to be an important observation because it links the use of LSW with person-centred care and change management. In this regard, the enthusiasm and commitment engendered through practice development groups can then be harnessed to influence organisational strategy:

> *"I am hoping the group won't finish after these five or six meetings, I am hoping you will agree to continue with the group and also implement Life Story Work in other areas as well, Life Story Work could be back up and run as you were hoping for in the early days (of the service)" (X9-PAR Meeting 0)*

The implications of promoting similar active collaborative working within the organisation on the part of the staff and the broader team are important too. These include the positive impact of participating in ongoing developmental projects and the correlating effect on clinical practice:

> *"Bringing the staff in for the focus (the project) is absolutely fantastic. Not only from the life story side, but I think in terms of having some research going on. I think that's really opened people's minds as to what is possible" (X4-interview)*

The use of LSW seemed to take on a variety of different meanings for all of the people with dementia, their carers and the clinicians involved in the process. This included: visualising reminiscences, prompting happy memories, enabling living in the present, helping people to cope with change, informing future care, regularly using the LSW ‘book’, appreciating LSW as a therapeutic process and reflecting on essential relationships. Furthermore, the positive emotions and mental imagery connected with visualising reminiscences and the associated reflection and enjoyment were acknowledged as another important benefit of LSW:

> *“I appreciate those relationships more because I've had time to sit down and think” (Interview 4)*

LSW also appeared to support the importance of ‘living well with dementia in the present’ following diagnosis, rather than becoming overly concerned about what the future may hold. In this regard, LSW and the methods utilised seem to be particularly helpful in improving the quality of life for the person, enabling them to adopt a different outlook on life, which focused more on the ‘here and now’, combined with relaxation, diversion and meaningful activity. Moreover, it allowed them to recapture and utilise skills that might have been lost or lain dormant:

> *“He’d taken it pretty much on himself and what he wanted to do. He, sort of, related his life story back into when he used to work on Excel and all these charts. It was amazing what he really did. And he felt like he’d gone back to his old self. He went up in his study. He’s cleaned all his study. He just wants that time on his own to get on, and he’s finding it really relaxing. Which makes a difference as well that he is actually so determined to do it. It was all sort of in (life) stages. All colour coded. Very sort of structured” (X3-PAR Group 2)*

> *“Having dementia has given me another life, a life that I didn't know; it's opened my eyes to these things. That is wonderful because it is wonderful that's happening to people who are diagnosed, the only thing is that there is not enough for people my age, it is more for the older generation. I think I'm the youngest. But I still enjoy it, don't get me wrong, because I am the sort of person that I'll talk to everybody. So it doesn't put me off, but it's nice as well to be talking to people who are on the same level as me” (Interview 4)*

Some of the clinical staff and the people with dementia and their carers expressed the view that LSW had a significant effect on informing future care, which may take place in a residential or nursing environment. However, in order to achieve this, the LSW activity used had to be readily available and accessible. Such a requirement appears to represent a critical consideration for the individual and their family, because staff who will care for the person with dementia in the future need to be provided with sufficient information to ensure that the service user can still be understood in the context of their life:

> *"I just think the book is more easily accessible than any other media. If you have got a DVD, and you haven't got a player no one is going to get to see it, but you have always got that book, it is there. They can access it better as well obviously further on in their journey" (XX-PAR Group 0)*
>
> *"Yes, and for M (my husband) to have a look back if he wants to. Or, as they've suggested, if you ever have to go into hospital for anything, you can take that with you, and you can keep, especially when you have dementia, and you forget things, it's nice to have that with you. And so I am going to, at the last pages, I'm going to put some more up-to-date photographs in that as well, and keep perhaps doing that, and perhaps make some notes about up-to-date things that he might like to see" (Interview 3)*

In a similar way, for some of the participants undertaking LSW, it provided the opportunity to leave a memento for their family and relatives. It was important that such a document detailed the personal achievements of the person during their lifetime but could also be used by care staff and relatives to help understand the person's individuality:

> *"I would like people out there, my family and my grandchildren, to know more about me than what's actually on my gravestone" (IE2-PAR Group 8)*
>
> *"If anybody asks me now about my life, I'll just give them that book and say, there you are" (Interview 3)*

There was also a growing recognition from all participants of the psychotherapeutic processes associated with LSW, such as life review. This awareness prompted a reflection on essential relationships that were both personal to the individual with dementia and existed for staff within a professional context:

> *"And then when they got stuck into it, as it were, a realisation it's quite you know, it's deeper than just getting a few photos together, it's much more about a review of your life, past relationships" (PA-PAR Group 7)*
>
> *"I'm into wise words and things like that, that are significant, that mean something to me, so I've put some wise words there. I've got wise words, me as a person, introduction to my life, my childhood, my working life. And as I've reflected on all the relationships, how can I put it, I've, well, you appreciate them more" (Interview 4)*

Among the PAR group clinicians, there was a recognition that, whilst the staff were generally very positive about using LSW, it further highlighted a need for mutual support. Ongoing supervision was important, owing to the emotional and unanticipated demands associated with facilitating someone to compile their life story:

> *"So, lots of hope I felt in this (PAR) group, and when you talk to each other and you've had a difficult hour with somebody, or, because it can be, quite emotionally challenging work for staff, of course" (PA-PAR Meeting 7)*

Furthermore, the practitioners enhanced their awareness of the multifaceted skills and knowledge required to help people write their life story effectively. Quite often the facilitation skills and background work needed only became apparent to the clinician as the support process was operationalised and the person started to recall life events. The LSW facilitators also explained that, in order to establish empathy and gain insight into the person's life and to understand their experience, quite detailed and extensive research was required in terms of investigating events and evaluating their importance:

> *"Sometimes you have to be a historian as well because people can't necessarily explain to you their experiences of significant events that may have happened in the world around them. So I end up spending quite a lot of time researching to actually try and understand what that experience might have been like, so you can try and understand, because someone may place themselves back at that particular point in time" (F1-PAR Meeting 3)*

In addition, the use of LSW seemed to help the staff recognise, question, prepare for and adjust to organisational change. This included a recognition of the values that underpin LSW and how these had influenced personal and professional perspectives on individualised care practices:

> *"The only thing with that is, once Journeys [Trust name for the forthcoming reorganisation] actually happens; whether or not changes that are made because of that will affect it. But I can't see why it would do because I think at the end of the day, it's such an important area that needs to continue" (X9-interview)*

Whilst some people found having the parameters of the project brief useful to work to, there was a risk that the person could feel under pressure to 'complete' their LSW within the established timeframe for the project. Consequently, it was made clear that ownership rests with the person, and they should be enabled to compile their life story in any way they wish and without pressure to finish it (from staff, family or the project deadlines). To ignore this principle would undermine the philosophy behind LSW. The staff were aware of this risk and so ensured that this did not impact on their support and facilitation work with the person and their relative. However, it is possible that the project deadlines and competing priorities for the person with dementia and their carers did have an impact on the uptake of LSW:

> *"So the sessions were sufficient, it was because X did that for me if you understand me? Otherwise, I might still be working on it" (Interview 3)*
>
> *"And I think some people don't want to get involved in research. So I think there's five or six factors that does slow it [referrals for LSW] down a bit" (X9 interview)*

Understandably, some participants found it difficult to fully appreciate the potential benefits of undertaking LSW before embarking on the process. This was borne in mind by the LSW facilitators, and so a judiciously constructed and reflective introductory shared group session to LSW was provided, using a range of individualised techniques:

> *"Another theme was you talked about difficulties of patient carers to see the benefits of life story work in advance. Some didn't seem to be able to grasp what it meant, what it actually firmly looked like. There was no firm template for it, which there shouldn't be, but it's hard for people to know what it is and how it will help them" (PA-PAR Group 7)*
>
> *"Actually, when they started, I think it was quite good that it was a group because when they started talking about things, they could see that there were different things that actually were important to them" (X2-PAR Group Meeting 1)*

In summary, despite the complex nature of LSW and its utilisation for diverse reasons, LSW reportedly had the potential to unite the individual with dementia, their family, the clinicians and the dementia services in a standard and shared activity that offers substantial mutual benefits. These benefits include enabling all concerned to contribute to the person's life story by promoting positive reminiscence, improving life quality, enhancing person-centred care, and aiding the person to live well. This, in turn, improves interpersonal relationships for all, help to restore lost skills for the person who has dementia, and enhances the specialist skills of the clinicians. Peer support and undertaking LSW at home are also vital. Finally, the LSW relationships that emerge can influence organisational strategy through informed practice.

4.5 Life story work is a strategy for providing post-diagnostic support

"We needed time to come to terms with the diagnosis and how it's going to affect us" (Interview 2)

This theme describes the challenges and potential value of using LSW as a component of PDS for the person, staff, carers and organisation. The problems encountered included a lack of continuing PDS and, hence, LSW was used to address this omission. Additionally, people were still adjusting to the diagnosis, and this manifested as a grief reaction. In this regard, LSW was utilised to help them cope with these feelings. Furthermore, the person with dementia and their carer often felt overwhelmed by the volume of information given to them. Staff often wrongly assumed that relatives were ready to take on a caring role. Lastly, personal pressure on the part of carers to undertake LSW was generated by a growing awareness of the benefits LSW might bring.

The clinicians did acknowledge that LSW might not necessarily be the right intervention for everyone so soon after diagnosis. Nonetheless, the value of undertaking LSW at this time was that it seemed to assist people in adjusting to a diagnosis, help them to cope with grief and loss, offer a means of providing PDS, and prevent people from feeling overwhelmed. LSW also reinforced the identity of the person, provided staff with an additional evidence-based therapeutic option, and helped relieve the burden being placed on carers.

4.5.1 LSW as part of a post-diagnostic strategy prompts the individual with dementia, their carers, clinical staff and the organisation to reflect on the support needed and the associated challenges

PDS, or at least its central components such as a named contact and consistent support, was initially seen as an integral part of the services on offer at the service. However, owing to the volume of other work now undertaken, these were no longer considered viable options or a priority by the service or the organisation, a situation that was seemingly accepted by the clinicians:

> *"That's exactly what we said when the dementia service initially, came into fruition. They would have a named nurse that would remain with them for their whole journey, and that that would be somebody that would be in touch regularly, and then even to the point that if someone eventually had to have an admission to the ward, we would be there when they came into hospital to greet (them), that type of an image, and of course, that's not been sustainable" (PA-PAR Meeting 6)*

Yet, by delivering LSW soon after the person with dementia had received a diagnosis, several unanticipated consequences became apparent from the views expressed by the person with dementia, their carers and staff. These unpredicted outcomes also had implications for the organisation because the participants were surprised to discover that they would be discharged, rather than being provided with longer-term support:

> *"And he (the Consultant Psychiatrist) said to P (the carer's wife) that, as far as I'm concerned, I'm going to discharge you. And I may call you back in a year's time or two years' time, but I'll do that through the GP" (Interview 2)*

As mentioned above, after a diagnosis of dementia, although some were offered short-term therapies at the service such as CST or carers' support groups, generally people were discharged back into the care of their GP until either a 'crisis' developed or their symptoms worsened. In this regard, the lack of available PDS was highlighted as a problem. Staff often assumed that charities should be providing the help and support required, but in fact they could only offer limited services at this point:

> *"Unfortunately, it (the services) are either at the beginning or at the end, and there's not a lot for those in the middle. I'm not even sure that the Alzheimer's Society really offers enough to support all these people. Because they've all got waiting lists as well" (X4-interview)*

For one participant and their carer, the process of discharging them back to their GP resulted in an unfortunate misunderstanding. Because his wife had been discharged, the carer thought that his wife had not been diagnosed with dementia. The misconception only came to light after they were invited to participate in the LSW project:

> *"So we thought, there's nothing wrong (but) then we got a call from the dementia service" (Interview 2)*

Throughout the implementation of the LSW process and during the evaluative interviews, it became apparent that the person who had dementia and their carers were still adjusting to the diagnosis and the implications of what it meant for them. This was understandable because they would only have received the diagnosis shortly before the LSW project commenced. In this respect, the conversation often digressed from LSW, and people talked about their fears for the future, the lack of treatment, feeling isolated, the possible effects of dementia such as short-term memory loss, regret at the loss of abilities, and the consequences of dementia for their family:

> *"I think sometimes still that's so early, it's hard for them to think about too much into the future what is going to happen because all of those processing the diagnosis and the emotional impact that that has and the changing roles between family members of people taking on more of a supportive or caring role" (F2-PAR Meeting 3)*
>
> *"And my husband is the one that sort of compiled it, because I didn't know how to do it, and it upsets me, because I've always been able to do these sorts of things, and now I can't. I couldn't sit down and write" (Interview 4)*

Couples also found that the number of forms to be completed and the volume of information on dementia given to them following diagnosis by staff, other services and dementia charities was overwhelming and even disorientating**.** Less information was required**,** and it needed to be provided in different formats and over a more extended period of time, combined with more personalised support:

> *"And I think in the end you go stir crazy about forms and language. It just is a blur. So when you say have you seen those papers and have you read them? Indeed, we must have done, but there is so much that was a shock to us within a short period of time it was like where did all this information go?" (Interview 1)*
>
> *"To be perfectly honest, you can't take in all the information, not at once; it's got to be a slow drip thing" (Interview 2)*

The adjustment also manifested in the observation that undertaking LSW so soon after diagnosis was difficult because there was 'so much going on'. Indeed, some participants felt pressure from others to participate in LSW because they were aware of the benefits it might bring:

> *"There were times when I did feel pressured about doing it (LSW), although they said to us at the service, don't feel pressured, it doesn't matter, you do it as and when you want, and they were fantastic. But I knew it was something I should do, and have ready if (my husband) needed it or wanted it, and so I felt pressured that I had to do it" (Interview 3)*

The data showed that psychological reactions to receiving a dementia diagnosis seemed to be manifested in the form of coping mechanisms. While these do help to protect the person in the short term, they can also impact on interpersonal interactions and can occasionally become maladaptive. In the absence of PDS, the use of LSW at this point appeared to tap into this phenomenon, and in this regard, it was noted that, immediately following a diagnosis of dementia, the person and their carers seemed to be in the initial stages of grief, with reactions such as denial, shock, anger and aggression being observed or expressed:

> *"Some people do go into denial. I met a gentleman when I first started when I did an information meeting, and he was determined there was nothing wrong with him. He wouldn't have wanted to share anything about himself probably there and then, because he was in denial" (X5-interview)*
>
> *"I actually thought I might be lynched. It probably came from that place actually, being angry about the diagnosis and maybe having the first opportunity through this (LSW), to actually talk about the diagnosis" (X2-PAR Meeting 1)*

Owing to the lack of continuing help after receiving a diagnosis, during the course of facilitating people to undertake LSW it became apparent that it was also being used by the person who had dementia as a form of PDS. Additionally, LSW appeared to be being utilised by both carers and the person to help cope with feelings of grief and loss. This was influenced by the fact that undertaking LSW was the person's first contact with the service following diagnosis and their first attendance at the service for an information meeting. The type of help being sought in this regard included assistance to reflect on the future, support with adjusting to a diagnosis, advice on how to access the range of services available, and the need for consistency of care worker input:

> *"One thing that I'm thinking about at the moment is that we've inadvertently tapped into the support that's needed for people after discharge; I mean, almost providing a service that's not necessarily there in a consistent way after diagnosis" (MO-PAR Meeting 6)*

In a similar way to the acknowledged lack of PDS, staff often assumed that family members were ready to take on a caring role even though they had received little in the way of preparation for this role or explanation of what this might entail, or even any choice in it. Placing such expectations on them only adds to the burden experienced by carers and close family members:

> *"Some people don't like being called carers or caregivers because again they don't necessarily feel it's a choice that they've been given. Some people think it's something that they've been thrown into and are again maybe struggling with that" (FI-PAR Meeting 3)*

On the other hand, some of the clinicians were mindful of the pressures faced by carers and other relatives and so were keen that LSW should not add to this burden. However, it did seem that on occasion LSW might have been contributing to the difficulties faced by the relatives and so the PAR group needed to consider whether there was a different way of undertaking LSW that prevented it from becoming onerous:

> *"I wonder if there's a way of making it seem less of a chore on top of everything else that's going on or whether there's a way to make that easier" (F1-PAR Meeting 3)*
>
> *"I think because it felt at the point where we, kind of, got started that there was, you know, that the people whom we were pushing (for LSW) were carrying a huge weight from other areas in the service, and I think we were*

> *trying to be a bit protective, so that you didn't have to have another rock in your rucksack, if you like" (PA-PAR Meeting 7)*

It was further acknowledged by the staff that LSW might not necessarily be the right intervention for everyone so soon after receiving a diagnosis, and that this might explain why only a relatively small number of people undertook LSW or participated in the research during the initial stage. Indeed, the value of LSW at this early point was not universally apparent to staff, people and carers and thus some did not want to become involved in the LSW project even though they were interested in LSW:

> *"It's got to be right for them at the right time; they've got to have done a substantial part of the life story work, they've got to have been through all three sessions. And I think some people don't want to get involved in research. So I think there's five or six factors that does slow it (referrals for LSW) down a bit" (X9 in S-interview)*
>
> *"Certainly, some people that I've explained it to, it's a case of, 'Oh yes, life story.' Then it's a case of, 'Oh there's actually some research going on at the moment.' Then it's a case of, 'No, I don't want to be involved in that thanks.' Very definite opinions, where research is concerned" (X5-PAR Meeting 1)*

Finally, a note of caution was sounded by some clinicians in respect of utilising LSW for PDS because LSW was also time limited in terms of the support provided by the project. Correspondingly, once the research ended, the participants would go back to being unsupported, and they and their family members may well experience loss as a result. Potentially, this would make it similar to the other therapies on offer at the service in the sense that all are short-term:

> *"You see you have got to be careful though because they enjoy the contact with us and you don't want them to get stuck with their bat and then have another loss, because she felt the loss when we withdrew her from the CST Clinic" (XX-PAR Meeting 0)*

4.5.2 LSW enables all parties to overcome these challenges by working with a shared set of values.

It was noted that undertaking LSW soon after receiving a diagnosis of dementia seemed to help some people adjust to the impact that this had, particularly in respect of focusing on the present, and being able to ‘live well with dementia’. In this regard, LSW seemed to instigate personal reflection and insightful responses on the part of the person with dementia and their carers. In addition, the use of LSW at this point appeared to have a positive influence on the person’s care and their thoughts regarding potential longer-term needs. This seems to be an important observation because, whilst LSW helped people to reappraise the present, the need to consider their future care was also frequently mentioned:

> *“I think there was also a bit of unpicking about different people’s perceptions of what the future could hold. Although it was still focused on the life story and getting people started, we had to do that work before we could actually even talk about it” (X2-PAR Meeting 1)*
>
> *“It’s an ideal time for planning and everything, so it almost kind of mixes in with your advanced care planning and everything doesn’t it? So, yes it’s the best time for it” (X4-interview)*

Although not everyone was initially ready to undertake LSW, it did appear to help some people adapt to and cope with the early challenges that a diagnosis posed. Indeed, the impact of the diagnosis was mentally re-examined by some participants in a way that allowed them to focus on the present in a more positive light. Thus, the LSW process seemed to be the trigger for this apparent reconfiguration, a phenomenon that appears unique to this study and demonstrates the enhanced value of using LSW. This aspect also included considering care needs and raising awareness of potential support services:

> *"I think, that we generally see people for information meetings after diagnosis to support them and guide them in what's available out there. In my experience, people are still absorbing and still don't really understand, so, you know, I have to continually explain what it is (LSW) again" (IE1-PAR Meeting 8)*
>
> *"I just put a lot of reinforcement in that he can live well with dementia, and it may limit some things, but it isn't going to stop him living his life" (X3-PAR Meeting 2)*

There was also a potential benefit in using LSW as a part of a PDS intervention for the person with dementia, staff and the organisation. Importantly, at this early point, the individual was able to take the lead and be fully involved in the compilation and sharing of their story. This observation may be pertinent and unique and gives further credence to the early use of LSW. In this regard, LSW seemed to help the person adjust to and cope with the initial challenges that a diagnosis posed:

> *"I completely understood why you would want to sit down with people after diagnosis and start it (LSW) from there because they could share it with you themselves. Whereas the people that we work with on the ward a lot of the time, because they're further down their journey, you have to get the family members to share. Although the person might be able to still try and talk to you about their experiences, once you've found that information out and you are kind of prompting them, I don't think it's as rich as if they share it themselves" (X5-interview)*
>
> *"This gave me the opportunity to bring up all my pictures" (Interview 4)*

A further advantage of using LSW at an early stage was that it seemed to reinforce the identity of the person as an individual in the context of their life and also helped the participants to realise that they still had a positive future even though they had been diagnosed with dementia. In some ways this was an expected part of using

LSW, but it also serves to illustrate how LSW enables the person to appreciate their individualism, personality and life attainments. The timing of the diagnosis of dementia at the initial stage also seemed to have an influence:

> *"But he felt like he'd got lost in amongst all of these diagnoses. And, actually, the life story would reinforce who he is and that he is a person with these diagnoses, but fundamentally he is the same person" (X2-PAR Meeting 2)*
>
> *"It sort of comes across like that and then when we say about, 'It could be a tool for the future', they're a bit like, 'Why, when we haven't got a future.' And in fact, we're sort of saying, well, yes you have" (X3-PAR Meeting 2)*

Some of the participants emphasised the importance of taking as much time as necessary to review and reminisce about their lives, encapsulated in comments such as "there is no rush". This element of 'taking time' seems particularly important as an underpinning value and subsequent influence of LSW. Bearing this observation in mind, the informants also mentioned feeling that "LSW is never complete", and consequently it will only be undertaken when the person with dementia is ready to begin the process, and at their own pace and direction:

> *"I'm only a layman; I'm just saying from a personal point of view that if they gave us time to let the thing sink in, from our point of view, that would have been better" (Interview 2)*
>
> *"A lot of people want to create a life story for their family members after they're not there, as a kind of reminiscence tool, if you like" (PA-PAR Group 6)*

The person who had dementia and their carers described how they utilised a variety of methods to 'look back' over their lives. Indeed, one of the benefits of utilising and integrating LSW as part of PDS was that it enabled the person to reminisce in a positive way about significant events in their life. Furthermore, the uniqueness of the

LSW strategies utilised, influenced by the person’s own life and experiences, was particularly noticeable:

> *“Just decided to start in his school days really, and I thought we'll just go back to that. And then I said you can cover your being evacuated, because that was interesting, and the fact that he was evacuated in the war, and the wartime is something that he often talks about, and so I thought it was nice to do that. And he was one of the fortunate people who went to a very nice home when he was evacuated, didn't you?” (Interview 3)*
>
> *“And my husband is the one that sort of compiled it because since I've been diagnosed, I don't see it, I'm not looking on the negative side. I'm not; I'm living a day at a time, enjoying everything that I do, and I'm not thinking about the future. I'm not, because the future, I could be bad tomorrow, or I could be bad in ten years' time, we don't know, so why worry now about something that might happen in ten years' time, or maybe tomorrow” (Interview 4)*

Some people did ‘look back’ with a feeling of regret but also an acknowledgement of the positive feelings that LSW evoked combined with an awareness of the many available methods for prompting meaningful reminiscence. The use of LSW in this way seemed to provide a handy communication tool that could then be used to enhance relationships between all parties and with external care services:

> *“Words are a lot more difficult for people as they go along on their journey, so pictorial things and objects are really, really important visual prompts for people to be able to share with you their thoughts and feelings. Even if they can’t express it verbally and with the words they want to use” (X5-interview)*
>
> *“Sometimes it happens that you hear a particular piece of music and it just reminds you of a particular time and place. Or even smells sometimes like a cooking smell or aroma of food can take you back to a particular time and place as well. I guess sometimes when you're sitting, maybe thinking about something else, that a memory might come back, it might be a song, or it might be something on TV” (Interview 2)*

An additional perspective on receiving a diagnosis involved the way in which individuals who had dementia required ‘space to adjust’ before a range of therapies was offered by the service. Time was needed to allow the implications of the diagnosis to be reflected on and absorbed. If sensitively facilitated, it seems that LSW can assist with diagnosis adjustment and help those concerned to develop coping strategies. In turn, this seems to protect people with dementia from becoming overwhelmed by the range of services available and allowing time for the diagnosis to be reflected on, which constitutes another important finding. The reflective elements of LSW then seem to enable the person to develop a more independent perspective that helps the individual with dementia to more effectively navigate the various care services:

> *“I think 12 weeks is a bit tight to get it all done in. It just seems, a lot of the time, they’re a bit, like, well, I want a bit longer to try and get something done. And as much as I say, well, it is part of the research; it needs to be on this amount of time, they’re still a bit, like, oh, well, I do need longer. I can’t, sort of, rush this. Which is totally understandable” (UF3-PAR Meeting 5)*
>
> *“Maybe life story work helps them face the diagnosis; you can’t separate supporting people. You can’t just go in and get them to coldly write their life story; it’s all about support, isn’t it, obviously” (PA-PAR Meeting 7)*

Another essential facet of undertaking LSW was helping to cope with the grief and loss associated with a diagnosis. This is a skilled process, but if handled sensitively by the staff, then positive outcomes can be attained. Therefore it appeared that clinician awareness and subsequent careful facilitation could potentially be an integrative aspect of the LSW process for staff and help them to develop their own skills. Thus, LSW also seemed to provide staff with an additional evidence-based therapeutic option with which to support people post-diagnosis:

> *“I guess certain people react to it (the diagnosis) in different ways. It also depends on whether you give the space for that grief to be there and actually to hold that grief whilst you are doing that process. That you grieve through the process of doing life story you can give the opportunity to grieve and the hope that there is still a future. But I think that is when it becomes much more of a complex task than just writing a life story” (X2-PAR Meeting 2)*

It was also reported that LSW seemed to have the potential to help relieve the burden being placed on the family carers. In respect of this, the clinicians explored the fact that the ‘burden process’ had to be worked through before a more supportive and therapeutic LSW interaction could be achieved. It was further noted that undertaking LSW at an early stage was innovative and useful to both carers and the person with dementia:

> *“So I think it has, you know, it (LSW) has a very therapeutic effect for carers, but specifically where people are, you know, probably lack capacity” (IE1-PAR Meeting 8)*
>
> *“There’s a concept that’s quite often talked about, and it’s called rupture and repair. Sometimes it’s something that we all have to do all the time because sometimes we do stumble and use language that isn’t necessarily helpful and what you do is then adjust what you’re doing to repair that rupture. It’s something that happens all the time” (F1-PAR Meeting 3)*

Overall, it became apparent that all of the challenges noted earlier within this theme were ameliorated by the use of LSW. In particular, it was documented that everyone utilised the LSW process as a form of PDS, to cope with grief and loss, and as a means of personal reflection on the diagnosis. LSW data was also used in new ways such as providing support in the person’s home, re-emphasising the identity of the person and alleviating the burden on carers. Furthermore, the clinicians utilised LSW as a basis for evidence-based and therapeutic practice. All aspects of LSW were valued highly, so much so, that an interesting perspective on PDS emerged, namely that some participants agreed to participate in the project as a ‘thank you’ for providing a PDS service. This was also influenced by the anticipation that their contributions and experience would help to improve the support on offer:

> *“So, I think there was lots of feeling in terms of the research of: this is something we really want to do because the services have provided so much support for us that, actually, we want to do something to, kind of, help that” (X2-PAR Meeting 2)*

4.6 Life story work is a framework for managing boundaries between staff and service users

“I think it’s something that to start with we have been giving a bit of a health warning so that people are prepared for that” (x1-PAR Group 2)

This theme explains how several boundaries were identified and described by all participants. These related to personal, professional, organisational and structural factors. For the individual with dementia, the need to keep some personal issues private was a significant consideration. The clinicians also preferred to maintain confidentiality on such matters as their own personal life story and further mentioned a requirement to preserve professional boundaries, a factor which had the potential to mitigate against the development of close personal rapport with the person with dementia. Similarly, for the people who had dementia and their carers, staff arriving on and keeping to time, adopting a professional manner and meeting at home were important. These factors exemplified the requirement to utilise a structured approach to LSW. In addition, it is possible for personal boundaries to be breached or moved when the person has been diagnosed with dementia because they are more vulnerable emotionally and psychologically. Organisational boundaries can also be affected, in particular, the resources and specifically the time available to support the project and the service priorities.

LSW enabled these boundaries to be managed by utilising structured approaches to LSW, and by staff adopting a professional attitude and developing person-centred and flexible strategies in respect of gathering personal information, as well as by using the person’s life story to inform the individual’s care journey. In the next section, the boundaries that were reported by informants to operate within the care services available are outlined.

4.6.1 LSW facilitates recognition of the importance of personal, professional, organisational and structural boundaries

Some people who had dementia took the view that certain material was too personal or private in nature to record, whilst others decided that some of the issues discussed were not to be made available to everyone or should only be mentioned briefly. This was an important consideration and illustrates one consequence of undertaking LSW, which is that often life events such as previously unknown relationships are uncovered, or personal trauma may even be brought to light as a result of an LSW conversation. The following comments prompt consideration of whether it would be more appropriate for some aspects of the LSW book to be recorded in a closed section, but they also highlight the importance of the positive recollection of memories that LSW evokes:

> *“I wouldn't show this to everybody because I think this is very personal, and to close family-this is for me. So things that might be a little bit difficult to talk about, I have only just briefly mentioned them because sometimes it's not good to be reminded of the past and if there had been anything very upsetting. Because it's something you want to look back on and enjoy, some things before we met, I didn't know” (Interview 4)*

> *“I saw somewhere where it asked whether you got upset by any of it, all this sort of thing, no, we didn't, because for one thing, if there had been anything very upsetting, I doubt whether I would have bothered to write it in. Because if it's something you want to look back on and enjoy. So no, we just did things, as he spoke about things, I tried to put them down, what I could get him to talk about, really. Because some things obviously in his earlier life, before I met him, I didn't know” (Interview 3)*

The difficulties described above were resolved by using a managed LSW strategy of briefing people with dementia and their carers about these potential problems and then focusing on positive reminiscence and enjoyment rather than evoking difficult memories. Also, some events could not be recorded because these occurred before the current marriage or relationship. Additionally, if anything was upsetting or had the potential to make the person feel uncomfortable, it was not recorded. Hence, painful memories were avoided by exploring memories and events that could only be recalled in a constructive way:

> *"I think it's something that to start with we have been giving a bit of a health warning so that people are prepared for that. So, that it doesn't feel comfortable to start down this line and not actually say to people, by the way, there is a risk. You know, we all have nice memories and some difficult experiences and when you reflect on your life both of those are going to be there in the room" (X2-PAR Group 2)*
>
> *"I go through it (the life story book), and I think, oh, that happened, it brings up more things, and I want to record everything. And my husband says to me, you've got to stop somewhere, and I said to him, I don't want to, I want to have everything there about my life" (Interview 4)*

Moreover, as the participants regarded LSW as a naturally occurring process, a variety of creative approaches were used to recreate or capture memorable moments from the person's life. Such re-creation was enjoyable rather than evoking 'difficult' or painful memories for all involved. Indeed this type of memory was 'avoided' because the intention was to look back on more meaningful moments. Some aspects were not explored because these occurred before the couple met:

> *"We've not been writing it down. We've been over one or two things that happened when I was younger, different things when we were little because it was '37 I was born, so I went through the war years" (Interview 2)*

An interesting perspective on the dilemma of whether to disclose personal information or memories that were potentially difficult was also offered by the clinicians. In this regard, the staff preferred to maintain privacy on such matters as the sharing of their own personal life story. The wish not to disclose was mentioned by the team and was dealt with by maintaining a ‘professional’ distance or by enforcing professional role boundaries:

> *“But it maybe be quite useful for yourself to actually have those boundaries where you’re actually saying, Okay, we have an hour. Make them clear that there’s an hour” (X10-PAR Group 2)*

4.6.2 LSW enables the individual with dementia, their carers, clinical staff and the organisation to manage these boundaries by evolving innovative strategies

The above-mentioned ‘maintenance of professional boundaries’ and the associated structured expectations of the clinicians were, however, important to the person who had dementia and their carers. It was mentioned that staff arriving on and keeping to time and maintaining a professional manner throughout the LSW process were regarded as particularly important. Indeed, it was further emphasised that the clinicians’ need to ensure the pressures associated with their own workload should not impact on the therapeutic encounter. Again this appears to constitute an important observation because the carers already have concerns of their own and so the professionals need to ensure that the therapeutic encounter remains their central focus:

> *"She was always on time. She never did the 'I'm running late', or 'this is my angst of the day'. You had no idea how to work that, what would one call it, that file. So she has a lovely manner" (Interview 1)*

> *"She was very practical about it all. So yes, definitely I found having X here was brilliant" (Interview 3)*

It is also possible for personal boundaries to be transgressed or moved when the individual has been diagnosed or when dementia progresses. This can result in the person becoming more vulnerable and hence reliant on close relatives and staff for psychological support and reassurance. In turn, this can impact on their confidence and independence, which may cause longstanding relationships to change with a corresponding effect on role expectations and autonomy. The relatively structured LSW approach used within the project seemed to help offset some of these potential difficulties but it needed to be combined with personalised guidance that enabled the person to develop their own strategy for undertaking LSW. Similarly, awareness of these inherent difficulties on the part of the clinicians is essential:

> *"Offering people guidelines and allowing them to do it because it's their life story, it's not us writing it for them. So I think it is about having a variety of tools (and templates) that you can offer and giving the guidelines for it" (IE2-PAR Group 8)*

> *"You have always got that book, it is there. They can access it better as well obviously further on in their journey" (XX-PAR Group 0)*

The structured approaches described above and awareness of the phenomenon further require the provision of personalised support and guidance. This was attained by meeting and undertaking LSW at the person's home (or providing them with this option). LSW was also acknowledged as an intensive process, and so the time allocated for the LSW facilitation support meetings allowed detailed and in-depth discussion of the person's life events to be undertaken:

> *"It was nice to have X visit the house because you didn't really want to go anywhere. We'd have been willing to, but it was nice to have her come to the house" (Interview 1)*
>
> *"You're supposed to be there for an hour, but you're there for two hours because you can't go. It's too important to go, isn't it" (PA-PAR Meeting 7)*

Clearly, time management issues also linked to the need to consider organisational boundaries critically. This issue is examined in more detail under the theme: 'Life story work is a mechanism for resolving inflexible paradigms in working practice' but deserves particular mention here because of the need for the Trust to allocate sufficient resources to support the project, which in turn might enable service priorities to be achieved. If organisational boundaries of this type are not considered prior to the project commencing and reassessed as the study proceeds, it can result in a lack of team commitment and even covert tactics for undermining the project aims:

> *"I sometimes think when it's brought up, a bit of them are like, 'Well we were going to be involved, and then we were shoved out, and we're not involved' I think there's a bit of resentment there that they want to be involved, but they got pushed out and not allowed to be" (X3-interview)*
>
> *"They're quite happy just leaving this going on at the sideline and it's like a chaotic busyness going on outside" (F3-PAR Meeting 3)*

Informants said as well as allocating sufficient time and using an appropriate structure, adopting a person-centred and flexible approach to LSW is another vital aspect of the facilitation sessions. This is described in more detail under the theme: 'Life story work is a mechanism for resolving inflexible paradigms in working practice', but also emerged as crucial to the effective management of the LSW boundaries, such as the need for compassionate orientation towards the person and the establishment of empathy:

> *"I think we were too prescriptive when we set the service up, you know, we will offer you this, and I think we probably wrongly had the vision that everybody would have this fantastic book of, you know, their life story, which I think, with hindsight, was too prescriptive. But I do think that the practitioners use the principles of life story work, that you know that's going to help relieve that sort of agitation or, you know, upset" (IE2-PAR Meeting 8)*

Another issue concerned the various boundaries that existed between the many different services that are involved with supporting the service user and their carer. The person with dementia may concurrently be in contact with statutory, voluntary, private and charity sector agencies, all of whom operate in different ways and within different structures. This could prove problematic for the person. However, the use of LSW in this context was reported by informants as helping to overcome some of these problems by establishing an information resource about the person which could then be used to inform the individual's journey and experiences of dementia care:

> *"I'm like; your life can be well enough, really promoting it, and then I'm like; Yes, but this could help in the future if you're go into a care home or hospital or whatever" (F2-PAR Meeting 3)*

In conclusion, several issues impacting on boundaries were identified, including: a requirement to safeguard personal information about the individual with dementia; staff wanting to keep their life stories private; the impact of professional boundaries; the need for effective resource management; the need to adapt to changing personal boundaries after diagnosis; and the effect of service boundaries. LSW was shown to provide a useful framework for managing these. In particular, the use of professional and structured yet flexible strategies for undertaking LSW emerged as effective approaches. Additionally, the utilisation of a person-centred life story strategy to support the service user’s care journey was shown to be important.

4.7 Chapter summary

This chapter has presented the four themes that were derived from an analysis of the research interviews, PAR group recordings, the investigator’s field notes and the PAR group observer’s notes. As previously mentioned, the themes were identified and coded by utilising the MAXQDA software and Miles and Huberman’s analytical framework; the four themes generated from the data are listed and summarised below. The implications and application of the above four themes are discussed in chapter five.

Life story work is a mechanism for resolving inflexible paradigms in working practice

The paradigm that operated at the service when this LSW project started was based on the medical model of care and this had a significant impact on the therapies, interventions and processes that were delivered. The omnipresence of this model and how it was promulgated throughout the service impacted on the perception of the service by people with dementia and carers. As a result, LSW was no longer seen as a priority. However, after the re-introduction of LSW, changes in the values and beliefs of the clinicians, people with dementia and their carers were noticed, including widespread awareness of the person’s life journey and their care needs. LSW appeared to enable the individual who had dementia to reactivate dormant abilities, and they also placed a higher value on living life in the present. Furthermore, carers had a greater appreciation of their partner’s life and this enriched their relationship. Additionally, after the re-introduction of LSW, changes to the organisational systems and the processes employed by the team were documented. Overall, this led to a paradigm change for all concerned and resulted in an enhanced person-centred care culture and innovative practice in organisation-wide LSW activity groups.

Life story work is a means of bringing people together in a collaborative manner

Several difficulties related to completing LSW were described, including a need to prepare people for LSW in a personalised manner and for clinicians to be suitably skilled in facilitating innovative and creative LSW approaches. Despite the complexity of LSW, it proved possible to overcome many of the extant problems and be proactive in relation to potential problems, resulting in individuals who have dementia, their relatives and friends and the clinicians working together in a collaborative way. This brought about positive outcomes where all became involved in writing the person’s life story. In turn, this had a positive impact on the broader organisational structures and the policies of the Trust and clinical team. It also resulted in the development of new knowledge and skills for all involved. LSW further took on differing meanings for everyone, including the positive utilisation of reminiscence, helping the person with dementia to ‘live well’ and enhancing quality of life.

Life story work is a strategy for providing post-diagnostic support

The challenges and potential value of utilising LSW for the staff, the person with dementia, their carers and the organisation as part of a post-diagnostic intervention have been described. These included a lack of continuity, which led to LSW being used to provide this type of support. In this regard, it was observed that LSW was used for post-diagnostic purposes, and this helped people adapt to a dementia diagnosis and their subsequent grief reaction. The information given out about dementia by the service was frequently perceived as overwhelming and provided in unhelpful formats. The needs of carers were not consistently considered, but LSW was again found to be helpful in relieving the burden experienced by close relatives. LSW was also believed to be very helpful in providing the right type of support throughout the post-diagnostic period because it enabled person-centred care to be delivered in a skilled and evidence-based way.

Life story work is a framework for managing boundaries between staff and service users

A number of important interpersonal, organisational and structural boundaries were described by all participants. These included a wish to keep some personal information private on the part of the person with dementia, with the staff preferring to do likewise, in order to maintain professional boundaries. Whilst this had the potential to impede the development of empathy and rapport, the importance of clinicians maintaining a relatively structured approach to LSW and a professional demeanour was highlighted by both carers and service users. Furthermore, when a person has dementia, this may result in them becoming more vulnerable psychologically and so could have an effect on personal boundaries. Organisational boundaries, such as the amount of resources and staff time available to support LSW, may also have an impact. In respect of these boundaries, LSW enabled the staff to maintain a professional attitude and deploy person-centred and flexible strategies, thereby using the person’s life story to inform their care experience and help them to access the available care services.

Chapter 5: Discussion

5.1 Introduction

This chapter is presented in two parts; an examination of the study findings in context followed by an explication of how the PIC model emerged from the study themes.

Part one provides a discussion of the findings and is organised around the four themes generated from the findings:

- Life story work is a mechanism for resolving inflexible paradigms in working practice
- Life story work is a means of bringing people together in a collaborative manner
- Life story work is a strategy for providing post-diagnostic support
- Life story work is a framework for managing boundaries between staff and service users

Each theme provided a unique perspective on LSW, and all have implications for the practice and theoretical underpinning of LSW.

Part two concerns the evolution of the PIC model and explains the impact of the organisational and cultural difficulties experienced. This is followed by an outline of how the findings further supported the integrative use of the concepts of PAR, innovation and creativity and the culture of care to achieve high-quality person-centred care. These concepts provide the rationale for the proposed ‘PIC Model’, a framework to be used to plan, implement and evaluate person-centred dementia care initiatives. This model ensures that the individual with dementia and their life story is integral to any person-centred intervention.

5.2 Part one: Analysis of the findings

This part of the chapter discusses the study findings; the outcomes of the themes are informed by reflective comment and compared with relevant literature and research.

5.3 Life story work is a mechanism for resolving inflexible paradigms in working practice

There were many benefits of utilising LSW identified by the people with dementia, their carers, PAR group members, the broader clinical team and the managers in the Trust. In this regard undertaking LSW led to transformational change for all participants.

5.3.1 The positive impact of LSW on care quality

The findings identify that LSW was perceived by those involved, as an exemplar of person-centred dementia care which had the potential to support individualised care practices, care formulation and evidence-based practice. This is comparable to the findings of Damianakis et al. (2010), McKeown et al. (2010) and Gridley et al. (2016) who noted the enhanced quality of care for the person with dementia and their family brought about by the introduction of LSW.

In the study, LSW was used as a specific therapy and it was perceived as having potential integrative use in home treatment and crisis work where it could help initiate therapeutic relationships. Research by Kellett et al. (2010) and Subramaniam & Woods (2016) had previously noted that LSW could enhance person-centred care and inclusive care practices. Similarly, improved partnership working between care staff, people with dementia and family carers has been observed by several researchers (Buron 2010, Kellett et al. 2010, Ingersoll-Dayton et al. 2013, Doyle 2014, Berendonk and Caine 2016).

Everyone involved in supporting the person with dementia, including carers, seemed to have developed an enhanced understanding of the service user and how their life story affected their experience of dementia. The study identified improved communication between those with dementia and their carers and the care team, this was also reported in Subramaniam & Woods' (2016) research. Improved knowledge of the individual with dementia obtained from LSW helped to explain their communication and behaviour, through a greater understanding of their personal story; knowledge that was then applied within therapeutic interventions and interactions and in care plans. The enhanced appreciation of the person that developed as a result, in turn improved the quality of interpersonal communication, and led to the subsequent acknowledgement by the clinicians that LSW represented an evidence-based and person-centred means of delivering therapeutic dementia care.

LSW facilitated a better understanding of dementia and assisted in overcoming labelling and stigma and helping to cope with some behaviours associated with dementia. Buron (2010), Subramaniam et al. (2014) and Subramaniam & Woods (2016) reported such improvement in staff knowledge and attitudes towards the person as a positive feature of LSW. The use of LSW seemed to prompt the staff to consider how the personal and diverse outcomes could be brought to the attention of the wider family and further used in a meaningful way in the person's care plan. For carers, often previously unknown information about their spouse was uncovered and, overall, this new information helped them appreciate and understand the experience of dementia in a different way.

The development of the PAR group and the re-establishment of LSW provided a focus within the team and a concomitant sense of community and positive communication (Kellett et al. 2010, Doyle 2014). It was noticeable that some members of the team were empowered through their individual role within the LSW project and the associated PAR; such empowerment will enhance team functioning as noted by Kellett et al. (2010); and less staff burnout (Gridley et al. 2016).

The experience of compiling a life story was highly personalised and unique, with a range of different methods being adopted. All participants used entirely novel and creative approaches to constructing their life story including personal photos, stories and poetry that exemplified their own journey and personality, and all spoke positively about the process (Wood et al. 2017). One life story book contained entries on unique relationships, individual achievements and poems written by family and friends. Music, aromatherapy, images of flowers to decorate pages, ‘wise words’ that are significant to the person and the noting of key events or memories were also utilised. Photos were the most common medium used, and these helped to initiate a discussion. Non-personal pictures of locations were also shown to be useful.

Reviewing the entries already made in the book prompted further recollection and subsequent entries. These very personalised approaches used by the participants reflect the well-documented requirement to be creative and flexible when using LSW (Clarke et al. 2003, Kindell et al. 2014). Bearing this point in mind, most people started their life story by reflecting on a childhood experience and then making notes which were added to their life story book. Relatives tended to take the lead with this process and in compiling the life story book. This then enabled some of the person’s formerly forgotten life achievements to be retrieved, which then facilitated an insightful review of the person’s life. In turn, this appeared to reactivate attributes previously believed to be lost, such as organisational and planning skills.

5.3.2 Clinician empowerment and PAR group cohesion

The use of LSW prompted many positive outcomes and several team, clinician and organisational changes. In this regard, the combination of LSW and PAR enabled the group to work effectively and become a productive and efficient implementation team. Indeed, under challenging circumstances, the PAR group fulfilled the aim of re-establishing the use of LSW as a therapeutic option. This is an encouraging result because it has been noted that the formation of PAR groups requires careful consideration and it can take time for a group to generate an action plan and become a cohesive project team (Reason & Bradbury 2001, Koch & Kralik 2006).

Correspondingly, change within the team and wider organisation was also achieved because the PAR members had developed not only new knowledge and skills but a renewed professional confidence. Accordingly, PAR and LSW were recognised by the group members as a means of facilitating change, and so this enabled the clinicians to achieve several positive outcomes at a time of considerable pressure on the team caused by Trust-wide reorganisation, NHS transformation and funding rationalisation. Such achievements correlate with the change concept of ‘gathering momentum’ whereby group members slowly became affiliated with the project aims, which then enables them to introduce new care initiatives (Chenoweth & Kilstov 1998, Goeman et al. 2016a). Thus, a shift in power from team leaders in favour of the PAR group members occurred because the clinicians had developed specialist knowledge in LSW and so became experts in the intervention.

Another consequence of this clinician empowerment outcome was that it initiated a constructive dialogue within the PAR group which then had an impact on the broader clinical team. The empowering of the clinicians in this way corresponds with the studies on the use of PAR in dementia care (Chenoweth & Kilstov 1998, Dupuis et al. 2012). Thus, the PAR group welcomed the chance to re-establish LSW in a more innovative way, even though at the beginning of the project the clinicians were concerned about the scope of the task that lay ahead and consequent pressure to devise creative approaches to LSW. This compares with the research on PAR use in dementia care that highlights the enabling of participants to effectively engage in change by their recognition of the potential positive outcomes (Hanson et al. 2007, Dupuis et al. 2012, Wiersma et al. 2016). Another example of staff empowerment in this respect is how initially the researcher felt that the PAR group looked to him for leadership, but this responsibility quickly moved to the clinical staff, with one group member taking on the combined facilitator and LSW lead roles.

The clinicians’ skill sets, including project management and specialist skills in delivering LSW, were also enhanced. When combined with the PAR group cohesiveness attained, this enabled the staff to more effectively influence clinical decision making by presenting persuasive cases for resource allocation based on evidence-based practice and their new expertise. Again, this type of positive outcome is common in PAR groups (Vikström et al. 2015, Goeman et al. 2016a) and resulted in group members becoming confident and assertive and thus feeling able to question and challenge the underlying reasons for the problems experienced, for example, why recruitment of participants to the project was lower than anticipated. Ongoing and consistent project support from the clinical management team and a well-organised implementation plan are essential for clinical projects to achieve positive outcomes (Goeman et al. 2016b, Wiersma et al. 2016).

In this respect, some of the pre-existing therapies on offer at the service, were initially seen as being in opposition to person-centred care approaches such as LSW. This manifested in the suggestion that the uptake of LSW would have been more successful if it had been delivered in another clinical environment such as in-patient wards. However, the recognition of these difficulties by the PAR group seemed to have a galvanising effect on the group members who viewed it as their responsibility to ‘sell’ LSW to the broader team and Trust by developing change and intervention strategies, resulting in several organisation-wide initiatives. This outcome appears particularly significant because one of the intentions of PAR is to foster productive group work but, once achieved, this can then have unanticipated consequences such as impacting on the way in which the wider team operates (Dupuis et al. 2012, Vikström et al. 2015).

5.3.3 LSW and service review

In line with the above-mentioned empowerment of PAR group members and the corresponding impact on initiating change, the use of LSW further challenged staff to reflect on and reconsider the focus of care provision at the service. This development was partially prompted by the use of LSW for PDS on the part of people with dementia and the feedback they provided. Nonetheless, LSW also started a discussion among the broader clinical team about the appropriateness of the therapies being offered, which, in turn, prompted a critical consideration of these, resulting in several learning points for the clinical team. The significance of such outcomes was documented in the research conducted by Goeman et al. (2016a), Goeman et al. (2016b) and Wiersma et al. (2016) who emphasised the importance of the reflective process in PAR and hence developmental opportunities for clinical teams. Another example of this from the project was how analysis of the use of LSW helped extend the services on offer by enabling LSW to become embedded within the service’s therapeutic programme during the active stages of the project. In addition, the evaluation of LSW initiated a review of the framework used for the information meeting by questioning whether all the material covered was needed and if this meeting could be delivered in a more person-centred way.

Additionally, it was encouraging to note a number of unanticipated changes, for example, a Trust-wide LSW interest group and recognition of the need for teams to create time for critical reflection on the appropriateness of the therapeutic provision. This creation of the opportunity for a dynamic review of service provision through PAR use was also documented by Clancy (2015), Goeman et al. (2016b) and Wiersma et al. 2016). Accordingly, it was further noted that, based on the service changes and broader impact achieved, integrating PAR and person-centred care might be an appropriate way of developing evidence to test new, creative therapies in dementia care. This aspect is considered later in this chapter in the section on the proposed ‘PIC Model’.

When people attend the dementia service, they are usually seen and assessed by several different professionals. Therefore, information about the individual is often elicited in various ways and from many perspectives. In this regard, the use of LSW for the project seemed to challenge the way in which personal data were collected and how it could be used to inform the person’s care. One such instance is the potential use of case formulation, which is frequently used in dementia practice and involves using the information collected in an integrative life story process (Cooney & O’Shea 2018). This then triggers a discussion in meetings and within in-patient ward handovers. Such encounters aim to increase clinician awareness of the individual being cared for and their journey and thus enhance the quality of care being given (Rainforth & Laurenson 2014). Hence it led to improved care planning and person-centred care (Cooney & O’Shea 2018). Similarly, it was shown in the findings that the individualised information obtained from LSW could help to inform other interventions that were being delivered at the service, particularly home treatment and crisis care. Again, this would enhance these therapies and improve communication by applying previously obtained knowledge of the person.

Moreover, while LSW involves asking for information about the individual, but in a different format, it could also potentially be used to supplement care plans and to contribute to individualised care (Gridley et al. 2016). It is vital that clinicians are aware of this potential so that they can not only reduce the potential for duplication of information gathering but also utilise LSW within therapeutic interventions. The notion of LSW enhancing care plans and embedding the LSW outcomes within care records and supporting personalisation would further suggest that life story books, or a summarised version, could be used to inform person-centred care by constituting the first page of a person’s electronic care record. In turn, this would ensure that the immediate care focus for the professionals becomes the person’s life and their individual needs, rather than dementia (Kellett et al. 2010, Doyle 2014). Similarly, it is possible that the information already obtained and recorded in the person’s clinical records could be used to contribute to their life story.

A project developed by Dementia Citizens (2017) provides an example of new and emerging approaches to LSW. This research acknowledges the difficulty of evaluating initiatives aimed at improving the quality of dementia care. As identified earlier, a significant problem in this respect is the cost of funding large-scale studies. To help address this difficulty, a ‘citizen science platform’ has been developed. It is similar to the digital life story books used by Subramaniam & Woods (2016) but, more specifically, this new project enables people with dementia and researchers to work together to collect naturally occurring data generated via two apps on tablets and smartphones that support listening to music or the development of a digital life story book. This is supplemented by wellbeing surveys. The data collected can help investigators to spot early signs and symptoms or the progression of dementia, provide scientific evidence and discover more about the needs of people who have dementia. This approach emphasises the importance of creative and innovative thinking about therapeutic interventions for dementia as well as helping to develop a community perspective. Some additional examples of these ‘new’ types of LSW are described in part two of this chapter and in the work of Keady et al. (2017) who summarise and explain this emerging phenomenon in dementia practice.

5.3.4 An enhanced organisational and research culture

The combination of LSW and PAR and corresponding use of LSW for PDS seemed to encourage an integrative approach to enhancing the research and the associated culture within the service. People with dementia and their carers were enabled to engage more fully with the service and so became central to developing its culture; in turn, a ‘whole team’ approach was adopted towards the generation of person-centred care. Having an active research project does result in many cultural changes (Hanson et al. 2007, O’Sullivan 2012, Vikström et al. 2015) and in this study resulted in several positive outcomes, including enabling the person and their relatives to become involved in research, and giving clinicians who were not always included in research studies an opportunity to participate, for example, healthcare assistants.

The research culture was further enhanced as awareness grew that the project would add to the existing body of knowledge on LSW, combined with the realisation that the study was, at that point, the only one to connect PAR and LSW. Once again, such achievements were noted in the published PAR studies undertaken in dementia care that implemented new approaches to therapeutic interventions (Nomura et al. 2009, O'Sullivan 2012, Clancy 2015, Goeman et al. 2016a, Wiersma et al. 2016). Based on their experience of the project, staff participants also thought that PAR was the most appropriate research option in relation to dementia care. The reasons given for this included the notion that PAR encouraged close collaboration between all participants and was useful when planning new therapeutic approaches to dementia care.

In terms of organisational impact, LSW led to greater recognition of the importance of this intervention and hence initiated several cultural changes and new and innovative ways of working throughout the Trust. In this regard, it has been documented that the empowerment of staff significantly impacts on the operational culture within the project setting (Hanson et al. 2007, Wiersma et al. 2016). Examples of this effect included the fact that the LSW template developed was adopted by other clinical teams and the framework used was considered to be an exemplar of good practice in LSW. A Trust-wide LSW specialist interest group was also initiated, which worked on several projects, including a proposal for a brief version of LSW within electronic care records, the development of an LSW board game and the delivery of a series of seminars on LSW. The LSW project was further acknowledged to be an example of positive interprofessional working and as improving reciprocity and mutual understanding between the PAR group and senior team.

As far as possible, new initiatives need to be part of planned care rather than an addition which could be seen as a burden by the clinicians (O’Sullivan 2012). To overcome this, change should be relatively gradual, with the intention of improving the quality of life for people (Day et al. 2009, Vikström et al. 2015). Therefore, although several difficulties were experienced with respect to the introduction of LSW, the group utilised these as a practice development opportunity to consider the potential of LSW and PAR for use in supporting person-centred dementia care. In this way, the problems were transposed and utilised to develop an assessment tool and change management framework with which to work on strategic clinical team issues, and to use such situations as an opportunity for reflection, research and learning.

To help support the change process, a project steering committee was established to oversee the research, which enhanced appreciation of the project and LSW on the part of the local managers, as well as developing mutual problem-solving processes. Consistent organisational support of this type and regular project progress reports at team briefings is critical, otherwise, momentum could be lost (Nomura et al. 2009, Clancy 2015, Wiersma et al. 2016). The reciprocity resulted in a proposal for continuing and expanding the use of LSW after the active stage of the research had ended. Furthermore, the positive outcomes attained helped to meet the requirements of the local clinical commissioning groups and their priorities for the development of the dementia service by prompting a review of the therapies currently delivered.

Such achievements emphasise the importance of the team and organisational environment being assessed and prepared prior to the project commencing (Brooker & Latham 2016) as this would then ensure that multi-stakeholder agreement of project aims and outcome measures is achieved before the project commences (Wiersma et al. 2016).

5.4 Life story work is a means of bringing people together in a collaborative manner

This theme showed that LSW generated different meanings for those who participated in it, ranging from reminiscence to reflections on their life and meaningful relationships. Consequently, LSW was used for diverse purposes, including occupational and practical use; this generated complexity in terms of how LSW was understood by those involved. Some of these intricacies have been discussed under the theme: ‘Life story work is a mechanism for resolving inflexible paradigms in working practice’, along with the exploration of the different LSW approaches used by the study participants to develop a person’s life story.

Not all clinicians seemed to appreciate these complexities when advocating the use of LSW; for example, the introduction to LSW was the final item covered in the information meeting delivered at the service. However, when staff adopted flexible strategies and innovative thinking towards LSW, these complexities were overcome with the outcome being that LSW brought people together in a positive, collaborative and reciprocal way. It is these enhanced collaborative relationships, and improved quality of care that provided the focus for this theme and hence the discussion that follows.

As mentioned, LSW had a different meaning for everyone involved, including promoting positive memories, enabling living in the present, helping to cope with change, informing future care, using the LSW ‘book’ in a practical way, appreciation of LSW as a therapeutic process and reflection on essential relationships. Whilst all of these factors correlate with the evaluative studies on LSW (McKeown et al. 2006, McKeown 2011, Gridley et al. 2016, Cooney & O’Shea 2018) and result in the positive application of LSW, the different meanings attached necessitates that people are prepared for undertaking it in a sensitive way. This also correlates with the observation from this study that the person with dementia has to be ‘in the right place’ emotionally and be carefully advised about what to expect by the LSW facilitators.

One of the reasons for being ‘in the right place’ is that the reminiscence aspects that underpin LSW tend to focus on the retrieval of important memories. Correspondingly, the emotions associated with these events will be re-invoked, and some of these feelings can be negative and unsettling (McKeown et al. 2006, Moos et al. 2006, Grondahl 2017). Consequently, the reminiscence aspects of LSW are not always suitable for everyone (McKeown et al. 2006). Some of the potentially harmful elements of reminiscence include feelings of regret and evoking painful or difficult memories (Subramaniam and Woods 2012). This potential difficulty was resolved in the project by holding an ‘LSW introductory meeting’ with the LSW facilitators at the service. This session aimed to provide the couple with information about LSW, including the rationale behind it and the materials with which to undertake it, but also to thoughtfully prepare them for some of the emotions and consequences they might experience as a result.

One of the other complexities identified in this theme is that, although there are many templates and recommended strategies for initiating LSW (McKeown et al. 2006, Kellett et al. 2010, Gridley et al. 2016), these also have the potential to impose limitations on the process. Bearing this point in mind, it was problematic for the participants to appreciate the potential benefits of LSW before embarking on the process. An important observation in this regard was the assertion that ownership of the LSW process must rest with the person, who should be supported to compile their life story in any way they wish (Clarke et al. 2003, Kindell et al. 2014). Staff were aware of this and so ensured it did not impact on facilitation work by using an open strategy that enabled the person to choose any aspect of their life with which to initiate the life story process, and by using a range of individualised techniques at the introductory session. This allowed the person to feel more empowered and led to a more thoughtful conversation about the individual’s life that then aided a careful selection of the personal events to be included in LSW.

A further intricacy noted in this theme concerned the observation that LSW is in many ways a naturally occurring process, whereby individuals re-enact aspects of their life story and experiences in everyday communications and interactions. This parallels the idea of dementia as an experience involving greater depth and hidden meaning that is often unknown to staff and relatives (Stokes 2000, Barker 2014). In this regard, it was noted that LSW brought couples together and enhanced relationships by providing a range of meaningful activities for them to undertake together. In turn, this enabled a greater understanding of the interpersonal interactions that took place and how these related to the person’s life story and were being re-enacted; an outcome that would not have been attained without LSW. The clinicians’ understanding also grew, which seemed to result in the enhanced therapeutic and reciprocal relationships as described by Stokes (2000) and Barker (2014). Therefore, to establish empathy and insight into the person’s life required detailed and extensive investigation and so the staff also enhanced their multifaceted skills and knowledge which enabled them to help people write their life story.

The findings further revealed that LSW results in the formation of new interpersonal relationships between all parties, including changes in the relationship between the person with dementia and the staff. This occurs because LSW promotes new modes of communication by utilising various creative activities and so allows everyone to contribute to the person’s life story (Berendonk & Caine 2016, Elfrink et al. 2017). In turn, this provides an opportunity for carers and clinicians alike to create what they described as ‘shared moments’. Peer support via the local dementia café and other groups are also useful in this regard because these provide a diverse range of perspectives. Additionally, because LSW is a good starting point for everyone to ‘get to know each other’ and initiates conversations through which new relationships are built, this results in everyone working together in a reciprocal and mutual way.

The outcome of the overall process is that roles become blurred and, in some ways, almost irrelevant. This reciprocity seems to be a unique outcome of this study and has not been previously noted in the published evaluations of LSW. Thus, the LSW process used with the couples enhanced the collective efforts of all parties, resulting in improved collaborative processes. The outcome was a detailed record of the individual’s life which had the potential for further use in assessment and care planning. Hence, LSW has considerable potential and added value, and so could also prove useful in care formulation, guiding staff to provide individualised care and in developing personal profiles. Therefore, when everyone can contribute to the person’s life story, it results in improved outcomes for the person that have a significant effect on informing current and future care. Similar positive and new findings were also outlined in the theme: ‘Life story work is a mechanism for resolving inflexible paradigms in working practice’.

An additional positive outcome was the participants’ assertion that LSW supports the person to live well with dementia after diagnosis as described in relevant policy guidance (Kellet et al. 2010, DoH 2015). In this regard, LSW improved life quality and enhanced the person’s outlook in the present, as well as reactivating skills previously considered lost. The clinicians involved in delivering the LSW were all experienced in dementia care and so were acutely aware of the need to promote the positive aspects of a diagnosis of dementia and to focus on the present by continuing to live well. Indeed, this constitutes a requirement of all current national policies and clinical guidelines and contemporary definitions of person-centred care (DoH 2015).

Such a philosophy also correlates with the principles of LSW (Gridley et al. 2016). However, attempting to promote and adhere to it in practise can cause dissonance for clinicians because, although they are focused on being positive by not regarding a diagnosis of dementia as having an immediate effect on the person’s lifestyle, they are also very familiar with the potential progression of dementia whereby self-care skills are lost, and long-term care is often required. Law et al. (2017) noted a similar difficulty, which they termed ‘the other side of caring’, as an outcome of their research with healthcare assistants working in care homes. It concerned what they perceived as the problematic features of their roles and how personal conflicts were responded to. However, as outlined in the theme: ‘Life story work is a mechanism for resolving inflexible paradigms in working practice’, such difficulties and dissonance can be overcome by using sensitive facilitation and providing opportunities for reflective practice.

A further complexity that emerged was a growing sense of collaboration within the PAR group prompted by the awareness of LSW as a critical foundation for the attainment of person-centred dementia care (McKeown et al. 2006, Moos et al. 2006, Grondahl 2017). Accordingly, LSW also influenced personal and professional perspectives on individualised care. In turn, this promoted the emergence of Trust-wide LSW action groups that were then utilised to affect organisational strategy and facilitate change. This was exemplified in the development of additional LSW activities such as the project framework being used as an example of good practice. Similarly, LSW helped the staff adjust to organisational change because they had developed new self-adaptation strategies.

In addition, ongoing supervision for the clinicians is essential, owing to the emotional and unanticipated demands of LSW (Subramaniam & Woods 2016). In this respect, even though a qualified team member supported the project and took the lead in implementing it, as well as helping to deliver the introductory session and supervising the support sessions in the persons’ home, most of the ongoing delivery of LSW was provided by an associate practitioner. Even though it is likely that unqualified care staff such as health or social care assistants will provide most of the support required for LSW (Gridley et al. 2016), this practice nonetheless raises issues about the skills of the team delivering LSW, their experience and how they have been prepared or trained for the LSW facilitator role.

As this study has shown, it is essential that all clinicians receive appropriate training and preparation to deliver LSW, a point corroborated by similar evaluative studies on LSW (Subramaniam et al. 2014, Subramaniam & Woods 2016). There are several courses available, such as those offered by the Life Story Network (2014). One of the clinical team had completed this programme, but was not asked to be involved in the project because the composition of the PAR group was determined by staff availability and nomination. Although the team member made the learning resources from their training available to the PAR group, the group undertook its own background research into LSW and then used this information to prepare for the project. The people with dementia and the carers also emphasised the importance of skilled LSW facilitator help, and the support provided in this respect was well received, while the skills of the staff were commended.

The mutual support engendered within the PAR group also provided a good opportunity for debriefing and support. Additionally, a qualified member of the team gave clinical supervision to the associate practitioner who facilitated the LSW support sessions in the person’s home. Overall this arrangement seemed reasonably successful, but the absence of a professional from the project, with experience in LSW appeared to reflect the relatively low value and priority assigned to LSW at the service. Enquiries were made about the possibility of the associate practitioner attending the approved training for LSW, but this was declined due to a lack of funding. All the systematic reviews and the research included in the literature review in this thesis emphasise the importance of staff preparation, training and supervision as critical to achieving positive outcomes (Cooney & O'Shea 2018). This point is substantiated by the Life Story Network (2014) who perceive such training as essential and explain that it should include methods of undertaking LSW and enhancing knowledge of how to deal with potential problems. The researcher's observations were that the project would have been more successful and recruited more people if the clinician who had completed the LSW course was involved in the project or if the associate practitioner had been able to undertake the LSW training programme.

In this study, participants attributed different meanings to LSW and so it was utilised differently depending on interpretation. LSW in this study was, consequently, complex but careful reflection and support resulted in many positive outcomes. These included: new and enhanced collaborative partnerships for everyone; improved quality of care; and a scenario in which assigned roles were rendered almost irrelevant because the mutual pooling of skills and knowledge for the benefit of the person with dementia became the primary objective.

5.5 Life story work is a strategy for providing post-diagnostic support

This theme discussed the challenges and benefits of undertaking LSW soon after a diagnosis of dementia. There are several guidelines that outline the pros and cons of when to commence LSW (Gridley et al. 2016), a critical element of which involves reflecting on the primary purpose of conducting LSW. Is it to:

- help with the present
- inform care
- produce something meaningful
- enable the couple to work together
- deliver something of high quality
- prompt a life review
- enjoy the activity of reminiscing
- leave something for the family?

These factors all have the potential to evoke different emotional responses so must be explored in advance (McKeown et al. 2006, Moos et al. 2006, Grondahl 2017). The PAR group were aware of these factors when planning the LSW project; however, a new, unanticipated phenomenon that added to these considerations became apparent whilst facilitating LSW, namely that it was also used by the participants for post-diagnostic support. The principles of good practice in PDS have been defined by the BPS (2014) as provision of a named link worker or ‘dementia advisor’ to give support for the first twelve months after diagnosis who should also facilitate access to local services; access to up to date information on the help available; peer support; assistance to plan future care and use of support groups and psychosocial interventions.

The need to provide such PDS has been identified in all recent policies and clinical guidance on good practice in dementia care as well as in charity and service user reports (Kellet et al. 2010, DoH 2015, Cooney & O’Shea 2018). Despite this, a lack of PDS and ongoing contact after receiving a diagnosis of dementia has been widely documented as a national problem (La Fontaine 2011, BPS 2014). The same phenomenon was observed in the dementia service where data were collected, with a lack of organised PDS at the service being identified as a significant issue by the study participants. Whilst PDS was initially seen as an integral part of the interventions offered by the service, owing to the shift to crisis type care, PDS was no longer being delivered. This finding is pertinent because, as most people with dementia are supported by their family, the need for ongoing, personalised and individualised provision is imperative, particularly given the demands of the caring role that relatives are confronted with (Adams 2008, Carers UK 2016).

In light of the lack of specific PDS help and the participants’ surprise that they would not be provided with longer-term support, it became apparent during the course of facilitating people to undertake LSW that the process was also being utilised by the individual and their relatives for the purpose of PDS. This was influenced by the fact that undertaking LSW constituted the person’s first contact with the service following the information meeting. The type of support being sought included help with reflecting on the future, support in adjusting to a diagnosis, advice on how to access the range of services available, and the need for consistency of care worker input.

This effect was unanticipated and caused some difficulties for the PAR group in implementing LSW because people were still adjusting to the diagnosis and the associated emotional reactions (Pepin & Blandin 2017).

This period of adjustment to diagnosis resulted in all participants mentioning the impact of receiving a dementia diagnosis at some point in the research interviews. This had the effect of moving the discussion away from LSW, as people talked about their feelings regarding diagnosis, worries about the future, care and treatment options, how to live well with dementia, concern about the effects of dementia such as memory problems, and the impact on their family. Thus, careful consideration is required about when to start LSW, and the decision to commence it shortly after diagnosis in this study was unique because LSW is usually undertaken at a later stage of dementia (Moos et al. 2006, Gridley et al. 2016, Grondahl 2017).

In the project the LSW sessions were delivered in the person’s home and were used as a form of post-diagnostic help. In this regard, the combined use of PDS and LSW enabled people to ‘reconfigure’ the initial despair they felt after diagnosis and cope with the early challenges and, in turn, explore how to live well in the present (Kellet et al. 2010). The LSW process also had a positive influence on the person’s care and planning of longer-term needs. Thus, there seemed to be an interplay between LSW and early diagnosis, in that LSW can help with adjustment to the multiple challenges of receiving a diagnosis and so can be used as part of a range of post-diagnostic interventions. Indeed, the PAR group agreed they would still respond to service user PDS requirements even if these were not explicitly integral to the LSW procedures used for this study.

Accordingly, LSW facilitators need to be aware of this potential phenomenon and consider and utilise it within the support and interventions offered. The PAR group were cognisant of the possible considerations in this respect, including the notion that people would still be adjusting to diagnosis and developing their plans to cope with the situation both in the short and longer term (Pepin & Blandin 2017). The group took these considerations into account but ultimately decided that beginning LSW at an earlier stage would enable the development of a more comprehensive, meaningful and potentially therapeutic process. This type of provision is not dissimilar to that delivered by specialist dementia nurses (Admiral Nurses), whose support is, in part, focused on providing PDS, an intervention that has been positively evaluated (Maio et al. 2016).

Thus, the people who enlisted for the study and who also used the LSW sessions for PDS seemed to be re-energised as a result, with LSW providing an opportunity to reflect on their achievements in a more thoughtful way. This then enabled them to utilise some of the skills they had acquired during their lifetime and to derive enjoyment and satisfaction from doing so. In addition, using LSW as part of an early PDS intervention resulted in the person taking more of a lead in the process and so being more fully involved in the compilation of their life story. Accordingly, it would seem that LSW can also be utilised therapeutically to help people cope with a dementia diagnosis, an assertion that was endorsed by all participants. Hence, another benefit of integrating LSW into PDS is that the person is enabled to utilise many different approaches to reminiscing and so reflect in a positive and more meaningful way about significant events in their life. An interesting outcome in this respect was that some people indicated that they were agreeing to participate in the LSW project as a ‘thank you’ for the team providing a post-diagnostic service.

In addition to the need to provide PDS, it has further been noted that there are many emotional reactions to a diagnosis of dementia (Moniz-Cook et al. 2006, BPS 2014) and so being asked to undertake LSW at this point seemed to tap into this phenomenon both for the person and their carer. The conversations between the LSW facilitators and individuals who had dementia and their relatives often digressed from LSW to diagnosis, as people talked about their fears for the future and the associated loss. Understandably, their responses appeared to reflect an early grief reaction including denial and anger. Such an attitude mirrors the separation (from their past life) stage described by Pepin & Blandin (2017) in their theoretical model of grief in dementia. In this respect, the commencement of LSW must be sensitive to individual needs because some couples felt that it was too early to introduce LSW at this stage as they were still adapting to a dementia diagnosis, while others found that LSW and the support provided was helpful and made it easier for them to come to terms with the diagnosis.

Correspondingly, it has been documented that LSW is not always appropriate to use with people with dementia as the reasons for developing a life story are multifaceted, and so clinicians need to be intuitive in this regard (McKeown et al. 2006). One of the challenges in this respect was that, due to the absence of ongoing help after receiving a diagnosis, LSW was apparently being used to help cope with the associated feelings of loss. Thus, there seemed to be a further value in using LSW for this purpose, thereby aiding the person and carer to deal with the grief associated with a diagnosis. Correspondingly, there was a need for the clinicians who encountered this situation to extend their therapeutic skills or acquire new ones, something which is explored within the theme: ‘Life story work is a framework for managing boundaries between staff and service users’.

An additional challenge of using LSW to help with grief is that the provision of LSW can often be time-limited (as was the case with this project) or become unavailable as the person moves through different care services (Kindell et al. 2014). So, although LSW was found to be helpful in this respect, the nature of the project meant that it ended after the scheduled three support sessions, resulting in a possible further loss associated with the feelings of separation for the person and carer. The importance of continuity was highlighted in the feedback, which suggested that ‘LSW is never complete’ because it takes time to review and reminisce about an individual’s life, a process that will be undertaken at the person’s own pace and direction. In addition, although generally the participants valued LSW at this point, and in particular its usefulness in developing coping strategies, they also highlighted the need for time and space to adjust to a diagnosis before a range of therapies was provided. This was important to protect them from becoming overwhelmed by too much information and too many services.

The lack of PDS by the service seemed to correspond with the observation that the family carers were presumed by the staff to be ready to take on the caring role. This observation resembles other studies on family carer support and the assumption of carer input as the starting point for care packages (Carers UK 2016). It is also worth mentioning here that, while LSW can seem like an extra burden at this point as, ‘there is so much going on’, it can also help the person and carer to overcome these feelings (Gridley et al. 2016). This point is particularly important in relation to the care burden experienced by the carers, as documented in this study. The PAR team explored the fact that LSW may initially feel like an additional burden, and so considered whether there was another way of undertaking LSW which would prevent it becoming onerous, a stage that had to be worked through before a more supportive and therapeutic interaction could be achieved.

In this respect, it was felt that LSW had the potential to help counterbalance the burden already being placed on carers, as Kaiser (2017) describes, by enabling the relationship between the couple to focus on a positive activity. Although one carer admitted that she felt pressure to complete her husband’s life story, this was not attributed to the facilitation but rather to personal motivation. Other carers also felt personal pressure to conduct LSW due to an awareness of the benefits it might bring (Kindell et al. 2014). The carers and individuals with dementia often perceived the volume of documentation presented to them at the information or diagnosis follow-up meeting as overwhelming. Instead, they favoured less information along with more personalised support; this aspect is discussed in the theme: ‘Life story work is a mechanism for resolving inflexible paradigms in working practice’.

Overall, undertaking LSW at such an early stage after diagnosis was felt to be innovative and useful by carers, the person with dementia and the clinicians. In this regard, LSW provided staff with an additional evidence-based therapeutic option to support people post-diagnosis. Furthermore, it also helped to protect the staff from being overloaded with therapeutic work by integrating a range of approaches within one intervention. Additionally, it provided evidence that was used by service users and carers to help protect them against becoming overwhelmed by the care services and, importantly, their own reactions to receiving a diagnosis of dementia. It further reinforced the identity of the person as a unique individual who still had a positive future after being diagnosed with dementia. As the clinicians involved in delivering LSW were relatively experienced in dementia care, they were fully aware of what might happen to the person in the future in terms of the dementia becoming more progressive, and thereby impacting on the person's life and personal care abilities. However, the use of LSW enabled everyone to focus on the present and living as well as possible with dementia. A similar perspective was also apparent within other interactions and therapies; for example, the staff provided support and guidance in a person-centred way.

5.6 Life story work is a framework for managing boundaries between staff and service users

This theme identified and described several essential boundaries (personal, professional, organisational and structural) relevant to LSW and explored how the LSW process helped to manage these. One such boundary was concerned with how to cope with the potential recall of personal information, for instance relationships before the couples met or events of a traumatic nature like wartime experiences. It has been shown that the use of LSW might trigger the recall of memories of this type (McKeown et al. 2006, Moos et al. 2006, Grondahl 2017) and so it is essential for clinicians to prepare for such an occurrence in advance (McKeown et al. 2006, McKeown 2011, Gridley et al. 2016). Thus, the LSW facilitators included a 'health warning' at the LSW introductory meeting and showed sensitivity to this possibility during the home support sessions. They also focused on positive reminiscence, enjoyment and the potential benefits of LSW. The published evaluative LSW studies undertaken further highlight this potential issue and suggest some strategies that might help, including advance agreement on plans with the person and their relative (McKeown et al. 2015, Gridley et al. 2016).

Bearing the aforementioned observation in mind, some of the carers thought that certain information was too personal and so did not document it, while others decided that they did not want to share specific issues with everyone. Overall, the responses from the research participants seemed to indicate that the approaches used within the project were successful, and, in a more positive sense, it was noted that LSW often uncovered significant life achievements on the part of the person that were unknown to the family. Another strategy that was not utilised in the study but has been shown to be useful is encouraging clinicians to write and use their own life stories as part of the facilitative process. This has the potential to enhance the therapeutic benefits (Kindell et al. 2014), as the staff could then share their own life story profile with the person and their relatives at the initial referral/assessment meeting. It has further been suggested that it might also help to reduce staff burnout and offer a way of supporting both person-centred care and the NHS personalisation agenda (Gridley et al. 2016).

Another perspective outlined within this theme is that cognitive decline and the memory problems associated with dementia might result in the person becoming more vulnerable in respect of a loss of control, leading to them revealing more than they might previously have wished about their life (Elfrink et al. 2017, Grondahl 2017). Thus, it is clear that having dementia could significantly change personal boundaries for the recently diagnosed person. This correlates with studies on the use of LSW which reveal that it might prompt the recall of life events that have been suppressed or forgotten for many years (McKeown et al. 2006, McKeown 2011, Gridley et al. 2016). Again, the clinicians were aware of this potential risk and so offered personalised advice and guidance to the person when developing their life story.

A professional approach on the part of the clinical staff was seen as essential to ensure that the intervention focus is on the person with dementia; this also helped the carers develop strategies to cope with these new vulnerabilities. Consequently, the professional attributes required of the LSW facilitators were: an ability to be prompt and punctual; to keep within the agreed meeting parameters; and not to bring their own work-related pressures into the encounter. These all correlate with the skills expected of the clinicians who deliver LSW and dementia care specialists (Maio et al. 2016) who are supposed to display intuitive skills, be well-organised and demonstrate empathy and practical communication skills (Cooney & O'Shea 2018).

To supplement and enhance the process described above, Kellett et al. (2010) emphasised the importance of the tripartite relationship between the LSW facilitator, the person with dementia, and their relative. Where these skills are effectively utilised within the LSW process, the result is positive personal outcomes that increase clinician awareness of the individual being cared for and their journey (Rainforth & Laurenson 2014), as well as improved quality of care and care planning

(Cooney & O’Shea 2018). As LSW is person-centred and flexible, it facilitates personalised and individualised support, which is particularly crucial for carers given the demands of the caring role they are confronted with (Adams 2008, Carers UK 2016). In this respect, LSW helps counterbalance the burden being placed on carers by enabling the relationship between the couple to focus on a positive activity (Kaiser 2017).

In recognition of the often intensive nature of LSW (Moos et al. 2006, Gridley et al. 2016), a more personalised approach was achieved by providing three support sessions in the person’s home. This support was positively evaluated and well-received, and the participants considered their own home to be the most suitable environment to support the LSW process. The reasons for this included helping to reduce potential barriers, facilitate discussion, familiarity, feeling more relaxed and the availability of personal artefacts. Therefore, the collaborative processes were improved by undertaking LSW in the home environment, and this helped to build rapport. However, the project deadlines meant that only three sessions could be delivered, and the person was subsequently left to continue writing their life story on their own with the corresponding potential for loss of personal support (La Fontaine 2011, BPS 2014).

The PAR group explored the questions of how many sessions to hold and of what duration, and how much help would be sufficient, as well as how the meeting should be structured. The group also discussed the need to keep within the designated time boundaries in the home support sessions. The provision of this support was considered significant because the process itself, the assistance needed and the resources required to help someone develop their life story can be considerable, owing to the potential volume of material to be covered (Berendonk & Caine 2016, Elfrink et al. 2017). Although setting time limits on this process could potentially be challenging and restrictive, it may also help to maintain a focus for the meeting and thereby ensure the person’s key life events are included in the life story resource. At the same time, the need to closely listen to the person’s life story is important, an aspect the investigator further acknowledged by asking each person to share their life story before the evaluative semi-structured interview proceeded. This seemed to be a critical point, particularly in terms of respect and empathy, despite the resource implications and the need to considerably extend the time allocated for the meeting.

Another critical observation covered within this theme related to the boundaries that existed between the many service providers and support networks that operate in dementia care. These statutory, voluntary, private and charity sector agencies all function in diverse ways and use different systems (Kaiser 2017). Consequently, the person with dementia and their carers are required to utilise a range of strategies to fully engage with, and to access, each service (Carers UK 2016). For example, a GP referral is usually necessary in order to access secondary NHS services, whereas charity and peer support groups generally offer ‘drop-in’ schemes.

LSW helped in this regard by establishing an information resource about the person which could then be used to inform the individual’s use of the various different systems and thus enhance their care experiences. LSW also enabled the carers to access the services and assess their appropriateness by encouraging reflection on the amenities identified. This information was then shared with other carers, thereby enabling mutual support and evaluation of the care provided. The associated use of LSW in this way is unique to this study, although the LSW evaluative studies undertaken to date do include the potential to use experiences of support services to enhance collaborative relationships (Kellett et al. 2010) and the potential of these improved relationships to ease the burden placed on carers (Kaiser 2017).

Within this theme, the participants described several boundaries that they perceived as important, including ‘staff being professional’ and the impact of such expectations on helping the person write their life story. Moreover, it was documented that being diagnosed with dementia could increase personal vulnerability and lead to the unintended disclosure of private information. In such situations, the therapeutic relationship developed with the LSW facilitators, combined with personalised support and the allocation of resources was critical to managing the identified boundaries, an important aspect of which was the positive use of LSW so that the individual’s life story could inform their care and aid access to support services.

5.7 Part two: The PIC Model

The PIC model evolved from the synthesis of study findings and the PAR research design. By combining these two structures a framework emerges from which good quality LSW delivery and activity can be gauged**.**

The way in which the positive outcomes of the four themes have been incorporated into the ‘PIC’ model are explained in the sections that follow. This framework also assimilates the conceptions of participatory action research, innovation and creativity and cultural change. Furthermore, ‘the essential LSW strategies’ as suggested by the participants, the positive outcomes of undertaking LSW as described in 5.9.2 and ‘the framework for locality-based change management’ as summarised in Box 13 in chapter six have also been subsumed within the PIC model. The model has to be implemented to achieve high-quality person-centred dementia care, although it will need to be evaluated.

5.8 The evolution of the PIC model

Following the detailed analysis and critical discussion undertaken of the study findings, and relevant research, policies and clinical guidelines, several key, influential factors were identified. Firstly, the person’s life story must provide the starting point and be used as the basis for all of the care that follows. This would ensure that the needs of the individual who has dementia are the focus for the support provided. Furthermore, as mentioned above, the strategies described by the person and their carers offer essential guidance for undertaking LSW (Box 14).

Historically, the culture of dementia care demonstrates pervasive and continuing concerns about care quality and a lack of consistency in the standard of care delivered (Kitwood & Benson 1995, Care Quality Commission 2014). Therefore, it was noted that high-quality person-centred dementia care could be achieved by combining PAR with innovation and creativity and cultural change. All of these factors have provided the rationale and framework for the proposed integrative PIC framework displayed on the next page (Box 10). The PIC model is based on both the positive outcomes and the project’s more challenging aspects. The emergence of the PIC model will now be described and examined.

Box 10: The proposed integrative model for the implementation of person-centred dementia care initiatives

‘PIC’ - A MODEL FOR PLANNING, IMPLEMENTING AND EVALUATING A PERSON-CENTRED DEMENTIA CARE INITIATIVE	
Participatory action research	The meaningful use of PAR principles, particularly partnership and co-production, to guide the implementation of person-centred dementia care activities. PAR should also be used as the research framework of choice to implement and evaluate such activities.
Innovation and creativity	The fostering of innovation and creativity, as described by Mueller (2017), combined with the concepts implicit in the ‘new’ ideas for therapeutic activities currently being utilised in practice.
Culture of care	The consideration and use of culture of care concepts based on an initial assessment and continuing evaluation of the culture of care in line with the work of Brooker & Latham (2016) and the findings of this study.

5.8.1 Outward manifestation of the extant bio-medical service model

LSW, and the positive aspects of it in particular, were seen as central to the dementia service’s operational philosophy and as an essential component of the range of services provided when the service was established eighteen months before the project’s commencement. However, although the benefits of LSW were still widely acknowledged by the clinical team, the service had moved away from providing LSW as a therapeutic option. Some operational reasons were cited to account for this change, including increased referral rates and the need for crisis care. It was also possible that more deep-rooted cultural explanations were influential. As part of the reflexive analysis of the study findings, the researcher realised that the planned re-introduction of LSW was perceived as challenging the justification for the interventions currently being delivered at the service and for why the team had deviated from their original plans. Indeed, it seemed that the operating culture at the service covertly prevented one of the central aims of the study from being fully achieved, i.e. the long-term embedding of LSW within the range of therapeutic options offered.

While there are many examples of excellent and innovative dementia care, there are also numerous instances of poor care practices (Cooper et al. 2013, Boye & Yan 2016). These poor practices usually result from a lack of quality assurance and effective clinical governance (Fortune et al. 2015). One of the reasons why this occurs is that people with dementia and family carers are frequently excluded from involvement in decision making. Indeed, in the dementia care sector, organisational structures are often set up to actively prevent partnership by presenting the professionals, and the medical staff in particular, as experts (Sterin 2002). Even though some clinicians such as nurses are often similarly excluded from decision making, when the ‘professionals as experts’ phenomenon is combined with a lack of person-centred care, it reinforces the view of the person with dementia as being unable to contribute (Kitwood 1997, Brooker 2007, Fortune et al. 2015).

A similar undercurrent of factors seemed to be initially operating at the service, and one of the outcomes appeared to be that the therapies on offer were based more on a bio-medical rather than a person-centred model of dementia care. One such example was an increased referral rate for memory assessment, a process that necessitates tests such as brain scans and the allocation of a dementia diagnosis.

Memory assessment is a very structured process, which must follow national clinical and commissioning guidelines (NICE 2006, BPS 2014). The use of such guidance results in clearly defined support roles, primarily for the nurses in the team but also other allied health professionals such as occupational therapists, who are becoming increasingly involved in supporting the memory assessments and subsequent memory monitoring appointments. The research and systematic reviews on memory services reinforce this perspective by pointing out the specific screening requirements that are embedded in national policy, CQUINs and NICE guidance (Hailey et al. 2016).

Although the potential benefits of LSW were acknowledged by the team, the impact of the covert operationalisation of this bio-medical perspective seemed to embody a form of ‘cultural resistance’ to LSW. Several contradictions were noted, for instance that innovation and person-centred care were openly cited as being aims of the unit, but while the value of LSW was recognised, staff were not supported to implement it other than in a token way. Such covert patterns of communication were also exhibited by core team members and some other staff who appeared to undermine attempts to restore LSW to the range of therapeutic strategies offered. There were several examples of this apparent ‘miscommunication’ or misunderstanding which resulted in the PAR group receiving mixed messages regarding how highly the service valued LSW. For instance, a group was set up to manage the project, but no resources (staff or financial) were allocated to support it.

Additionally, briefing meeting dates were changed at short notice without notifying the researcher and LSW was not actively endorsed, which left PAR group members feeling that the onus for promoting LSW rested with them. Another aspect of this cultural resistance was the lack of priority given to LSW which impeded the fulfilment of all the study aims. Examples included LSW being the final agenda item at information meetings, staff suggesting that LSW was ‘in competition’ with CST and the investigator not being informed at the planning stage that LSW was no longer being offered.

The PAR group responded to some of these issues by suggesting several creative ways of delivering LSW such as holding evening sessions or combining LSW with the person’s therapeutic programme but, unfortunately, due to the difficulties faced, these were unsuccessful in terms of increasing referrals for LSW.

This apparent lack of support for the staff delivering LSW also seemed to form an essential part of the overall cultural phenomenon encountered. In some situations, it was difficult for the LSW facilitators, who were relatively inexperienced, to positively challenge the prevailing culture. Indeed, it has frequently been found that the delivery of care initiatives such as LSW is delegated to healthcare assistants and unqualified staff whom, despite possessing the required interpersonal skills and knowledge of the person, are not always involved in planning and team meetings (Ward et al. 2016). Hence, it follows that if an experienced researcher encountered difficulty in establishing the project, then the PAR group members and people with dementia would also face problems in ensuring their views are heard and taken into consideration regarding the services being offered and the culture operating at the service.

The PAR group did explore the decision-making processes in respect of the ‘regular’ interventions offered and the motives for these, which included the broader team’s lack of support and resistance to using LSW. The reasons for the problems encountered were also discussed in the evaluative interviews with the group members. Explanations given included: the perception that as LSW had not been successful previously it was likely to ‘fail’ this time too; the diversion of staff time into other activities deemed ‘more useful’ such as CST and crisis work; and the volume of material covered in the information meetings combined with a pervasive sense of negativity about the way in which LSW was presented to people with dementia.

The need for LSW to happen in ‘a more natural way’ was further mentioned, as was the view that LSW was not appropriate so soon after diagnosis because staff wished to focus more on how to live well with dementia. Finally, it was thought that a planned Trust reorganisation was likely to prevent the enduring use of LSW after the project was completed. This also seemed to constitute a ‘blocking’ tactic because, at this point, scant detail of the changes had been released.

5.8.2 Erroneous assumptions about service users’ experiences

The situation described above appeared to correlate with the notion of mental health care being dominated by professional staff who viewed high levels of activity as corresponding with and achieving innovative practice (Brandon 1991). In other words, a belief system operates amongst clinicians that innovation is occurring, yet the interventions being delivered do not conform to good practice principles of person-centred care. Brandon (1991) highlighted two critical concepts in this respect.

Firstly, the idea of ‘match or mismatch’, whereby the expressed needs of service users are perceived entirely differently by clinicians. The delivery of carer education groups at the service, as opposed to the requested provision of a named contact person from the team, constitutes an example of this. Secondly, the concept of innovation without change is pertinent, whereby staff invest considerable time and effort into an activity, believing it to be innovative, yet all this energy expended does not succeed in achieving any change or improvement for service users. An example of this is the utilisation of crisis work instead of PDS that might have prevented a crisis occurring in the first instance.

A similar phenomenon to that described by Brandon (1991) can be seen in the current concern about the quality of care in the NHS following the publication of the Francis report (2013). When senior managers are informed by staff that a high-level quality of care is being delivered, and this is also documented in care records, how do the managers, who are remote from the clinical interface, verify and triangulate this information? In the Mid-Staffordshire Trust, the reality for care recipients was utterly different from the standard of care being cited. This could be seen as an instance of ‘illusion of quality’, whereby the experience of care for service users bears no resemblance to that espoused by practitioners. Such problems could also be characteristic of the broader value system of the organisation or the NHS Trust. For example, therapies such as LSW can be notionally supported but implementing them requires resources which are often withheld.

Contradictions like this are not uncommon in NHS organisational cultures which are bound by norms and rules usually consisting of many different layers. Huw et al.

(2000) explained that the culture of an organisation is critical to efficient performance and can comprise various levels: the basic level represents ‘underlying assumptions’ where workers operate unconsciously; once these are established then values become more conscious and constitute a standard that is respected. In turn, more observable actions are seen in operation as representations of the organisation’s culture. Huw et al. (2000) further related this to the NHS by describing three levels of culture: ‘assumptions’ that are ‘taken for granted’, for example the utilisation of the scientific method to generate knowledge and the application of the medical model; ‘values’ for establishing judgements such as professional codes of conduct; and ‘artefacts’ which include the physical and behavioural cultural indicators such as approaches to delivering care.

All the above assumptions outlined by Huw et al. (2000) seemed to be apparent in the belief systems that operated at the service and to have been utilised in both a conscious and unconscious way to prevent LSW from becoming wholly embedded. The research summarised in the literature review on LSW demonstrated that, in order for implementation to succeed, a ‘whole culture’ approach is required. While some aims appear to be valued on a surface level by an organisation, such as the requirement to be person-centred, these are not necessarily respected at a deeper level when attempts are made to integrate them as a component of regular care. This results in care staff receiving conflicting messages and experiencing indecision and uncertainty about what their role should involve, for example being asked to deliver LSW but being informed there is no time to provide it. Critical cultural considerations for LSW to become embedded have been extensively documented, such as the need for it to be agreed by all stakeholders and included in care planning

(Buron 2010, Kellett et al. 2010, Doyle 2014). If these requirements are not achieved, and where care is task driven and staff time is restricted, LSW can become just a ‘tick-box’ exercise (Berendonk & Caine 2016).

Bearing this latter point in mind, Campling (2015) cited Menzies Lyth’s research in the 1950s to explain how nurses were frequently exposed to several psychological stressors from which senior managers seemed to be protected. Campling (2015) further stated that, while the context of health and social care has evolved since Menzies there is still scant evidence from NHS staff surveys that the situation has changed; in fact, it may even have worsened. However, one critical difference was noted, namely that the unquestioning implementation of consistent change and the new ideologies of contemporary healthcare are still causing a high level of disintegration and burden that removes clinicians from essential caring responsibilities.

Such organisational processes appeared to operate in this study, as person-centred care only seemed to be supported in a superficial way. Some experienced members of staff did not actively support the project but did contribute to some of the PAR groups once it became clear that the problems associated with implementing LSW could ‘leak’ to more senior managers. Additionally, the perceived volume of clinical work, as mentioned in the exploration of Brandon’s (1991) ‘innovation without change’ concept in 5.8.2, such as the care routines, lack of time, workload pressures and staff shortages, operated to prevent the introduction of new ideas like LSW. Therefore, in some respects, LSW was perceived as an unwelcome addition to workloads and as ‘getting in the way’ of the team’s real care priorities.

5.8.3 Tacit rules and traditional practices

While many positive outcomes were achieved in respect of implementing LSW, the hidden rules of the culture operating within the team and Trust seem to have prevented the complete embedding of LSW. A critical component of this culture appears to have been the structures in place within the team when the project was introduced.

Contemporary dementia services must conform to the requirements of the clinical commissioners and DoH targets, but on the basis of the cultural influences documented here, the clinical teams still seem to have considerable leeway and hence influence regarding the services that are offered. Consequently, staff would seem to have the opportunity to implement new approaches to care, yet this option is not always taken up. Therefore, many of the therapies utilised were based more on personal preference and traditional models of treatment rather than on empirical evidence and research. Such evidence shows that holistic approaches to the treatment of dementia are evolving and even indicate that memory loss and cognitive impairment can be delayed by using LSW as one of a range of therapies (Bredesen 2017). There is also considerable research to demonstrate that, when LSW is used, then person-centred care is achieved (Kellett et al. 2010, Subramaniam et al. 2014, McKeown et al. 2015, Cooney & O’Shea 2018).

5.9 Underpinning principles of the PIC model

As outlined in Section 5.8, the re-introduction of LSW challenged both the interventions currently being used and the culture of care that operated. While many positive outcomes were achieved in respect of LSW, this covert culture acted as a barrier to the broader and sustained use of LSW. This culture consisted of multiple layers, both conscious and unconscious. Recognition and documentation of these appear to add several important observations to the current literature on LSW and the contemporary culture of dementia care. These considerations include the notion that the current drive for organisations to focus more on person-centred care had not significantly influenced the culture operating in the clinical team in which this study took place. While the importance of individualised care was acknowledged, there was a pervasive lack of clarity about what it consisted of, resulting in a target-focused culture rather than concentrating on what people with dementia actually require. Consequently, the biomedical model of care and the contracting requirements of the local CCGs dominated the therapies, screening methods and treatments on offer.

It was noted in part one how the outcomes of all four themes provided an original perspective on the use and application of LSW. The integration of these findings combined with the other influencing factors is briefly mentioned in 5.1. A comprehensive explanation based on the study findings and relevant literature to support and justify the proposed PIC model is also outlined in the following sections.

5.9.1. Essential LSW strategies

As can be seen from the discussion within the study themes, several practical LSW strategies were utilised in the project which the people with dementia and their family carers considered to be particularly useful. All were asked about their ideas for enhancing the LSW approach utilised, but only a few suggestions were made, for example, the transfer of family films to a digital format. A further observation about this positive outcome is that, based on the findings, the way in which LSW was used in this project was indeed advantageous for the participants and constituted a positive experience for them.

Many fundamental good practice principles for LSW were established, and the feedback obtained from the people with dementia was invaluable in developing a new service-user perspective on undertaking LSW (Wood et al. 2017). The participants also had access to personal resources and help that enabled them to engage fully with LSW. The feedback received seems to further reinforce the notion of LSW as an exemplar of person-centred dementia care and the ideology that underpins it. Indeed, during the individual interviews with the PAR group members, all mentioned extending the use of LSW and adapting the model used within the research to in-patient wards and long-stay care settings. The project outcomes are, hence, also reflective of the essential recent guidance, reports and policies on LSW (Gridley et al. 2016, Subramaniam & Woods 2016).

Overall, as can be seen from the feedback received, all the individuals who had dementia and their carers were very positive about the experience of compiling their life story and the support provided by the service. In addition, a careful analysis of the four themes highlights many positive practice principles associated with undertaking LSW. The constructive outcomes of undertaking LSW that were cited included valuing the reminiscence aspects and the opportunity to create a memento to share with family members. Everyone found the use of LSW to be of significant personal benefit, with the LSW process often uncovering considerable life achievements on the part of the individual that were previously unknown to their family. Additionally, after evaluating the data, the people who have dementia, family carers and clinicians were all in agreement that the following LSW strategies were essential. The study themes from which these strategies were mainly derived have been included in brackets.

- Prior training for staff in LSW and its methods and knowledge of how to deal with potential problems (Themes two and four)
- LSW should be used as a positive practice example of person-centred care and a strategy that supports the personalisation agenda as exemplified in national policies (Themes one and four)
- The approaches taken to engage people with dementia in LSW should be individualised, creative and supported by long-term facilitation (Theme three)
- The material provided for LSW should be similarly flexible; for example, the provision of an excessive amount of information is not recommended. Instead, a supportive and exploratory discussion is suggested (Themes two and four)

- The most appropriate setting for introducing LSW soon after a diagnosis of dementia is the familiar environment of the person’s own home to facilitate a more open discussion, or a dementia café where there is peer support (Theme four)

- The timing of the introduction session if delivered in conjunction with a therapeutic programme also seems relevant; the participants said this should be scheduled to coincide with other therapies or groups to ensure everyone’s time is used appropriately, or evening sessions should be offered for people to fit around work or other commitments (Themes one and two)
- The follow-up support sessions in the homes of the people with dementia and the use of online LSW packages were well received. This suggests that LSW would be more widely adopted if Wi-Fi and internet access and laptop and tablet computers were made more readily available (Theme four)
- The commencement of LSW must be sensitive to the needs of the person. Some people felt the timing of the LSW process adopted in this study was too soon because they were still adapting to a dementia diagnosis while others found that LSW and the support provided was helpful at this early stage (Themes two and three)
- The use of the two separate books for the compilation of LSW was positively evaluated: “we were surprised but pleased to be given something for free” (Theme one)

Key:

(4.3 Theme one): ‘Life story work is a mechanism for resolving inflexible paradigms in working practice.’
(4.4 Theme two): ‘Life story work is a means of bringing people together in a collaborative manner.’
(4.5 Theme three): ‘Life story work is a strategy for providing post-diagnostic support.’
(4.6 Theme four): ‘Life story work is a framework for managing boundaries between staff and service users.’

5.9.2 The positive outcomes of undertaking LSW

In addition to the above essential LSW strategies, the research already undertaken on LSW, the systematic reviews conducted, the literature reviewed in chapter two, and the thematic findings of this study provide sufficient evidence to support the following positive outcomes of undertaking LSW:

- When an enhanced culture of care and care environment has been established, LSW will flourish
- LSW will lead to individualised care and improvements in care when staff see the person, not the dementia
- LSW is an enjoyable experience for people with dementia who also value the reminiscence aspects of it
- LSW can improve relationships between the person and their relatives and provides a meaningful activity for them to undertake together
- LSW can help maintain personhood and can temporarily restore aspects of the person's personality considered lost to the dementia
- LSW is an essential component of the evaluated holistic approaches to dementia care that have been shown to slow the dementia process
- LSW has the potential to be utilised as one of the psychological approaches within a new, personalised, therapeutic dementia programme (Bredesen 2014)
- For individualised dementia care to be achieved, the PIC model indicates that LSW is a significant contributory factor and should be the starting point for and central component of all person-centred care models.

The positive outcomes of LSW listed above further reinforce the good practice principles of person-centred dementia care, and so exemplify the components contained in the proposed integrative PIC model. In this respect, it seems appropriate to note that the use of LSW was espoused in the ‘Alzheimer's disease bill of rights’, published by Bell & Troxel as far back as 1994:

Box 11: An Alzheimer's disease bill of rights (Bell & Troxel 1994)

An Alzheimer's disease bill of rights (Bell & Troxel 1994)

Every person diagnosed with Alzheimer's disease or a related disorder deserves the following rights:

- To be informed of one's diagnosis
- To have appropriate, ongoing medical care
- To be productive in work and play for as long as possible
- To be treated like an adult, not like a child
- To have expressed feelings taken seriously
- To be free from psychotropic medications, if possible
- To live in a safe, structured, and predictable environment
- To enjoy meaningful activities that fill each day
- To be outdoors on a regular basis
- To have physical contact, including hugging, caressing, and hand-holding
- ***To be with individuals who know one's life story, including cultural and religious traditions***
- To be cared for by individuals who are well trained in dementia care.

The rights also correlate with the more recent list of seven ‘I’ statements contained within the National Dementia Declaration (Dementia Action Alliance 2010) that outline a vision of how individuals who have dementia and their family carers might be supported by communities (Dementia Action Alliance 2010). Therefore these rights remain relevant as a guiding philosophy for dementia care and seem as pertinent today as when first published, particularly in terms of supporting the attainment of person-centred care and the achievement of national policy objectives.

5.9.3 The three components of the PIC model

As was shown in the study themes one and two in chapter four, there are many challenges involved in achieving individualised care; these have not been comprehensively researched, particularly the way in which project groups collaborate and devise change management strategies (Fortune et al. 2015). Developing the necessary partnerships to attain high-quality care is also problematic and, as demonstrated in theme one, can result in only nominal staff co-operation. Thus, creating and taking opportunities to collaborate with people with dementia and their carers at all stages is essential. In this way, the outcomes of any project will be significantly enhanced and decisive actions and sustained change more likely (Dupuis et al. 2016).

Consequently, based on the guiding principles that have evolved from this and other published research, it is asserted that the three components of PAR, innovation and creativity, and the culture of care are integral to the effective implementation of person-centred initiatives in dementia care and, when combined, these facets support an integrative model that will result in meaningful change within the care environment. Accordingly, the author proposes that, to achieve and evaluate optimal person-centred dementia care, these three principal components are necessary. These have been summarised within Box 10 and are also included in the recommendations contained in chapter six.

An important observation about the PIC model is that the principles of utilising PAR appear to correlate closely with those of person-centred dementia care. This is explained further in the following sections, but it shows that, in addition to being used as a research framework, PAR also has the potential to assist with team problem solving and so can be utilised to guide a review of a dementia service, particularly in terms of whether, and if so how, the therapies offered comply with the concepts of person-centred care. An example of this could be whether full stakeholder involvement was attained and if care recipients were involved in all operational aspects of the project. Despite PAR's potential in this respect, research that actively combines the use of PAR in dementia care with cultural change and innovation is quite limited, hence the focus on this in the literature review in chapter two.

Moreover, the principles and benefits of the social enterprise organisational model outlined in chapter one also supports the rationale for integrating these three dimensions. Social enterprises appear to provide an appropriate alternative to the organisational models currently used in dementia care owing to a focus on quality improvement (Ógáin & Mountain 2015). Consequently, one of the essential 'new' elements in the PIC model is the reappraisal and integration of creative and innovative thinking about the use of therapeutic strategies in dementia practice.

Based on the outcomes of this study and the literature used within this thesis, each of the three dimensions of the PIC model is described and further justified followed by an example of how the model template could be utilised in dementia care.

5.9.3.1 Participatory action research

The literature review conducted in chapter two explored the use of PAR in dementia care settings. This review highlighted that the PAR studies that achieve the most favourable outcomes and positive service user responses utilised a longitudinal design, combined with full stakeholder involvement and the use of innovative ideas that aimed to enhance the quality of life of the participants. The feedback obtained from the people with dementia and their carers in this project also provided an invaluable perspective on the usefulness of PAR. Whilst the comments were not directly concerned with the research methods utilised, these nonetheless initiated a discussion in the PAR group and staff semi-structured interviews about the use of PAR. A number of positive outcomes were noted such as PAR being helpful in enhancing an aspect of the care (LSW) and so improving the support for people with dementia and their family carers. Where problems were recorded with its use, these were re-appraised and new guidance provided on how to use PAR for future dementia care projects. The recommendations that follow in this section are based on these observations. Additionally, several influencing factors became apparent after analysing the themes and findings, and these also support the proposed use of PAR as a central component of the PIC model.

One such factor is that it was anticipated that PAR would be further utilised after the active phase of the project was completed. This was based on the need to reflect on how LSW was employed, to subsequently refine it, and then to start a new implementation cycle. Even though the LSW project only completed two action cycles (Figures 3.0 and 3.1), aspects of it did continue after the funded stage of the project had finished in the form of seminar deliveries, and the Trust-wide use of the LSW tools developed. Such activities did not collect new data but disseminated the good practices developed from the research and operationalised through the PIC model. Accordingly, it seems essential to consider the long-term use of PAR when initially planning projects, combined with a suitable change framework and strategy. This assertion is supported by the PAR dementia care related research undertaken by Goeman et al. (2016a) and Goeman et al. (2016b) who emphasise the importance of longitudinal plans. Furthermore, having a clearly agreed evaluation strategy and outcome measures also helps the longevity of the project and increases the likelihood of project success (Nomura et al. 2009, Caine 2013, Clancy 2015, Dupuis et al. 2012). Additionally, PAR in this study initiated critical reflection on aspects of service delivery by the clinical team, i.e. the focus of the therapies and interventions. Therefore, the reflexive analysis undertaken on the use of PAR in this study identified several key elements that are integral to achieving local change:

- To support any change or new initiative, there should be an articulated operational strategy for the delivery of local services that involve all stakeholders, including service users and their family
- For successful project implementation and positive outcomes, there needs to be a steering group, project team, key informant or informants, a PAR or change group and a driving force in terms of local management. This driving force might be a core team member or an organisational commitment to promoting the project
- There also needs to be unanimous agreement on the project aims at the outset, that includes PAR group involvement

- The full clinical team need to be informed of and involved in implementing the change via regular project updates at team meetings and through the adoption of collaborative processes
- It is essential for clinical teams to ‘come up for air’ from time to time or perhaps, as Johns (1995) advocates, ‘bring the mind home’. The pressures of working in the NHS which is in a state of continual redesign are considerable; however, ‘being busy’ should not be used as a reason for omitting to take time for reflective practice.

The points listed above can be classified under the four main categories of ‘Organisational’, ‘Local Management’, ‘Project Group’ and ‘Reflection’ and are presented in Box 13: ‘A framework for locality-based change management’, under the recommendations contained in chapter six.

Theme two additionally showed that, despite several difficulties, such as a need to be sensitively prepared for the emotional aspects of LSW, many of the problems associated with undertaking LSW could be overcome through the use of skilled facilitation. This is instrumental in bringing together the person with dementia, their carers and clinicians in a co-operative and collegiate way; a positive characteristic which correlates with the principles of PAR.

As highlighted in the literature review, the use of qualitative methodologies, longitudinal design and objective evaluation strategies are more likely to produce improvements in the quality of care (Keatinge et al. 2000, Nomura et al. 2009, Goeman et al. 2016b). Use of PAR will also lead to new ways of working and improved team dynamics (Chenoweth & Kilstoff 1998) and opportunities for clinicians to engage in research and care improvements (Keatinge et al. 2000). In addition, Dupuis et al. (2012) emphasised the potential of PAR to provide personal growth opportunities for staff, to enhance team-working (Caine 2013) and to foster positive staff attitudes (Nomura et al. 2009). Finally, PAR is effective in promoting staff empowerment because it adopts a ‘bottom-up’ approach, utilises clinician time effectively and turns problems into solutions (Hanson et al. 2007, Vikström et al. 2015). Overall, there is a marked correlation between achieving high-quality care, the use of PAR in the dementia research reviewed and the findings of this study.

5.9.3.2 Innovation and creativity

It was suggested in chapter one that the VIPS framework established by Brooker & Latham (2016) could be enhanced by the addition of ‘I’ for innovation. This would then ensure that innovation, creativity and relationship-based dementia care is wholly embedded within modern frameworks of person-centred dementia care. It was also proposed that, owing to a lack of research evaluating the VIPS framework, an alternative, integrated approach was required. As mentioned above, PAR seems particularly suitable for this type of creative strategy because it aims to achieve cultural change by enabling the involvement of participants, the fostering of partnerships, social change, group problem-solving and the transformation of a work culture (Fortune et al. 2015). To complement using PAR as the first component of the PIC model, the type of innovation and creativity being proposed involves the use of approaches that have given rise to innovative and inclusive practice in dementia care and LSW such as walking life stories or digital life story books (Keady et al. 2017).

Innovation and creativity are exemplified in all of the themes generated in this study and are particularly evident in themes one and three. In theme one, it was identified that the staff were empowered to initiate change as a result of using LSW, with new operating structures emerging in response to innovative practice and the utilisation of LSW principles in Trust-wide working groups. In theme three, owing to a lack of PDS, LSW was used for this purpose and prevented people from feeling overwhelmed. This theme also highlighted the value of undertaking LSW after a dementia diagnosis as well as how LSW appeared to help people adjust to a diagnosis and cope with grief and loss. Such innovative use of LSW also supports the notion that there are many positive benefits of change in practice, including improved communication patterns and teamwork, enhanced patient care and reduced staff turnover and sickness rates (Travaglia et al. 2011).

The use of LSW in this way and the resultant positive outcomes correlates with the work of Mueller (2017) who describes how to foster creativity and innovation. The concept of ‘creative change’ that he advocated involves the encouragement and enabling of creative thinking within organisations. Such an approach highlights how the most successful organisations acknowledge the difficulties involved in executing the creative ideas put forward by their staff and so establish structures that enable these ideas to be tested and then implemented (Mueller 2017). This type of creative strategy is useful because it can simultaneously achieve cultural change by enabling the involvement of participants and the fostering of partnerships. Creative thinking strategies of this type that have been found to be useful in helping healthcare professionals deal with constant change include developing personal resilience and the use of mindfulness and similar techniques. The use of such creative concepts is paralleled by the ‘new’ ideas for therapeutic activities currently being utilised in dementia care and within life story work.

To exemplify this final point, since commencing the study, LSW has evolved and, as a result, many creative and innovative methods are now being utilised. Therefore, if the planning stage of the PAR process for this study was re-visited, as well as reappraising the care culture, use of a book for the LSW template, and individualised support, the potential offered by these new approaches would need to be considered. The following paragraph outlines several ideas that have their basis in this emerging evidence or have been extrapolated from guidance on good practice in dementia care.

There has been considerable interest in the use of ‘walking interviews’ to enable people with dementia to become more involved in research. This concept has been adapted and used by Ward et al. (2017) in the form of ‘walking life stories’ and ‘the biographical neighbourhood’, whereby the person takes the clinician for a walk in their neighbourhood and talks about places that have been important in their life. Locations that appear ordinary, such as a sports field, could be meaningful to the person and help with the recall of memories which can aid communication. It would not be possible to elicit such information solely by using the traditional approaches to LSW. Additionally, there is a need to utilise a narrative or biographical strategy within dementia research because this enriches the interview process and facilitates improved cultural awareness (Jutlla 2014). Similarly, Keady et al. (2017) describe how social researchers can adapt data collection methods for people with dementia, by utilising approaches such as videos, biographical music and photography.

Strategies for developing a person’s life story might also include the concept of ‘photovoice’, as used by Bryant et al. (2015), whereby an entire life story profile could consist of just thoughtfully selected photos. It has also been suggested that LSW could be combined with individualised music playlists, with approaches such as ‘playlist for life’ emerging. In this regard, the notion of ‘appearance biographies’ could be linked with LSW; this involves people using photographs to discuss their appearance throughout their life (Twigg & Buse 2013). Brief life story work can also be of practical use because so much can be discovered about a person’s life from a one-page LSW questionnaire. Finally, the development of staff videos to promote person-centred care, entitled ‘catch a glimpse of me videos’, has been shown to be helpful. This initiative uses recorded videos about the individual’s life and history to enable care staff to see the person in a more holistic way (Gendron et al. 2016).

5.9.3.3 Culture of person-centred care

Several historical, cultural problems still seem to exist in contemporary practice including the way in which organisational structures frequently operate to exclude people with dementia and family carers from decisions about their care (Sterin 2002, Fortune et al. 2015). In this regard, theme one initially explained how a biomedical framework operated which meant that service users were not directly involved in the decisions taken about their care and the therapies that were offered at the service. In contrast, it has been noted that the engagement and involvement of people with dementia and their carers are essential and should be the first consideration if high quality, person-centred care is to be attained, a requirement that is embedded in all health and social care policies (Kaiser & Eley 2016, Mitchell 2018).

In this respect, the service users and carers who participated in this study highlighted within theme two that LSW produced different meanings for all involved, and how these understandings helped the person to live well with dementia. In turn, this improved their quality of life, informed their care and enhanced their awareness of the benefits of LSW. Theme one reiterated this point by showing how LSW helped the person to appreciate life in the present more and enabled them to plan for care in the longer-term.

In addition to the importance of meaningful service user engagement, theme three also seemed to reinforce the uniqueness of the person and helped to show how LSW relieved the burden being placed on carers. Meanwhile, theme four demonstrated the importance of staff employing a professional approach by using person-centred and flexible LSW strategies. Such invaluable insights would not have been achieved without providing the opportunity for individuals who had dementia to feedback on their experiences and to be involved in developing and enhancing the approaches used for LSW (Wood et al. 2017). In chapter one, the continually evolving field of people with dementia and their carers sharing and publishing their experiences of, and their feelings associated with, having dementia was summarised.

The sharing of these perspectives is critical to improving care quality and, when combined with the fact that the more successful PAR studies included service users in project teams at all stages of development, appears to further reinforce the importance of and need for co-production. Thus, to effectively enhance the culture of dementia care and to improve standards of care, service user involvement and engagement forms an essential part of the PIC model and the culture of care component in particular. To support this assertion, Brooker & Latham (2016) emphasised the importance of the care environment in achieving change and identified seven factors as being essential to the successful embedding of individualised care initiatives. These factors correlate with good practice principles in LSW, and so exemplify person-centred care and a participatory approach to its implementation.

It has also been shown that PAR can be utilised to evaluate the outcomes of therapies and new interventions, which can then be shared as good practice principles more widely throughout the organisation. In turn, this enhances the care culture and brings about change. A critical point concerning organisational culture is the impact of hidden or covert influences. These may consist of many cultural layers that can potentially prevent or hamper the implementation of new initiatives. An example of this occurred in theme one, which showed that even though LSW was valued when this study started, it was still not appropriately utilised. However, after using LSW in an improved way, staff and carers alike gained a greater appreciation of the person and their life which led to care improvements. LSW also enabled changes to be made to the operating systems of the clinical team and the organisation, including the development of a more individualised approach. Theme two further supported this assertion by demonstrating how, despite the initial difficulties such as resource allocation, LSW use overcame these problems and brought the team and the organisation together in a co-operative and collegiate way. This resulted in new therapeutic relationships and collaboration and had a positive effect on organisational strategy.

5.9.3.4 Integrative example of the PIC model’s utilisation

The components used and questions developed in the model as presented in Box 12 below relate to the principles of good practice for LSW and PAR identified and discussed in the research and published literature reviewed in this thesis. The outcomes of these studies are also considered to offer the most effective means of embedding positive outcomes for the participants and in attaining person-centred care. Furthermore, and as demonstrated throughout this chapter, the findings of this study have also been synthesised to provide the foundation for and the principles which underpin the PIC model. These values have then been translated into several critical questions that should be utilised to plan for and/or determine if any person-centred dementia intervention is likely to be successfully embedded.

In order for care teams to utilise the model, it has been developed into the practical tool included in Figure 5.0. This would then ensure that the individual with dementia is central to the person-centred initiative and that their life story is the starting point for and underpins all care that follows. Currently, the intention would be to use the PIC model as a reference guide for planning, implementing and evaluating a person-centred dementia care initiative. Examples of this would be to use it to appraise whether current therapies used in a dementia service accord with the principles of person-centred care: an action plan would then be developed, to determine the appropriateness of a new intervention and its potential for successful delivery, to appraise whether the care culture is suitable for the embedding of individualised dementia care, and to generate ideas for innovative practice.

Such initiatives would then enable the PIC model and its associated principles to be tested and evaluated in clinical service, the outcome of which would be the development of Good Practice Guidelines and case studies for its use. These guidelines could then be utilised to help plan and appraise new service developments such as the initiation of new therapeutic groups, the development of creative and innovative interventions, responses to policy initiatives and the requirements of CCGs, the implementation of clinical evaluations and audits, practice-related participatory research and Trust developments such as service improvement initiatives. The learning that results from the use of such advances would then enable the PIC model guidance to evolve further in line with the PAR principles and so become a dynamic process.

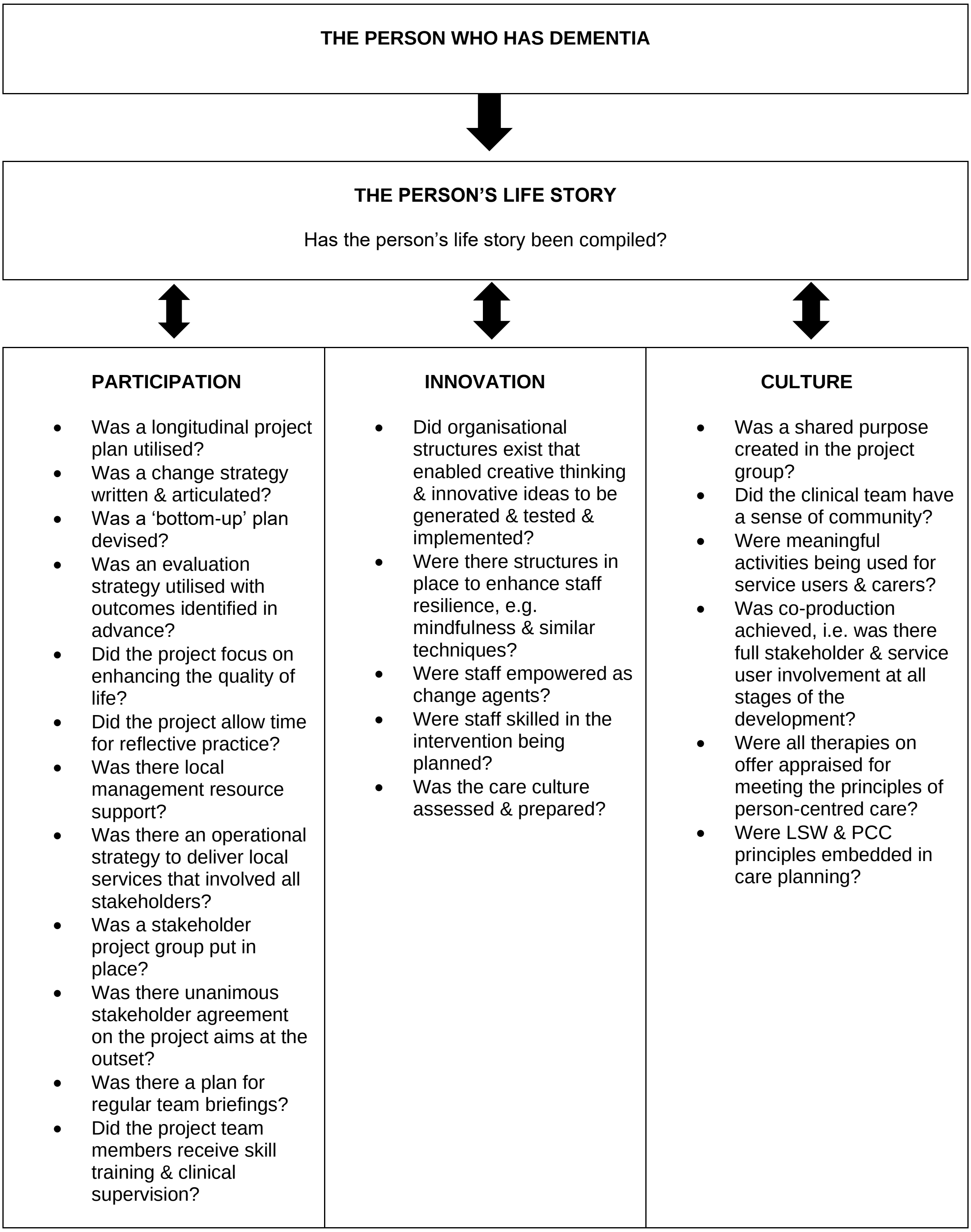
Box 12: the PIC model-a reference guide for planning, implementing and evaluating a person-centred dementia care initiative

THE PIC MODEL

A REFERENCE GUIDE FOR PLANNING, IMPLEMENTING AND EVALUATING A PERSON-CENTRED DEMENTIA CARE INITIATIVE

DIMENSION	THEORETICAL UNDERPINNING	QUESTION
PARTICIPATION **(Participatory action research)**	PAR principles of good practice:	• Was a longitudinal project plan utilised? • Was a change strategy written & articulated? • Was a 'bottom-up' plan devised? • Was an evaluation strategy utilised with outcomes identified in advance? • Did the project focus on enhancing the quality of life?
	Principles derived from this study including the use of 'A framework for locality-based change management':	• Did the project allow time for reflective practice? • Was there local management resource support? • Was there an operational strategy to deliver local services that involved all stakeholders? • Was a stakeholder project group put in place? • Was there unanimous stakeholder agreement on the project aims at the outset? • Was there a plan for regular team briefings? • Did the project team members receive skill training & clinical supervision?
INNOVATION **(and creativity)**	Creative change, as described by Mueller (2017), combined with the concepts implicit in the 'new' approaches to dementia care:	• Did organisational structures exist that enabled creative thinking & innovative ideas to be generated & tested & implemented? • Were there structures in place to enhance staff resilience, e.g. mindfulness & similar techniques?
	Principles derived from this study:	• Were staff empowered as change agents? • Were staff skilled in the intervention being planned? • Was the care culture assessed & prepared?
CULTURE **(of care)**	Brooker & Latham (2016) 'Seven principles' (staff empowerment; staff training; management support; effective change management, have been incorporated into other components):	• Was a shared purpose created in the project group? • Did the clinical team have a sense of community? • Were meaningful activities being used for service users & carers?
	Principles derived from this study:	• Was co-production achieved, i.e. was there full stakeholder & service user involvement at all stages of the development? • Were all therapies on offer appraised for meeting the principles of person-centred care? • Was the person's life story work completed? • Were LSW & PCC principles embedded in care planning?

Figure 5.0: the PIC model-a reference guide and planning tool for implementing and evaluating a person-centred dementia care initiative



THE PERSON WHO HAS DEMENTIA

THE PERSON'S LIFE STORY

Has the person's life story been compiled?

PARTICIPATION

- Was a longitudinal project plan utilised?
- Was a change strategy written & articulated?
- Was a 'bottom-up' plan devised?
- Was an evaluation strategy utilised with outcomes identified in advance?
- Did the project focus on enhancing the quality of life?
- Did the project allow time for reflective practice?
- Was there local management resource support?
- Was there an operational strategy to deliver local services that involved all stakeholders?
- Was a stakeholder project group put in place?
- Was there unanimous stakeholder agreement on the project aims at the outset?
- Was there a plan for regular team briefings?
- Did the project team members receive skill training & clinical supervision?

INNOVATION

- Did organisational structures exist that enabled creative thinking & innovative ideas to be generated & tested & implemented?
- Were there structures in place to enhance staff resilience, e.g. mindfulness & similar techniques?
- Were staff empowered as change agents?
- Were staff skilled in the intervention being planned?
- Was the care culture assessed & prepared?

CULTURE

- Was a shared purpose created in the project group?
- Did the clinical team have a sense of community?
- Were meaningful activities being used for service users & carers?
- Was co-production achieved, i.e. was there full stakeholder & service user involvement at all stages of the development?
- Were all therapies on offer appraised for meeting the principles of person-centred care?
- Were LSW & PCC principles embedded in care planning?

5.10 Chapter summary

In part one, this chapter discussed the findings in respect of the four themes generated. As they related to extant literature, these themes provided an original and unique stance on the utilisation and practical application of LSW, including insight into how LSW changes the values and beliefs of people who are engaged in it, how LSW promotes collaboration between all involved, how useful it is as a means of delivering PDS and how LSW can be used to manage a range of essential boundaries.

In part two, the organisational and cultural problems experienced during data collection were surfaced.

The study findings supported the use of principles and strategies when utilising LSW and endorsed the integrative use of the concepts of PAR, innovation and creativity and the culture of care to achieve high-quality person-centred care. These concepts were used to provide the rationale for a new ‘PIC model’ to plan, implement and evaluate person-centred dementia care initiatives.

The discussion of the study outcomes also showed that, for clinical teams to apply the PIC model, a practical tool or reference guide is required to ensure that the person with dementia and their life story is integral to any development that purports to be ‘person-centred’. It was also suggested that although the PIC model would need further testing and evaluation to develop a handbook of good practice for its use, the framework still supports the attainment of high-quality dementia care.

Chapter 6: Conclusion and recommendations

6.1 Introduction

6.1.1 Chapter overview

This study aimed to explore how life story work can be embedded into an age-inclusive dementia service. Four objectives were stated to enable this aim to be evaluated, namely to:

- describe the cultural and organisational changes required for practitioners to internalise life story work as part of delivering high-quality dementia care;
- determine how the use of a life story profile can be embedded into an age-inclusive dementia service;
- develop a model of service redesign which facilitates the introduction of good practice in dementia care;
- analyse the essential and desirable components of life story work from the perspective of the person, their carers and practitioners.

Participatory action research was used as the research design, and interpretive phenomenology methods were utilised during data collection and analysis. The use of PAR ensured that the research study was completely embedded in clinical practice from the initial generation of ideas to the project resolution and beyond. The data were analysed and coded using Miles and Huberman’s (1994) three-stage analytical structure, with four themes being identified: ‘Life story work is a mechanism for resolving inflexible paradigms in working practice’; ‘Life story work is a means of bringing people together in a collaborative manner'; 'Life story work is a strategy for providing post-diagnostic support' and 'Life story work is a framework for managing boundaries between staff and service users'.

The themes have been synthesised within a proposed new 'PIC' model which is also a framework for integrating the three concepts of participatory action research, innovation and creativity and cultural change. In addition to incorporating the insights derived from the study themes and being based on these three concepts, the PIC model further assimilates the essential LSW strategies as proposed by the study participants, the positive outcomes of undertaking LSW as identified in chapter two and the framework for locality-based change management as defined in chapter five. Accordingly, when implemented, the PIC model will result in high-quality person-centred dementia care.

This chapter:

- Outlines the methodological issues and limitations of this study
- Describes the planned project dissemination strategies
- Explains the recommendations and conclusions

6.2. Methodological issues and limitations

The themes generated from the data produced an original and unique perspective in respect of the use of LSW, including its contribution to enhancing collaborative working, its use as part of PDS, how it helps overcome boundaries and how it changes personal values and beliefs. Correspondingly, PAR places emphasis on planned change, partnership, creative practice and care enhancements (Chenoweth & Kilstoff 1998, Day et al. 2009, O'Sullivan 2012) and, in this regard, the use of PAR as a research framework also produced several positive outcomes for the participants. These benefits included the embedding of LSW within the therapeutic options available at the service during the project and LSW being perceived as a beneficial activity on the part of people with dementia and their family carers. These findings not only supported the use of several essential principles and strategies when utilising LSW but also endorsed the integrative use of the concepts of PAR, innovation and creativity and the culture of care to achieve high-quality person-centred care.

However, despite these positive achievements, several problems were still experienced in re-establishing LSW including difficulties with organisational structures and the impact of the care culture. These problems were critically evaluated in the discussion chapter and are now considered within the exploration of the study limitations.

6.2.1 Utilisation of participatory action research

One of our PAR group learning points was concerned with the need for meaningful stakeholder involvement at all stages of the project (Nomura et al. 2009, Wiersma et al. 2016). The planning group were aware of the importance of this principle in the first phases but decided not to directly involve people with dementia and family carers in the project team. The reason for this was the assertion that the clinicians were driving the implementation of LSW and thus, as PAR was being utilised, the care culture at the service was likely to be subjected to critical scrutiny. People with dementia, family carers and representatives from the local Alzheimer’s Society were involved in the study design and the generation of research themes at a launch event.

It is possible that the number of people who undertook LSW and, in addition, the project outcomes would have been more sustainable if a more collaborative approach had been used for the stakeholder group. However, while the importance of co-production is advocated in the published papers on PAR (Chenoweth & Kilstoff 1998, Dupuis et al. 2012), only three of the studies in the literature review included people with dementia at all stages (Hanson et al. 2007, Dupuis et al. 2012, Wiersma et al. 2016). Additionally, carers were only fully involved in two of the studies (Chenoweth & Kilstoff 1998, Dupuis et al. 2012). Hence, operational difficulties become apparent with multi-stakeholder involvement and so this project has taken reasonable measures to try to ensure representation. The approaches used further correlate with the research conducted by Dupuis et al. (2012), and Vikström et al. (2015) who developed care recipient-led project groups, Goeman et al. (2016a) who used expert stakeholders, and Wiersma et al. (2016) who utilised three advisory groups.

There has been a significant increase in research and guidance on the involvement of people with dementia and their carers since this project was planned and implemented (Oliver 2016, Swaffer 2016, Whitman 2016, Mitchell 2018). Consequently, if the PAR group membership approaches employed in this study were revisited in line with the direction now available, individuals who have dementia and their relatives would be included as core members of the PAR group.

The study duration of seven months also corresponds with similar clinical projects (Caine 2013, Goeman et al. 2016a, Wiersma et al. 2016) but possibly a more extended period might have enabled the more deep-seated and cultural problems to be addressed more systematically. However, the published PAR studies vary considerably in project length, fluctuating from five years (Nomura et al. 2009) to six months (Caine 2013). Given that most PAR studies are seeking to establish quite significant changes, it seems that longitudinal studies are more likely to achieve this aim (Hanson et al. 2007, Dupuis et al. 2012, Wiersma et al. 2016). Published PAR studies completed in dementia care were further concerned with implementing new models, guidelines and therapies such as LSW (Chenoweth & Kilstoff 1998, Nomura et al. 2009, Clancy 2015, Goeman et al. 2016a, Goeman et al. 2016b, Wiersma et al. 2016). The settings for these were similar to the context for this study and included community services and an outreach project. Therefore, the use of PAR for age-inclusive dementia services seems appropriate although the evidence in this respect is quite narrow.

The study used a cyclical PAR process as the framework, and this was based on established approaches to PAR (Fine et al. 2000, Koshy 2010). The cyclical method seemed to work well in the PAR group; however, at the time, the team were not aware of possible alternative strategies that had already been used in dementia care (Day et al. 2009, O’Sullivan 2012). Nonetheless, it is unlikely that this knowledge would have influenced the chosen PAR framework because all the studies reviewed adopted a different structure. They all had some degree of cyclical action, but only two used a recognised framework (Hanson et al. 2007, Vikström et al. 2015), while each study utilised a different structure to plan and deliver the project.

6.2.2 Sampling

The clinicians were allocated to the PAR group by a core team member, and so judgement sampling was utilised based on the expectation that the staff in the group would be facilitating the LSW. This approach to sampling worked reasonably well and enabled the study outcomes to be achieved. Even so, due to the pressure of work in clinical practice, the attendance at meetings was inconsistent, and it was not possible for all eight group members to attend every meeting. This caused some difficulties with decision making, but the two staff members who had been designated to deliver the LSW did participate in each session, as did the researcher and group observer, so a core for the group was established.

Convenience sampling was used for the semi-structured interviews with people who had dementia and their family carer. This was as age-inclusive and reflective of the population group as possible. However, the sample size of four people with dementia and three carers was too small to address all the variables expected of an age-inclusive dementia service such as age, gender, diagnostic category and stage of dementia. This is a significant limitation but all the people who wanted to undertake LSW were interviewed, and those that did come forward were of different diagnoses, ages, genders and stages. The attendees were all in the early phase of adjusting to a diagnosis of dementia although one participant was more advanced than the others regarding his dementia. These interviews were just one part of the data collection process, and so generally a reasonably broad perspective of LSW was obtained by comparing staff, carer and person views of LSW.

The sample was small, and the single case study approach taken may have restricted the transferability ability of the findings, but the samples utilised for this research are comparable to other LSW studies (McKeown 2011, Gridley et al. 2016). A significant problem with sample sizes in LSW research is the capacity to consent to the longitudinal project (Subramaniam & Woods 2016, Cooney & O'Shea 2018). Similarly, qualitative investigation usually operates with small samples of between 10-12 participants so again this study is comparable in this respect (Marshall 1996). Seven of the PAR studies evaluated in the literature review also consisted of relatively small samples with some of these comprising just five participants.

6.2.3 The life story work methods utilised

Even though the LSW methods used were carefully considered by the PAR group, with the final decision based on the available evidence, in practice, only a template or book was utilised, and thus restricted the range of LSW materials available to the participants. Nevertheless, the resources used were positively evaluated, and indeed several other supplementary approaches were utilised by participants, which were prompted by the use of the LSW book.

Only two facilitators delivered the LSW which might have contributed to the broader clinical team feeling isolated from the LSW process. Similarly, this could have restricted the expertise available to the people who had dementia and their carers. However, there are positive aspects of using just two LSW facilitators such as enabling relationship building with the participants and skill enhancement for the clinicians.

LSW was introduced through the medium of small groups, but after these sessions, the couples did not meet up again. A more collegiate process and additional meetings with the participants might have enhanced the uptake of LSW and provided additional support.

Based on new referral rates to the service (approximately 80 each month), it was anticipated that LSW would be more widely undertaken. LSW as a therapy was offered as part of a research project, although people with dementia could still participate in LSW without having to be included in the research. It is possible that ethical considerations and the other well-documented difficulties as cited in chapter three associated with research in dementia care impacted on the uptake of LSW. Additionally, even though many people were offered appointments for the introductory meeting on LSW only a small number attended. Possible reasons for this, as referred to by one informant, could be the time commitment and the other concerns already documented after a diagnosis of dementia as cited in chapter four. Indeed, it is possible there was just ‘too much going on’ for people with dementia and their carers when LSW was initially offered after diagnosis. The couples were still adapting to the diagnosis, which is similar to adjusting to loss and dealing with the family implications at the same time as trying to make sense of the volume of information on dementia available to them. Therefore, the LSW process became perceived as ‘something else to be dealt with’ and thus was not always considered a priority.

Finally, undertaking LSW should be seen as an ongoing process (Moos et al. 2006, Gridley et al. 2016, Grondahl 2017) and so perhaps the deadline established for involvement in the research was set at too early a stage. Possibly a more extended period for people with dementia to compile their life story would have enhanced the number of participants contributing to the research.

6.2.4 Data analysis

Miles & Huberman’s (1994) three-stage analytical framework was utilised to analyse the data collected, code it and then organise it into themes. This model was employed as it uses an interpretive phenomenological strategy to generate a comprehensive perspective of the data and hence the experiences of all participants. It has also been extensively adopted to organise and evaluate qualitative data that aims to be collaborative. The use of this framework proved to be an efficient and systematic way of analysing the data, although this was quite a lengthy undertaking that required each stage to be carefully followed. The analytical framework facilitated the identification of the reasons for the resistance to the reintroduction of LSW and the many underlying cultural issues.

The possible limitations of Miles & Huberman’s (1994) model were concerned with the time it took to identify and organise the data into themes. This is, however, an essential and necessary process. The use of the MAXQDA software and Bryman’s

(2004) coding process were also beneficial resources regarding the identification of themes. As mentioned earlier, if person-centred and co-production principles were fully applied, then the person with dementia and the family carers should have been more involved in the thematic identification stage. Nevertheless, the emerging themes were presented at the launch event where further discussion took place and agreement was reached.

6.2.5 Data collection methods

An inter-disciplinary staff PAR group was established to plan, deliver and evaluate a new approach to LSW. This consisted of an LSW book using a template with additional guidance which was presented to people recently diagnosed with dementia and their relatives in an introductory meeting. Three support sessions were also provided in the person's own home.

6.2.5.1 Semi-structured interviews with people with dementia and their carers

These semi-structured interviews were audio-recorded and aimed to be exploratory regarding the person's approach to LSW and the support received from their carer and the LSW facilitator. Semi-structured interviews are a central component of qualitative research (Nieswiadomy 2012) and, judging by the in-depth feedback received, were an appropriate method to use. The data collected enabled a comparison of the views of the clinicians, carers and people with dementia. In turn, this provided rich data in respect of their experiences and significantly contributed to the sound practice principles in LSW, as documented. It further enabled potential problems to be resolved as the project proceeded.

The investigator’s clinical and academic experience also seems to have had a positive impact on conducting the semi-structured interviews with the people who have dementia. While there were some difficulties in this respect, such as being asked questions about prognosis and the nature of dementia, the researcher’s expertise enabled him to develop empathy and insight and so conduct the interviews successfully.

The investigator encountered some challenges in these interviews primarily where participants tended to focus more on their life story rather than the process of undertaking it. This issue was resolved by listening to the person’s story and then moving the conversation on to their views on the process. Additionally, in two interviews the relatives also asked the researcher about the diagnosis and possible treatments. In this respect, the researcher pointed to information sources and the support of the team at the service.

6.2.5.2 PAR group meetings

The PAR group met on eight occasions over a seven-month period. All PAR group meetings were audio recorded, transcribed, analysed and then coded. The group comprised an inter-disciplinary sample of the clinical team. However, as mentioned previously, members were selected who had an interest in LSW or who were allocated from the broader team. The difficulties associated with the allocation of group members have already been explored. Despite these difficulties, the group became a cohesive project team, which is reflected in the quality of the data collected during the group meetings. The impact of the culture of care and the issues associated with it was initially noted in these group meetings, with the outcomes then informing and influencing the evaluative interviews with staff and the themes generated.

6.2.5.3 Semi-structured interviews with PAR group members

Semi-structured interviews were conducted with PAR team members, in which the opportunity was taken to inform the evaluative stages of the project by reflecting on the success of and lessons learnt from using PAR, LSW and the overall plan. Again, these interviews proved invaluable in terms of clarifying the issues that contributed to all themes, in particular, the problems that arose in respect of the culture of care and the use of the biomedical model. Unfortunately, not all PAR group members could be interviewed because one member left the Trust shortly after the project finished. This group participant was one of the LSW facilitators who would have added a valuable perspective on the process. The researcher made significant efforts to contact this clinician but without success.

6.2.5.4 Personal reflections on the PAR process

The PAR group consisted of staff from a range of professions, who varied in terms of ages, qualifications and clinical experience. The researcher was also a member of the PAR group. Many of his own reflections have been documented throughout this thesis and, in this regard, the researcher has provided thoughtful comment at critical points. However, the section that follows outlines some additional personal perspectives on the PAR process.

During the course of the investigator's involvement with the PAR and other staff groups in the project, he was aware that his experience in recent years had been as an academic rather than clinician. Nevertheless, he felt that his expertise as a manager, academic and clinician would be a significant asset in establishing the project and the LSW but was also aware he could be seen as an outsider with his own agenda. For example, the participants knew the project was Trust funded and that the researcher had been appointed to deliver the project and ensure it attained its aims. This posed a dilemma for the investigator in the early stages because the PAR group expected him to take the lead in implementing LSW, whereas he needed the group to assume the decision-making responsibilities. Following discussion, clarification and negotiation about this matter in the PAR group, the lead person for the delivery of LSW agreed to facilitate the group after the initial meetings.

The researcher was also aware of how problematic it is to deliver high-quality care to people with dementia, particularly in light of the current challenges facing the dementia services. He was concurrently leading a project evaluating another memory service in the same Trust and was also a member of many different clinical working groups, such as a team seeking Practice Development Unit status and a project group implementing and evaluating a communication framework for dementia care. Although he had previous experience of research and service development he was also aware that he was a comparative novice in the use of PAR. In this regard, the PAR group had to work very cooperatively, and this seemed to create momentum and support for the project and did not seem to impact on his role or credibility as a researcher.

The PAR team meetings were also examined regarding the interactive group processes, with notes compiled by an independent observer. The feedback from the observer was used within the meetings to explore the dynamics of the group so that modifications could be made to the way in which the team managed these sessions. The observations have also contributed to the themes identified. Occasionally, the boundaries of the observer's role were reflected on because she had some involvement in the PAR group discussion. There was also some initial uncertainty about how to integrate the observer's feedback into the PAR process. Overall though, the PAR group observer's feedback provided valuable data on the quality of the group processes and the resulting cohesive and effective PAR team collaboration.

The researcher also compiled reflective field notes on the difficulties experienced in initially re-establishing LSW and setting up the project. A synopsis of these problems was included in chapter two. The records compiled were also used as part of the researcher's supervision procedure. The notes were perhaps more useful in the early stages of the project as a means for the investigator to reflect on and analyse the difficulties experienced and potential solutions. It was problematic to completely integrate and represent these within the research report, but as this thesis has adopted a narrative similar to PAR in sections, the value of these notes became more apparent.

6.3. Dissemination of the findings

The initial findings and a summary of the project was published as a Trust report in November 2014. This was disseminated at the launch event to all participants, team members, clinicians and Trust representatives. Copies have also been distributed to student cohorts, in specific Trust seminars on LSW, in University consultation events, to local dementia care organisations, in presentations to inter-professional audiences and to Trust directors. An external web page and the Trust intranet site were also used to share the project outcomes.

A short course on LSW was also developed, and the study outcomes have been presented at the University of Essex annual research conference. The project was included in the School of Health and Social Care’s positive practice in research submission and the outcomes of the project initiated a Trust-wide LSW group. A short paper summarising the experiences of the people with dementia and their carers of undertaking life story work was published in an academic journal (Wood et al. 2017).

The design, learning and findings which emerge through this thesis should be made available to a wider audience; this will facilitate greater scrutiny of the work but also place the work within the growing body of work concerning life story work and PAR. Initially three topics have been identified as the basis of future academic publication:

- The use of the PIC model as a means of supporting person-centred dementia care
- The benefits of utilising LSW for people with dementia and their carers
- The use of PAR in dementia practice

Papers on these three themes will be submitted for publication to journals with an international health and social care audience; this will ensure that the use of PAR is debated and strengthened within the research community and our understanding of life story work continues to develop to better meet the needs of people and carers who are living with dementia.

6.4 Main recommendations

The main recommendations of this study are outlined in the three sections that follow.

6.4.1 Service development

The use of the PIC model (see Box 12 and Figure 5.0) that combines PAR, innovation and creativity and the culture of care is indicated if person-centred care initiatives are to be implemented effectively. This model provides an alternative to the VIPS framework (Brooker & Latham 2016) because it can be utilised to both implement and evaluate new therapies and interventions for dementia care.

Additionally, ‘A framework for locality-based change management’ (see Box 13 below) should be used to promote positive change within dementia care services. Without this, in respect of the culture and management structure, the initiation of any new person-centred intervention will ultimately fail.

Box 13: A framework for locality-based change management

A FRAMEWORK FOR LOCALITY BASED CHANGE MANAGEMENT			
Organisational	**Local management**	**Project group**	**Reflection**
An operational strategy for the delivery of local services	A partnership steering group with representation from the project group	A representative inter-professional project group from the clinical team	Provision of time for reflective practice
An organisational commitment to actively promote the project and implement the outcome	Provision of a ‘key informant’ from the clinical team	The project or research group may transform into a ‘change’ or ‘hub’ group	Adoption of reflective processes within the project group
An organisation wide strategy for the provision of time for reflective practice	A project ‘driving force’ from local management; this might be the team leader	Full group involvement in the agreement of project aims	Facilitative project group leadership
Support for the emergence of ‘expert’ practitioners	Application of organisational commitment to the project	Provide regular project updates at clinical team meetings	
	A unanimous agreement on the project aims at the outset that includes PAR group involvement		
	Plan for regular project updates at clinical team meetings		
	Adoption of collaborative processes throughout the project		

6.4.2 Using life story work with people with dementia and carers

Many planning and implementation strategies in LSW were considered essential by the individuals who had dementia and their family carers. Consequently, the re-introduction of LSW demonstrated that eight practice principles seem integral to good practice in LSW (see Box 14 below).

Box 14: Good practice principles in LSW as proposed by the study participants

GOOD PRACTICE IN LSW MEANS THAT:
Staff training in the use of LSW is critical
LSW is essential if person-centred dementia care is to be attained
The LSW approaches used must be individualised and creative
LSW is never complete and so long-term support is required
The LSW materials must be flexible, with the use of IT and creative approaches, sensitive to the needs of the person
The setting for LSW must be a supportive environment such as the person’s own home
LSW must form part of an overall therapeutic programme for the person
The starting point for LSW must be sensitively considered

This study also demonstrated that when a conducive environment has been established, LSW will usually result in individualised care, constitutes an enjoyable experience for people, improves relationships, can help maintain personhood and is an essential component of person-centred care. The use of LSW in this project soon after a diagnosis of dementia had the additional benefit of informing the person’s care and subsequent care experiences.

Without the assistance of family carers, it is unlikely the person with dementia’s life story book would have been completed. Several factors were reported as having a significant influence on this: providing a productive activity to undertake with the person after diagnosis, using LSW to help with the adjustment to the diagnosis, having regular contact with a dementia service and utilising LSW to enhance their relationship with the person who has dementia.

6.4.3 Recommendations for further research

This study has established that when person-centred care initiatives are combined with PAR and innovation, a high standard of dementia care will result. In this regard, PAR has considerable potential to support the implementation of change in dementia care settings. Additionally, PAR as a framework for implementing the new and creative LSW approaches has potential for more extensive use and application in dementia care. Therefore, the use of PAR and the proposed PIC model for achieving person-centred dementia care require further research and evaluation and broader adoption in suitable dementia care settings.

Also, there is a burgeoning field of innovative ideas in the utilisation of LSW that appear to warrant more extensive application and evaluation; PAR seems to offer an appropriate framework for implementation in this respect. Similarly, the use of LSW, narrative or a life history approach could be adopted as a central data collection strategy in dementia research.

6.5 Conclusions

6.5.1 Synopsis of the research findings

A brief summary of the findings of this research in respect of the four study objectives is outlined below.

Describe the cultural and organisational changes required for practitioners to internalise life story work as part of delivering high-quality dementia care.

For any person-centred dementia strategy to be implemented successfully, the activities outlined in Box 13: ‘A framework for locality-based change management’, should be completed before any project commences. Once a favourable environment is attained, individualised care will be achieved, a process that must be underpinned by several good practice principles in LSW.

Determine how the use of a life story profile can be embedded into an age-inclusive dementia service.

The utilisation of the PIC model to guide the planning, implementation and evaluation of dementia care initiatives indicates that high quality LSW and person-centred dementia care will result.

The expertise of the clinicians in delivering LSW is also essential, but the support of family carers is critical to the successful completion of LSW. Several factors influence this process, such as continuing contact with the dementia service.

Develop a model of service redesign, which facilitates the introduction of good practice in dementia care.

The PIC model has been developed as a suitable model because it integrates three major concepts, a change management framework and the essential strategies and good practice principles of undertaking LSW and hence, person-centred dementia care.

Analyse the essential and desirable components of life story work from the perspective of the person, their carers and practitioners.

Eight principles were considered integral to good practice in LSW by the participants, and many positive outcomes of using LSW were reported, including utilising LSW soon after receiving a diagnosis of dementia.

6.5.2 Reflective summary

The researcher, having worked as an academic for many years, was looking forward to engaging with a clinical team again and the opportunity to contribute to a project that had the potential to enhance the quality of care provided to people with dementia and their relatives. Despite the investigator’s previous experience, the operationalisation of the project and the difficulties faced proved challenging and required new personal strategies to overcome them. In some respects, this type of reflection exemplifies using PAR which provides a generalised structure but correspondingly questions and challenges the values that one holds. Such a challenge can only be a positive experience for researchers with the dissonance this creates being a critical aspect of the self-reflection required of competent investigators.

There was evidence of service users’ positive stance towards LSW noted by the researcher and clinical team. All of the participants who undertook LSW found the process to be extremely helpful and beneficial shortly after being diagnosed with dementia. Furthermore, after a period of eight months had elapsed since the study completed, all the people with dementia and their carers attended the project launch at the service, with some bringing their updated life story books for more discussion. This response demonstrated the importance of LSW to the informants and their commitment to the study. The positive outcomes of the study also had a wider impact in the Trust, prompting several additional projects to be initiated, which is to the great credit of the clinicians in the PAR group and, in particular, the two LSW facilitators.

The use and application of LSW have further evolved since this study was completed, with the greater use of information technology and inventive practice in its use. At the same time, the need to develop creative approaches to person-centred dementia care and to provide meaningful and effective support to family carers continues to be a fundamental priority in all health and social care policies.

Therefore, the outcomes of this research remain highly relevant to these policy priorities and the importance of using innovative approaches to the utilisation of LSW in dementia care.

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APPENDICES

APPENDIX ONE:
FEATURES TO BE CONSIDERED BY ORGANISATIONS FOR ACHIEVING PERSON-CENTRED DEMENTIA CARE

FEATURES TO BE CONSIDERED BY ORGANISATIONS FOR ACHIEVING PERSON-CENTRED DEMENTIA CARE (Brooker & Latham 2016)					
	Feature (Brooker & Latham 2016)	**Preparation for the study**	**Ongoing support provided during the project**	**Positive outcomes on the organisational culture**	**Problematic study outcomes for the organisation**
1	A practical, **shared purpose** in providing person-centred care.	Pre-project assessment & preparation in terms of establishing PCC & LSW was not apparent in any of the other studies reviewed. However, the research undertaken by ***Gridley et al. (2016)*** did suggest several important considerations for the organisation.	LSW became or was a regular part of the service provided in all of the studies reviewed whilst the project was in progress.	***Berendonk & Caine (2016):*** Public authorities in Germany require & review documentation of residents' life stories by care homes. ***Damianakis et al. (2010):*** Positive outcomes for the people with dementia & their families. ***Gridley et al. (2016):*** Care quality improved (QoL assessed). ***McKeown et al. (2010):*** Care quality improved. ***Subramaniam et al. (2014):*** Staff knowledge of people with dementia & attitudes to dementia improved. ***Subramaniam et al. (2014):*** LS books appeared to have had a significant impact (new information about residents) on homes with some developing LS books for other residents & integrating it within the care programme. ***Subramaniam & Woods (2016):*** Staff considered digital LS books as useful & that communication & interaction was enhanced.	***Berendonk & Caine (2016):*** LSW is challenging for staff to deliver because care is task driven, care & time is restricted. ***Gridley et al. (2016):*** 'Organisational challenges may prevent positive outcomes being achieved' because 'an individually tailored approach is essential to ensuring maximum benefit'.
2	**Connectedness** & community between all involved **in the organisation**	***Subramaniam & Woods (2016):*** Participatory design was used, with participants actively involved in the LSW decision-making process,	***Subramaniam & Woods (2016):*** Participatory design was used, with participants actively involved in the LSW decision-making process,	***Doyle (2014):*** LSW Promotes positive communication between staff, families & people with dementia. ***Kellett et al. (2010):*** 'Complementing the organisation' is concerned with promoting	***Kellett et al. (2010):*** Organisational challenges: some families not ready for LSW until they accept changes in people with

		designing and creating & directing their own life story movie.	designing and creating & directing their own life story movie.	a sense of community. ***Kellett et al. (2010):*** Improved partnership between staff, people with dementia & carers. ***Kellett et al. (2010):*** Staff & carers worked together. ***Ingersoll-Dayton et al. (2013):*** Some people were interviewed in own homes.	dementia (some never accept this). ***McKeown et al. (2015):*** In some cases, staff were unaware of the existence of life story books, and consequently, they were not used with residents.
3	**Staff are empowered** to take responsibility for the well-being of people receiving care & are **supported to do so through active management** processes	***Subramaniam & Woods (2016):*** Care home managers initially consulted with but not staff. ***Subramaniam (2014) et al.:*** Care home managers and carers initially consulted with but not staff. ***McKeown et al. (2010; 2015):*** Practice development approach applied to the LSW intervention. This included working with the Senior Management team and all participants.	***Doyle (2014):*** Positive staff views of LSW sought.	***Buron (2010):*** Staff knowledge of residents' families improved. ***Gridley et al. (2016):*** Considered staff burnout & attitudes. ***Gridley et al. (2016):*** Staff attitudes significantly improved. ***Kellett et al. (2010):*** Empowered staff to engage in inclusive care practices. ***Subramaniam & Woods (2016):*** Staff gained information & knowledge about the people with dementia.	
4	**Management mediates the impact of external factors** on front-line care delivery	Not apparent as an initial factor in any of studies reviewed.	There was evidence of notional but not always explicit senior management support during the research period in all studies.	***Doyle (2014):*** Continuity of staff important. ***Kellett et al. (2010):*** Organisational Challenges: Solutions include: commence info collecting at home ***Kellett et al. (2010):*** Organisational Challenges: Solutions include: use life stories as staff training. ***Kellett et al. (2010):*** Organisational Challenges: Solutions include: link new families with a staff member. ***McKeown et al. (2010):*** Taking a practice development approach ensures LSW can be implemented sensitively	***Doyle (2014):*** Should commence LSW before admission. ***Doyle (2014):*** Need to include LSW in care planning. ***Gridley et al. (2016):*** Staff time pressures mean research time is often wasted. ***Gridley et al. (2016):*** Researchers need to be based at or close to setting. ***Gridley et al. (2016):*** Staff

				& sustained in practice.	fatigue contributed to a lack of data being collected. ***Gridley et al. (2016):*** 'Formal evaluation of LSW would be possible only with substantial staffing'. ***Kellett et al. (2010):*** Organisational challenges: Admission time = multiple form filling. ***Kellett et al. (2010):*** Organisational challenges: Care plan written within the first month; if biography info isn't available then opportunity lost.
5	**Ongoing & gradual change** for the benefit of people receiving care	No evidence of change management in any of the studies reviewed.	No evidence of change management in any of the studies reviewed.	***McKeown et al. (2015):*** Planned approach to implementation including facilitation, education & supervision is essential.	No mention of change management in any of the studies reviewed.
6	**Using the environment** for the benefit of people receiving care through **conscious reflection** on the environment	No evidence of initial staff training undertaken (only information sharing) in any of the studies reviewed.	***McKeown et al. (2010; 2015); Subramaniam & Woods (2016) & Subramaniam et al. (2014)*** appeared to provide ongoing support to the staff. Ongoing training not explicitly mentioned in any of the studies.	***Gridley et al. (2016):*** Training important. ***McKeown et al. (2010):*** Training important. ***Subramaniam et al. (2014):*** Training & supervision important.	***McKeown et al. (2015):*** The potential 'over-use' of the life story books - need to find 'correct' balance in using the LS Book.
7	**Meaningful engagement & activity** is embedded within the care work undertaken	Not apparent as an initial assessment factor in any of studies reviewed.	***Subramaniam et al. (2014):*** Family carers supported by a Clinical Psychologist. ***Kellett et al. (2010):*** Family carers, care staff & the researcher,	***Berendonk & Caine (2016):*** Some evidence of working in partnership with people with dementia & carers. ***Buron (2010):*** Worked in partnership with staff. ***Buron (2010):*** Staff knowledge of	***Berendonk & Caine (2016):*** Some staff didn't involve people with dementia. ***Buron (2010):*** No evidence of working in partnership with people

			worked collaboratively in a series of support sessions. ***Ingersoll-Dayton et al. (2013):*** The practitioner supported the couple in their home, a care facility, or the home of a family member.	residents' families improved. ***Subramaniam & Woods (2016):*** Staff considered digital LS books as useful & that communication & interaction was enhanced.	with dementia & carers. ***Buron (2010):*** Staff perceptions of PCC did not improve.

NOTE: The four factors used as headings for the above table i.e.the preparation for the study, the ongoing support provided during the project, the positive outcomes on the organisational culture and the problematic study outcomes for the organisation were determined as critical LSW requirements in the five systematic reviews already conducted on LSW (McKeown et al. 2006, Moos & Bjorn 2006, Kindell et al. 2014, Gridley et al. 2016, Grøndahl et al. 2017).

APPENDIX TWO:
CASP SUMMARY (1): RESEARCH ON THE IMPACT OF DEMENTIA LIFE STORY WORK ON THE ORGANISATIONAL ENVIRONMENT AND THE CULTURE OF CARE

Author - year	**Aim**	**Setting & country**	**Design**	**Sample & size**	**Key findings**	**Care Culture Themes**
Berendonk & Caine (2016)	To explore care staffs' understandings of life story work when caring for persons with dementia. Aim was to derive recommendations for improving LSW practice.	Germany. Nursing homes. Public authorities in Germany require & review the homes' documentation of residents' life stories. To achieve this staff just use questionnaires. However, this has become a tick box exercise.	**QUAL** Grounded theory using semi-structured interviews and group discussions.	A convenience sample of 36 staff (Nurses and HCAs) from seven nursing homes (not just people with dementia).	Further study needed in care homes; Two different narratives resulted: Staff like to get accurate information but ask relatives rather than people with dementia for it. Staff understood people with dementia as storying persons so more open-minded about & committed to LSW.	**PREPARATION & ONGOING SUPPORT:** Not apparent but probably not appropriate as just sought staff views. **OUTCOME(S):** LSW is challenging for staff to deliver. Why? Task driven care & time; Some evidence of working in partnership with people with dementia & carers but some staff didn't involve people with dementia.

Author - year	**Aim**	**Setting & country**	**Design**	**Sample & size**	**Key findings**	**Care Culture Themes**
Buron (2010)	To evaluate the effects of PC life history collages on nursing staff knowledge about individual residents living with dementia & staff perceptions of individualised care practices.	Two nursing homes in the USA.	**QUAN** RCT. Intervention staff members were exposed to life history collages for 4 weeks. Pre-test & post-test data were analysed using multivariate analysis of covariance & analysis of covariance.	36 nursing staff participants (18 experimental & 18 control) who cared for 5 residents with dementia in two nursing homes	Directions for future research are provided; Staff knowledge of residents' family improved significantly post-test, & at 3 weeks' post-test; Perceptions of individualised / PCC did not improve. Potential reasons for this are given.	**PREPARATION & ONGOING SUPPORT:** Not apparent. **OUTCOME(S):** Staff perceptions of PCC did not improve; Staff knowledge of residents' families improved.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Cooney & O'Shea (2018)	To explore whether knowing the person's life story enhances professionals' understanding of the person with dementia and whether this understanding impacts on the person's care.	Study undertaken in long-stay care settings in Ireland (four dementia care units). Staff received training on reminiscence then undertook LSW with residents (continued after original RCT). Staff then interviewed.	Descriptive qualitative study using data from an existing dataset (an RCT that evaluated a reminiscence programme). Constant comparative analysis (Corbin & Strauss 2008).	11 RNs & 12 HCAs.	Staff enabled to see the person behind the dementia; changed staff's thinking on what is important when delivering care. Aim achieved but how person-centred care is implemented is important.	People with dementia and not involved in design or evaluation; Small sample; LSW directly enhances quality of care; Staff training & engagement is important.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Damianakis et al. (2010)	The purpose of this feasibility pilot project was to observe people with dementia & MCI responses to personalised multimedia biographies (MBs).	USA: 'a multiservice geriatric care institution located in a large urban centre'.	**QUAL** Used digital video technology to construct DVD-based MBs. Collected archival materials to best capture the families' & patients' life histories. Filmed patients, conducted follow-up interviews with families & patients at 3 & 6 months. Thematic content analysis of the interview & video data.	6 family members & 6 people with dementia from one centre. Purposive sampling. Health & social care professional referred clients for the project. Students helped sample produce their biographies.	Showed how evoked long-term memories stimulated reminiscing for people with dementia & family carers but also some sadness.	**PREPARATION & ONGOING SUPPORT:** No evidence of staff, care home or organisational preparation or involvement**.** **OUTCOME(S):** None for the organisation; Lack of staff involvement in the project - not mentioned at all; Positive outcomes all for the people with dementia & families.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Doyle (2014)	To explore the experiences of formal carers who participate in LSW with people with dementia.	Residential Care setting in Dublin, Ireland.	**QUAL** A qualitative descriptive approach using semi-structured interviews.	8 formal carers (Nurses & HCAs)	LSW facilitates PCC by relieving loneliness, anxiety & agitation; Promotes trust, security & rapport & communication between staff, families & people with dementia; Friends are important information source.	**PREPARATION & ONGOING SUPPORT:** Not possible to determine but positive staff views of LSW sought. **OUTCOME(S):** Need to include LSW in care planning; Continuity of staff is important; Promotes positive communication between staff, family & people with dementia; Should commence LSW before admission.

Author - year	**Aim**	**Setting & country**	**Design**	**Sample & size**	**Key findings**	**Care Culture Themes**
Gridley et al. (2016)	To establish if full evaluation of LSW was feasible.	England: Survey: generalist & specialist care homes; NHS dementia care settings; community dementia services. Feasibility study: care homes & NHS dementia care wards.	**QUAL / QUAN** Mixed-methods feasibility study. A systematic review on best practice & change. In-depth interviews & focus groups explored experiences of LSW & best practice with people with dementia, family & staff; Dementia providers survey.	567 care providers surveyed (response rate: 57%=288); Interviews & focus groups (10 people with dementia, 12 carers, 30 staff). Focus groups & interviews with staff in care homes.	LSW learning points: LSW never complete; More likely to do LSW using template; Community teams - less structured LSW used; Carers do LSW to inform people with dementia care; LSW spreading but practice varies; 2 different models evident- appropriate at different stages; Can’t attribute QoL improvement just to LSW; Highlighted costs; Dearth of outcome data in literature & many challenges for future research, but LSW may help improve staff attitudes & QoL. Full evaluation of staff attitudes & QoL possible if researchers based at or close to setting.	**PREPARATION & ONGOING SUPPORT:** No mention of this or organisational implications in good practice learning points but a review of the project conclusions suggests the following. **OUTCOMES**: Training important; Care quality improved (QoL assessed); Considered staff burnout & attitudes; Staff attitudes significantly improved; Staff time pressures mean research time is often wasted: researchers need to be based at or close to setting; ‘Organisational challenges may prevent positive outcomes being achieved.' because ‘an individually tailored approach is essential to ensuring maximum benefit'; ‘Formal evaluation of LSW would be possible only with substantial staffing'; Staff fatigue contributed to a lack of data being collected.

Author - year	**Aim**	**Setting & country**	**Design**	**Sample & size**	**Key findings**	**Care Culture Themes**
Ingersoll-Dayton et al. (2013)	To describe the way in which interventionists participated in the development of an intervention for dyads in which one person is experiencing memory loss.	USA & Japan Developed & used a 'Couples Life Story Book' which included the couple's narrative.	**QUAL?** No research methods stated other than: An analysis of cases (see sample). 'Members of the Japanese and American teams met together to analyse the progress of couples who participated in the project.' 5-week intervention, the Couples Life Story Approach, helps dyads to reminisce about their life together as a couple, work on their communication patterns & develop an LS book.	USA – 20 couples Japan – 9 couples Used life review techniques, but team worked conjointly with couples to aid reminiscence and to tell story of their lives together.	Clinical themes emerged for the couples; Similar themes in USA & Japan emerged; Not really LSW, more reminisces & couple focused. Themes: Partner affirmation; Improved engagement; Handling losses; The fullness of life as a couple.	**PREPARATION & ONGOING SUPPORT:** The practitioner generally meets the couple in their home, a care facility, or the home of a family member. **OUTCOME(S):** Not considered, but some people were interviewed in homes.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Kellett et al. (2010)	To assess the influence of participation in the Family Biography Workshop (FBW) & the impact of developing biographical knowledge on family-staff caregiver attitudes, perceptions of roles, conflict & the subsequent management of stress using participatory care practices.	Australia Staff working in a care home.	**QUAL** A qualitative descriptive approach. Following completion of the workshops, two focus groups were held. Researcher field notes. Followed by thematic analysis.	Seven family caregivers, seven staff & one researcher working collaboratively through a series of six weekly two-hour sessions, designed to help them build a biography of the person with dementia.	Enabled family carers to see the person; Substantiated the use of FBW. Themes: Family - standing outside; Staff - opening possibilities; Person with Dementia – knowing how; Organisational Issues - complementing the organisation.	**PREPARATION & ONGOING SUPPORT:** Seven family caregivers, seven staff & one researcher working collaboratively through a series of six weekly two-hour sessions. **OUTCOME(S):** Empowered staff to engage in inclusive care practices; Improved partnership between staff, people with dementia & carers; Staff & carers worked together; 'Complementing the organisation' emerged as a theme with three characteristics: promoting community, challenges, and staff responsibility. Organisational challenges: Some families not ready for LSW until they accept changes in people with dementia; some never accept. Admission time = multiple form filling. Care plan written within the first month, if biography info isn't available then opportunity lost. Solutions include: commence info collecting at home, use life stories as staff training, & link new families with a staff member.

Author - year	**Aim**	**Setting & country**	**Design**	**Sample & size**	**Key findings**	**Care Culture Themes**
McKeown et al. (2010)	How LSW is understood & developed in practice; experienced by all participants & affects the delivery & outcomes of care.	Four sites across one NHS Health Trust in the UK (3 wards & 1 day centre).	**QUAL** A multiple case study design was adopted within a constructivist approach. Semi-structured interviews, observation, and conversations were employed. Thematic analysis.	LSW was undertaken with four people with dementia, their family carers and care staff. 4 people with dementia; 4 carers; 17 care staff. Implementation of LSW was facilitated by the researcher.	LSW helps staff see the person; Helps relatives support personhood; Individualised care provided; Helps people with dementia live well; Needs to be sensitively facilitated; LSW enhances PCC; Enjoyable for people with dementia who feel proud of their lives; Voice of people with dementia heard. Three themes: From patient to person: Can you hear me? and Pride, and Enjoyment.	**PREPARATION & ONGOING SUPPORT:** **Practice development approach** applied to the LSW intervention, including project purpose being explained to Senior Management team and supplemented by presentations to all participants. Links between theory and practice also emphasised. **OUTCOME(S):** Training important; Care quality improved; Taking a practice development approach ensures LSW can be implemented sensitively & sustained in practice.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
McKeown et al. (2015)	A critical appraisal of some challenges that may be faced in practice.	An NHS Mental Health & Social Care Trust.	**QUAL** An in-depth case study analysis was undertaken. Data collection included semi-structured interviews, observation, conversations & field notes.	**Extension of the study described above**.	Private memories not suitable for inclusion; LSW can be challenging; the quality of LS books variable (staff spelling mistakes).	**PREPARATION & ONGOING SUPPORT:** **OUTCOME(S):** Planned approach to implementation, including facilitation, education & supervision essential; In some cases, staff were unaware of the existence of life story books, and consequently, not used with residents; The potential ‘over-use’ of the life story books - need to find ‘correct’ balance in using the LS Book.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Subramaniam et al. (2014)	To evaluate the effect of different pathways for developing a life story book (LSB) for people with dementia.	Three care homes in North Wales.	**QUAN** Preliminary RCT. Outcome measures used (QoL).	Randomly allocated 23 care home residents to 2 groups: group 1 = 12 individual life review sessions & co-created a LS book; group 2 = relatives prepared a 'gift' LS book for person. 68 staff directly involved as a carer.	LSW has benefits for all involved even if the person not involved in process; A life review process, resulting in a life story book and/or the provision of an LS book, is associated with improved autobiographical memory, compared with usual care (relative involvement might explain the improved memory).	**PREPARATION & ONGOING SUPPORT:** Care home managers but not staff involved throughout; Carers consulted with & supported; Support provided by a Clinical Psychologist. **OUTCOME(S):** Training & supervision important; Staff knowledge of people with dementia & attitudes to dementia improved; LS books appeared to have had significant impact (new information on residents) on homes with some developing LS books for other residents & integrating LSW within care programme.

Author - year	**Aim**	**Setting & country**	**Design**	**Sample & size**	**Key findings**	**Care Culture Themes**
Subramaniam & Woods (2012)	To establish an evidence base for the acceptability and efficacy of using multimedia digital life storybooks with people with dementia in care homes, in comparison with conventional life storybooks.	Care homes in North Wales. A study was undertaken as part of a PhD. A multimedia digital life storybook gives potential to add music, audio, video clips.	A **mixed method study** (both **QUAN & QUAL**) using a multiple single-case approach with six participants recruited, having completed a previous life storybook project. **Follow-up to above study.** **Participatory** design to create an LS movie based on a previously completed conventional LS book. Quantitative questionnaires on conventional LS book. Semi-structured interviews collected feedback from participants, relatives, & care staff.	6 people with dementia (4F). Staff added comments to the questionnaires (number unclear).	5 participants showed improvement in QoL measures & auto-biographical memory; All showed improvement or stabilisation in depression scores; All viewed digital LS Books as useful memory trigger & had (largely) positive emotions; Participants, relatives, & staff welcomed the idea of developing an LS movie and reported a positive experience of taking part in this project.	**PREPARATION & ONGOING SUPPORT:** Care home managers involved; Participatory design used, with the participant actively involved in the decision-making process, designing and creating, & directing their own life story movie with the researcher acting as co-editor. **OUTCOME(S):** Staff considered digital LS books as useful & that communication & interaction was enhanced; Staff gained information & knowledge about the people with dementia.

THEMES

SETTING	
Berendonk & Caine (2016)	Germany. Nursing homes.
Buron (2010)	Two nursing homes in the USA.
Cooney & O'Shea (2018)	Four dementia care units in Ireland.
Damianakis et al. (2010)	USA: 'a multiservice geriatric care institution located in a large urban centre'.
Doyle (2014)	Residential Care setting in Dublin, Ireland.
Gridley et al. (2016)	England: Survey: Generalist & specialist care homes; NHS dementia care settings; community dementia services. Feasibility study: Care homes & NHS dementia care wards.
Ingersoll-Dayton et al. (2013)	USA & Japan: Community or home.
Kellett et al. (2010)	Australia. Care home.
McKeown et al. (2010)	Four NHS Health & Social Care Trusts in the UK (3 wards & 1 day centre).
McKeown et al. (2015)	An NHS Health & Social Care Trust in the UK.
Subramaniam et al. (2014)	Three care homes in North Wales.
Subramaniam & Woods (2012)	Care homes in North Wales.

SAMPLE: Largest sample of people with dementia: 23 Smallest: 4	
Berendonk & Caine (2016)	36 nursing staff.
Buron (2010)	36 nursing staff.
Cooney & O'Shea (2018)	11 Registered Nurses & 12 HCAs.
Damianakis et al. (2010)	6 family members; 6 people with dementia.
Doyle (2014)	8 nursing staff.
Gridley et al. (2016)	567 care providers surveyed (response rate: 57%=288); Interviews & focus groups (10 people with dementia, 12 carers, 30 staff).
Ingersoll-Dayton et al. (2013)	USA: 20 couples; Japan: 9 couples.
Kellett et al. (2010)	7 family caregivers; 7 staff; 1 researcher.
McKeown et al. (2010)	4 people with dementia; 4 family carers; 17 care staff.
McKeown et al. (2015)	4 people with dementia; 4 family carers; 17 care staff.
Subramaniam et al. (2014)	23 care home residents.
Subramaniam & Woods (2012)	6 people with dementia. Staff added comments to the questionnaires (number unclear).

RESEARCH METHODOLOGY USED: QUALITATIVE (8) – QUANTITATIVE (2) – MIXED (2)	
Berendonk & Caine (2016)	Grounded theory using semi-structured interviews and group discussions.
Buron (2010)	Randomised Control Trial.
Cooney & O’Shea (2018)	A qualitative descriptive approach using semi-structured interviews.
Damianakis et al. (2010)	Qualitative: thematic content analysis of the interview & video data.
Doyle (2014)	A qualitative descriptive approach using semi-structured interviews.
Gridley et al. (2016)	Mixed-methods: In-depth interviews & focus groups. Survey.
Ingersoll-Dayton et al. (2013)	Qualitative: an analysis of cases.
Kellett et al. (2010)	A qualitative descriptive approach: focus groups, field notes and thematic analysis.
McKeown et al. (2010)	Qualitative: A multiple case study design: Semi-structured interviews, observation, conversations and thematic analysis.
McKeown et al. (2015)	Qualitative: An in-depth case study analysis: Data collection included semi-structured interviews, observation, conversations & field notes.
Subramaniam et al. (2014)	Randomised Control Trial.
Subramaniam & Woods (2012)	Mixed method study using a multiple single-case approach.

LIFE STORY APPROACH USED	
Berendonk & Caine (2016)	Life story questionnaires.
Buron (2010)	Life history collages.
Cooney & O’Shea (2018)	Life story book.
Damianakis et al. (2010)	Used digital video technology to construct DVD-based personalised multimedia biographies.
Doyle (2014)	Life story book.
Gridley et al. (2016)	Reported on a range of life story approaches, mainly a life story template & informal.
Ingersoll-Dayton et al. (2013)	A ‘Couples Life Story Book’.
Kellett et al. (2010)	A family biography workshop designed to help staff and carers build a biography of the person with dementia.
McKeown et al. (2010)	Life story book/template.
McKeown et al. (2015)	Life story book/template.
Subramaniam et al. (2014)	Life story book.
Subramaniam & Woods (2012)	Multimedia digital life storybooks.

STUDY AIMS	
Berendonk & Caine (2016)	To explore care staffs' understandings of life story work when caring for persons with dementia.
Buron (2010)	To evaluate the effects of person-centred life history collages on nursing staff knowledge about individual residents living with dementia & staff perceptions of individualised care practices.
Cooney & O'Shea (2018)	To explore whether knowing the person's life story enhances professionals' understanding of the person with dementia and whether this understanding impacts on the person's care.
Damianakis et al. (2010)	To observe persons' with dementia & mild cognitive impairment responses to personalised multimedia biographies.
Doyle (2014)	To explore the experiences of formal carers who participate in LSW with people with dementia.
Gridley et al. (2016)	To establish if full evaluation of LSW was feasible.
Ingersoll-Dayton et al. (2013)	To describe the way in which interventionists participated in the development of an intervention for dyads in which one person is experiencing memory loss.
Kellett et al. (2010)	To assess the influence of participation in the Family Biography Workshop & the impact of developing biographical knowledge on family-staff caregiver attitudes, perceptions of roles, conflict & the subsequent management of stress using participatory care practices.
McKeown et al. (2010)	To assess how LSW is understood & developed in practice as experienced by all participants & how LSW affects the delivery & outcomes of care.
McKeown et al. (2015)	To conduct a critical appraisal of some challenges that may be faced in (LSW) practice.
Subramaniam et al. (2014)	To evaluate the effect of different pathways for developing a life story book (LSB) for people with dementia.
Subramaniam & Woods (2012)	To establish an evidence-base for the acceptability and efficacy of using multimedia digital life storybooks with people with dementia in care homes, in comparison with conventional life storybooks.

ORGANISATIONAL PREPARATION FOR THE STUDY & ONGOING SUPPORT PROVIDED DURING THE PROJECT	
Berendonk & Caine (2016)	Not apparent but probably not appropriate as just sought staff views.
Buron (2010)	Not apparent but probably not appropriate as just sought staff understandings.
Cooney & O’Shea (2018)	Not apparent but staff received training on reminiscence then undertook LSW with residents.
Damianakis et al. (2010)	No evidence of staff, care home or organisational preparation or involvement.
Doyle (2014)	Not possible to determine but positive staff views of LSW sought. No mention of any preparation undertaken in respect of the service.
Gridley et al. (2016)	No mention of this or organisational implications in good practice learning points but a review of the project conclusions suggests several organisational considerations.
Ingersoll-Dayton et al. (2013)	The practitioner generally meets/supports the couple in their home, a care facility, or the home of a family member. No mention of any preparation undertaken in respect of the service or care facility.
Kellett et al. (2010)	Seven family caregivers, seven staff & one researcher, worked collaboratively through a series of six weekly two-hour sessions. No mention of any preparation undertaken in respect of the service.
McKeown et al. (2010)	Practice development approach applied to the LSW intervention, including project purpose being explained to Senior Management team and supplemented by presentations to all participants. Links between theory and practice also emphasised.
McKeown et al. (2015)	Same as above.
Subramaniam et al. (2014)	Care home managers initially consulted with but not staff. Carers consulted with & supported (support provided by a Clinical Psychologist).
Subramaniam & Woods (2012)	Care home managers initially consulted with but not staff. Participatory design used, with participants actively involved in the LSW decision-making process, designing and creating, & directing their own life story movie with the researcher acting as co-editor.

STUDY OUTCOME(S) FOR THE ORGANISATION - BOTH POSITIVE & PROBLEMATIC	
Berendonk & Caine (2016)	LSW is challenging for staff to deliver. Why? Task driven care & time. Some evidence of working in partnership with people with dementia & carers but some staff didn't involve people with dementia.
Buron (2010)	Staff perceptions of PCC did not improve, but their knowledge of residents' families improved.
Cooney & O'Shea (2018)	Staff enabled to see the person behind the dementia; changed staff's thinking on what is important when delivering care. Improved care quality.
Damianakis et al. (2010)	None for the organisation. Lack of staff involvement in the project not mentioned at all. Positive outcomes all for the people with dementia & families.
Doyle (2014)	Need to include LSW in care planning; Continuity of staff important; Promotes positive communication between staff, families & people with dementia; Should commence LSW before admission.
Gridley et al. (2016)	Training important; Care quality improved (QoL assessed); Considered staff burnout & attitudes; Staff attitudes significantly improved; Staff time pressures mean research time is often wasted, so researchers need to be based at or close to setting; Staff fatigue contributed to a lack of data being collected. 'Organisational challenges may prevent positive outcomes being achieved.' because 'an individually tailored approach is essential to ensuring maximum benefit'. 'Formal evaluation of LSW would be possible only with substantial staffing'.
Ingersoll-Dayton et al. (2013)	Not considered, but some people were interviewed in own homes.
Kellett et al. (2010)	Empowered staff to engage in inclusive care practices; An improved partnership between staff, people with dementia & carers; Staff & carers worked together. 'Complementing the organisation' emerged as a theme with three characteristics: promoting community, challenges, and staff responsibility. Organisational challenges: Some families not ready for LSW until they accept changes in people with dementia; some never accept. Admission time = multiple form filling. Care plan written within the first month, if biography info isn't available then opportunity lost. Solutions include: commence info collecting at home; use life stories as staff training; & link new families with a staff member.
McKeown et al. (2010)	Training important; Care quality improved; Taking a practice development approach ensures LSW can be implemented sensitively & sustained in practice.
McKeown et al. (2015)	Planned approach to implementation including facilitation, education & supervision essential; In some cases, staff were unaware of the existence of life story books, and consequently they were not used with residents; The potential 'over-use' of the life story books - need to find 'correct' balance in using the LS Book.
Subramaniam et al. (2014)	Training & supervision important; Staff knowledge of people with dementia & attitudes to dementia improved; LS books appeared to have had significant impact (new information on residents) on homes with some developing LS books for other residents & integrating LSW within care programme.
Subramaniam & Woods (2012)	Staff considered digital LS books as useful & that communication & interaction was enhanced. Staff gained information & knowledge about the people with dementia.

APPENDIX THREE:
CASP SUMMARY (2): THE LITERATURE ON THE USE OF PARTICIPATORY ACTION RESEARCH IN DEMENTIA CARE

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Goeman et al. (2016a)	To develop an inclusive model of culturally sensitive support, using specialist dementia nurses.	A home nursing service that provides community support for people with cognitive impairment from culturally and linguistically diverse communities in Australia.	A 2-year qualitative study that used co-creation and PAR, based on reflection, data collection, interaction & feedback from participants and stakeholders in a cyclical manner.	62 (41F, 21 M) received support from SDNs, of which 15 were relatives. Other 47 were people with dementia. Also used expert stakeholders' (13) meetings to develop a new model of CALD dementia care.	The model helped people with dementia and their carers to overcome barriers to accessing health and social care services; The model helps adjust to living with memory loss & remain living in the community as long as possible.	Low level of people with dementia and carer engagement; Very loosely defined PAR qualitative approaches used; Stakeholder & working group used; Reasonable community engagement over 2 years; Helping a cultural group; No outcome measures used.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Goeman et al. (2016b)	To develop and refine the Vietnamese Dementia talking-book. The book aims to address low health literacy in Vietnamese people with dementia through the provision of an online resource.	Vietnamese community planned activity groups in the suburbs of Melbourne, Australia.	2-year qualitative study using co-design & PAR that used two stages. Working group included researchers. Content agreed in collaboration with expert stakeholders. Focus groups, semi-structured interviews. Interviews audio-recorded, transcribed & coded/themed using NVivo. Interviews continued until data saturation. SPSS used to describe participant demographics.	Convenience sample of 59 from Vietnamese community, 11 stakeholders. 22 from Vietnamese community appraised the final product. 59 participated in consultation on content 22 Vietnamese people participated in either a focus group or an individual interview to evaluate the final version. Also used expert stakeholders (11) meetings	Enhanced the knowledge of members of the Vietnamese community in regard to understanding dementia and navigation and accessing of available services.	Low level of people with dementia and carer engagement; Stakeholder & working group used; Reasonable community engagement over 2 years; Helping a cultural group; PAR stages described but not linked to a framework; No outcome measures used.

Author - year	**Aim**	**Setting & country**	**Design**	**Sample & size**	**Key findings**	**Care Culture Themes**
Vikström et al. (2015)	The aim of this paper is to describe a model for implementing national evidence-based guidelines for care of persons with dementia in nursing homes. The secondary aim is to outline the nursing home staff experiences during the first year of the implementation process.	Sweden – Nursing home was already a good example of PC dementia care. A multi-professional team (7) from local HEs (3 nurses, 1 physio, 3 OTs) facilitated implementation.	Implemented using Taylor's (2004) 6 step PAR empowering model. Interventions: educational activities; thematic seminars; unit-based seminars; information dissemination in seminars & poster-exhibitions. Data extracted from these by qualitative content analysis. All 24 units met x 10 over 8 months & had quality strategy. Resident demographic data also collected.	Staff (200) = 170 nurse aides, 25 professionals (RNs, physical & OTs) & 5 managers.	Findings showed that implementation of guidelines was perceived by staff as beneficial for both staff and residents; However, barriers to identification of relevant sources of evidence and barriers to sustainable implementation were experienced.	No evidence people with dementia, carers or staff involved in study design; No stakeholder group? Claimed to be empowering but initial design was top-down; PAR structure used: Taylor (2004); Peer reviewed; Guidelines useful for planning purposes but impact on care quality in long term not evaluated.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Wiersma et al. (2016)	To translate knowledge about living well with dementia into a self-management program for people with dementia. To examine the process whereby people with dementia and other knowledge users are engaged meaningfully in program development.	Three multi-stakeholder advisory groups were set up in 3 locations across Canada.	A PAR study. First meetings explored what self-management meant to the group members. Conversations then structured around themes which emerged from initial discussions & ideas generated from a literature review. The meetings were tape-recorded and transcribed. The data that was abstracted was then coded. Quotes were grouped according to themes & discussed in the meetings. Through an iterative process of reviewing the transcripts & quotations, & discussions. A thematic analysis of these ongoing discussions coalesced around 4 inter-related themes.	Three advisory groups consisted of 20 people with dementia, 13 care partners, and three service providers. The hubs met monthly for up to two years. Ethics obtained.	Four inter-related themes: creating safe space; maintaining voice and being heard; managing the balancing act; the importance of solidarity. Underpinning these was fifth theme: recognition that 'one size doesn't fit all'. Also presence of family could have unintended consequences in relation to creating the space for active citizenship to occur in small groups of people with dementia although it could also offer some opportunities.	Good representation of people with dementia; The involvement of care partners was discussed and questioned; Good way to develop a new quality initiative for people with dementia; Good, reflective approach to PAR – they kept feeding the emerging themes back into the groups; Good size sample of people with dementia; No follow-up.

Author - year	**Aim**	**Setting & country**	**Design**	**Sample & size**	**Key findings**	**Care Culture Themes**
Caine (2013)	The purpose of this practitioner research was to test: if (preferred) music was prescribed daily to a person with dementia using an MP3 player and headphones could this impact positively on their mood/ well-being and would this have a positive impact on the carer?	Participants were attending a Dementia Café in Edinburgh PAR used to set up & evaluate an intervention.	Used qualitative research: combination of discussion groups, semi-structured interviews, feedback forms and diaries. Evidence from both carers & people with dementia entailed measuring mood & identifying if music had any effect on mood; then measuring how long this lasted. Interviews & discussion groups audio taped & transcribed. Semi-structured interviews were conducted with both carer & people with dementia on an individual basis after the listening period. A grounded theory approach: a thematic analysis to categorise various themes initially. Repeated re-analysing of these themes distilled them down to eight.	Five couples were recruited to take part in this small-scale study and all completed it. The participants with dementia were in the early to moderate stages of their illness. The criteria for participation were that the person should enjoy music; and be in the early to moderate stage of their illness. Ethical approval obtained.	The results of feedback from people with dementia showed the music had affected their mood positively on 33 out of 35 occasions; The carer diaries revealed that the effect during and after was positive and the person's mood had improved; How long the positive effect lasted was different for each person.	Report not peer reviewed but reflection published in Journal of Integrated Care in 2014; 2 months later only 1 person still regularly listening to the music; People with dementia involved? Not in overall design but in feedback & how they listened to music; PAR helps to gain service user views but supports service users and providers to work in an integrated way.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Nomura et al. (2009)	To describe the implementation and process evaluation of a programme based on cognitive rehabilitation aimed at empowering the elderly with early dementia, and education and counselling programmes aimed at likewise empowering their family caregivers.	A rural town in Japan. The PAR lasted for 5 years and evolved over three cycles: individual, group, and community. This study used a community health action research model.	PAR was conducted through a cycle of planning, action, and reflection to identify effective interventions to empower people with dementia and their caregivers. A focus group interview was used for assessment. A monthly activity-based programme based on cognitive rehabilitation was developed to improve cognitive function. 3 types of data collected: observational during the activities; written comments from the carers; record of phone interviews & counselling with carers. These data were compiled in chronological order into a portfolio for analysis.	This project involved 37 community-dwelling elderly people with early or mild dementia and 31 family caregivers. In total, 6 researchers & 11 clinicians participated in the PAR. The researchers participated in the activity programme.	Cognitive rehabilitation theory was useful to restore lost procedural skills and regain confidence for people with dementia; This PAR illustrated the importance of interventions for both community dwelling elderly people with early dementia and their family caregivers.	Data seems to have been collected from 1995-1997; No evidence people with dementia were involved at any stage other than undertaking the programme; Full stakeholder involvement not apparent; Longitudinal study, strictly following PAR, evaluating a cognitive programme.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Dupuisa et al. (2012)	To gain a comprehensive understanding of the meanings and experiences of leisure from those living with dementia who were at various stages of the disease.	The Partnerships in Dementia Care Alliance, a collaborative research network based in Ontario, Canada, that works with people with dementia to improve care.	PAR cycles of planning, acting/ observing & sharing reflections on the process. All data collected after cycle 2 underwent thematic analysis by a sub-committee from larger PAR team guided by hermeneutic phenomenology Cycle 3-from themes a number of actions were identified. Study length?	Online, open-ended questionnaire for persons in the early stages of dementia, family & professionals (*n* =215). (PAR) project brought together people with dementia, family members, recreation professionals from a range of settings (i.e. the community, day programmes, long-term care homes).	Described the reflections on the process, including struggles & insights on the possibilities of the approach; Lessons from partners with dementia & how to support them in similar processes; Understanding leisure from the perspectives of people with dementia, family & professionals.	Difficult to read paper; not presented in classic AR format; Emphasises involvement of people with dementia at all stages; Suggests approaches to partnership; Follows 3 stage PAR process & adds AI; Explores philosophical aspects.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Keatinge et al. (2000)	To measure how agitation manifested, to measure the severity of agitation and to identify current nursing practices used to manage it and their outcome. The nurses identified that the management of agitated behaviour was a major challenge.	Study undertaken by nurses in a nursing development unit in New South Wales, Australia.	A pilot PAR study. Over 10 months: Initial observation period; analysis & discussion of results; repeat phase 1; evaluate impact of changes made in phase 2. Data then used for content analysis. Descriptive statistical analysis also undertaken by SPSS. 2-3 staff observed & rated residents' agitation during their normal duties over a 3-week period, during which 10 episodes of agitation were rated.	10 residents were required to participate. Consent /ethics was sought from carers.	Nurse actions triggered majority of most highly rated episodes of agitated behaviour and most related to carrying out activities of daily living.	People with dementia and carers not involved in design or evaluation; Small sample; Very clearly defined study; Aim to improve care by modifying nursing input.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Chenoweth and Kilstoff (1998)	The day care staff and carers consulted with clients to design, implement and evaluate a new therapy program (mainly alternative therapies). Stated willing to participate as ethics.	A multi-cultural day care centre in Sydney.	PAR study undertaken from June 1995 to 1996, which arose out of the initiatives of people caring for clients attending a multicultural dementia day-care program. Study research involved a number of spirals (12 stages). The researchers acted as facilitators. Data collection: Focus group memos, in-depth interviews, client observation logbooks, rating scale & field notes.	The day care staff and family carers consulted with clients: people with dementia (16), their carers (16), staff (8).	Outcome of therapy program: People with dementia: renewal of close personal relationships with carers, increased alertness & reduction in some distressing symptoms; Carers: awareness of new purposes in caring role & so less distress; Staff: re-conceptualisation of dementia care program purpose & benefits from community collaboration in program design.	Stated PAR but then talked about AR; No evaluation of therapy program's impact on clients & people with dementia; International Journal of Nursing Practice; Used PAR to develop, implement and evaluate a new therapy program. Carers and staff devised stage 1; Good sample and study intentions for the time.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Clancy (2015)	To investigate the nature and delivery of a service model in a rural dementia outreach service.	A dementia outreach service in rural Australia.	PAR used to collect data through four focus groups. A research action team, comprising all 5 DOS staff, was involved in tasks such as sampling criteria & service improvement issues arising from the data. Focus group recordings & transcribed, field notes recorded key themes in focus groups & post-group debriefings with facilitator. Analysis was an iterative process so that data from each focus group informed questions for subsequent groups.	22 participants comprised staff of the service, representatives of the community dementia service sector, and medical and health staff with expertise in dementia. Ethical approval obtained.	Transcriptions from groups were coded into themes, which were developed into working models. Models changed as new data were added; Developed a practice model for a dementia outreach service, including a theoretical framework of person-centred care, five practice principles and seven core activities.	No carers or people with dementia involved; Small sample; Further evaluation needed; PAR was used to develop a new practice model.

Author - year	Aim	Setting & country	Design	Sample & size	Key findings	Care Culture Themes
Hanson et al. (2007)	The Assisting Carers using Telematics Interventions to meet Older People's Needs ICT-based service was developed with family carers and frail older people living at home to provide them with early information, education and support.	Researchers, practitioners and technicians in West Sweden worked together with older people with early stage dementia and their family members to develop a user-friendly technology-based information, education and support service, based on the generic ACTION participatory design model. ACTION involves a participatory approach that draws on the expertise of all participants.	The ACTION design process comprises three phases: identifying user needs; early programme development; testing and refining. Group met at local day centre for 9 months, weekly for the first 4 months & then on a fortnightly/ monthly basis. Users' needs & preferences explored in tape-recorded. discussion groups. Videos & photos from members' homes & outings also used. After completing programme in-depth interviews were conducted.	In total 7 people with dementia (4M, 3F aged 68–81) & and one member's wife also attended to support her spouse. Ethical approval obtained.	People with early dementia can be actively involved in entire research process. Essential prerequisites: time, support by professionals & carers; People with early dementia can learn & benefit from user-friendly IT, especially when used with others; Ways of partnership working with people with early dementia & carers explored & lessons noted.	Uses PAR and LSW combined; People with dementia & carers involved at all stages.

APPENDIX FOUR:
STUDY PROTOCOL FOR ETHICAL APPROVAL

RESEARCH PROPOSAL

TITLE

The use of life story work in an age inclusive dementia service: a participatory action research study

SUMMARY

Using participatory action research, this two-year study examines how life story work can be embedded into an age-inclusive dementia care service.

Contemporary research and practice acknowledges that involving people and carers and understanding the person through life story work is integral to good practice and high quality care. Life story work supports the delivery of a person-centred care plan by promoting a better understanding of the person and improving relationships between the person, their carers and staff.

This study will investigate how the use of a life story profile can be embedded into an age-inclusive dementia service. It will describe the cultural and organisational changes that are required for practitioners to value life story work as part of delivering high quality care and will explore the strategies necessary to internalise and externalise such work.

An inter-disciplinary participatory action research (PAR) group will be established to develop a strategic vision and operational processes to capitalise on the potential of life story work to revolutionise traditional care practices. To achieve this, the group will establish a new approach to life story work that involves choice for the person in relation to how their life story could be captured. The concept of life story work will be introduced to 30 people recently diagnosed with dementia and their carers in a two hour group setting. They will then be given three further individual one hour support sessions.

It is anticipated that the PAR group will meet on a monthly basis for an initial period of six months. These groups will be audio recorded and the data analysed as part of the study.

Data collection will also include interviews with people with dementia and their carer. This will demonstrate how people's unique life stories might contribute to the provision of high quality dementia care.

RESEARCH AIM

The aim of the project is to:
Examine how life story work can be embedded into an age-inclusive dementia care service

RESEARCH OBJECTIVES

The objectives are to:

1. Explore the cultural and organisational changes required for practitioners to internalise life story work as part of delivering high quality dementia care.
2. Determine how the use of a life story profile can be embedded into an age-inclusive dementia service.
3. Develop a model of service redesign which facilitates the introduction of good practice in dementia care.
4. Analyse the essential and desirable components of life story work from the perspective of the person, their carers and practitioners.

BACKGROUND

The research aim has partly evolved in response to the development of a new age-inclusive dementia service within The Trust.

Using a participatory action research approach, this two year study examines the use of life story work in an age-inclusive dementia service.

The process of planning to meet the care needs of those with dementia is a primary task of health practitioner work. Traditionally this has been perceived as a professional task undertaken in isolation from the person living with dementia. Contemporary research and practice with those with dementia acknowledges that involving people and carers and understanding the person through life story work, or their biography, is integral to good practice and consequently good quality care. Life story work supports the delivery of a person-centred care plan by promoting a better understanding of the person and improving relationships between staff, the person and their carers.

Currently, there are around 750,000 people living with dementia in the UK, including around 16,000 under the age of 65. With an ageing population this figure is expected to rise to over 1 million by 2020 (Alzheimer’s Society 2007). In addition to its profound personal and social impact, dementia has significant financial implications for people with dementia, their families and for health and social care providers. The current financial cost to the UK economy is over £18 billion a year (Alzheimer’s Society 2007) and is likely to treble in the future as the number of people living with dementia increases (Goodchild 2009). In a time of government reforms and financial constraints (Department of Health 2010) providing high quality care and support to people with dementia is of significant concern for health and social care services. To meet these challenges there is a need to develop services which are flexible and responsive to people with dementia and to support them and their carers to live well

with dementia. This involves listening to the people for whom the services are being provided and developing services accordingly to meet their needs.
If practitioners are to deliver person-centred care, then they need to learn more about the person as an individual and have an understanding of their personal meanings, experiences and attitudes. One way that this might be achieved is through life story work or biographical approaches (Clarke et al. 2003). The use of a biographical approach may enhance the personhood of the person and thus promote person-centred care; and can strengthen relationships between staff, the person and their carers, empowering staff to engage in flexible, inclusive care practices (Keady & Williams 2007). Kitwood (1997) defined personhood as a status bestowed upon one human being, by others, in the context of relationships and social being.

The strategy “Living Well with dementia; A National Dementia Strategy” (DoH 2009) provides a framework of 18 objectives for organisations to improve dementia services. Service integration and partnership with people with dementia and their carers is key to achieving the objectives set out in the strategy which highlights three key areas where improvement in dementia care services should be made:

- Improved awareness
- Early diagnosis and intervention
- High quality care and support

The focus of this project is in this last area. Quality dementia services should be designed to meet individual needs However, dementia may impact adversely on a person’s ability to communicate their needs effectively (Murphy et al. 2005; Acton et al. 2007).

When the dementia service was established 14 months previously, life story work was considered integral to the operational model. However life story work has recently received lower priority. However, there is now a growing recognition of the evidence base that underpins life story work and hence a commitment to re-establish its use in a meaningful and sustainable way. This notion correlates with the principles of life story work in that any book or other media produced should accompany the person on their dementia journey to underpin person-centred care.

Person-centred dementia care

The contemporary principles of caring for someone with dementia have been greatly influenced by the work of Tom Kitwood (1997). Within this person-centred framework, care is based on the assumption that all humans have five fundamental psychological needs:

- Comfort, the provision of warmth and strength
- Attachment, the forming of specific bonds or attachments
- Inclusion, being part of a group
- Occupation, being involved in the process of life
- Identity, having a sense and feeling of who one is

Based on this assumption Kitwood undertook research into personhood i.e. how biography and personality influence a person's experience of dementia. His research sought to provide a better understanding of how personhood was undermined for those people who were living with dementia. In addition he sought to understand how 'good' dementia care could be implemented through the adoption of positive person work and Dementia Care Mapping (Kitwood 1997). He also believed that to view dementia as an ‘organic mental illness’ ignored the important human issues and so attempted to change the perspective of dementia to one in which 'the person comes first'. Kitwood’s research and work have provided the impetus for the development of individualised and holistic care approaches including personal biographies and the sharing of the lived experience of dementia.

Life story work

There is an increasing volume of literature concerning the importance of life stories to providing person-centred dementia services (Clarke et al. 2003; Kellet et al. 2010). These studies suggest that through developing a broad knowledge of a person deriving from several sources a more person-centred plan of care may be developed.

RESEARCH METHODS

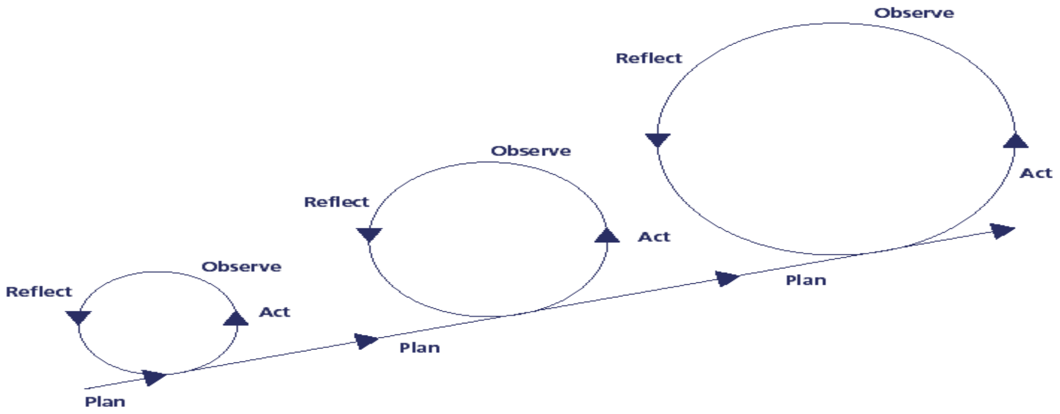
An inter-disciplinary participatory action research (PAR) group will be established to develop a strategic vision and operational processes to capitalise on the potential of life story work to revolutionise traditional practices in dementia care. To achieve this, the group intend to establish a new approach to life story work that involves choice for the person in relation to how their life story could be captured. This will use traditional life story books but also memory boxes, reminiscence items and photos, personal videos and podcasts. The concept of life story work will be introduced to 30 people recently diagnosed with dementia and their carers by an experienced practitioner in a two hour group setting. They will then be given three further individual one hour support sessions. It is anticipated that the PAR group will meet on a monthly basis for an initial period of six months after which the aims of the groups will be revisited. These groups will be audio recorded and the data analysed as part of the study.

The methods to be used to collect the qualitative evaluative data will also include interviews with people with dementia and their carers. Collecting this data will provide different perspectives on life story work, contribute to local initiatives and support the development of local guidelines. The anticipated outcomes for the study will demonstrate how people's unique life stories might contribute to the provision of high quality dementia care.

Participatory action research

The focus of action research (AR) is the ‘action’ aspect, i.e. the research aims to bring about change through a process which is flexible and involves a ‘cycle’ or ‘spiral’ of action (change, improvement) and research (understanding, knowledge) with individuals affected by the change involved in the research so that understanding is shared (Action Research and Action Learning Association 2013).

This spiral of action can be commenced at any point and repeated as new evaluative data emerges:



According to Reason and Bradbury (2008) AR is concerned with ‘working towards practical outcomes’ and ‘creating new forms of understanding’. They also state that the term AR was coined by US psychologist Kurt Lewin in 1944. Early AR was concerned with research by practitioners for practitioners with a focus on problem solving in professional structures and organisations (Heron 1996).

> ‘AR is a participatory, democratic process…..which seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people’
> (Reason and Bradbury 2008)

The core elements of AR (Reason and Bradbury 2008) are as follows:

- Context-bound and the addressing of real life problems;
- Where participants and researchers co-generate knowledge through collaborative communicative processes in which all participants’ contributions are taken seriously;
- Treating the diversity of experience and capacities within the local group as an opportunity for the enrichment of the research/action process;
- Where meanings constructed in the inquiry process lead to social action or these reflections on action lead to the construction of new meanings;
- Where the credibility/validity of AR knowledge is measured according to whether actions that arise from it solve problems (workability) and increase participants’ control over their own situation.

Action research has been utilised in many health care contexts and has become an established means of supporting change (Koch and Kralik 2006).

Similarly, participatory action research (PAR) aims to explicitly collaborate with the participants to establish mutual understanding of situations followed by action (Rahman 1985). Taylor et al. (2004) suggest that PAR is more focused on learning and eliciting the views of participants whereas AR is more concerned with social action/change and policy reform. Whilst there are similarities, there are also significant differences, philosophically and methodologically (Greenwood 2004).

Reason and Bradbury (2008) indicate that some action researchers may add the word ‘participatory’ to demonstrate a commitment to a collaborative process. Fine et al. (2000) further state that ‘PAR is distinct because it is driven by participants (a group of people who have a stake in the issue being researched) rather than an outside researcher, academic or manager (although they may be invited to help) because it:

- Offers a democratic model of who can produce, own and use knowledge
- Is collaborative at every stage, involving discussion, pooling skills and working together
- Is intended to result in some action, change or improvement on the issue being researched’

It is for the above reasons and the need to re-establish the use of life story work in the team in a meaningful and sustainable way that PAR was been chosen for this research project.

DATA COLLECTION

Staff focus group

As this is a PAR study it is important to mention that the research will be driven by the staff group so that all discussions and actions within the group become part of the data collection process. Therefore the research and model will constantly be evolving.

Thus there will be a reflective element to the participatory action research group which will explore staff perceptions on the opportunities to involve people and their carers in developing their life stories and identify positive and negative features of life story work. It will also explore the reported strategies staff use to involve people and carers in capturing their life story and their perceptions of peoples’ responses to this involvement. Furthermore staff views will be sought on how life story work has facilitated the development of the DCS as a service.

Interviews with person and carers

Qualitative interviews will seek the views and perspectives of the person and carers in relation to the use of life story work within the DCS. The data generated will reflect the uniqueness of each individual experience and will be exploratory in nature.

The objectives of the interviews are to investigate:

1. Perceived opportunities for people and carers to be involved in developing their life story
2. Evidence of involvement in life story work and the information given to support this
3. Perceived benefits and challenges of being involved in life story work

The topic guide for the interviews will be developed with the PAR group but is likely to include the following:

- In what ways have you been involved in developing your life story; are there other ways in which you would have like to have been involved or other methods that could have been used?
- Did you find the group and support sessions useful?
- Could you explain to me whether you felt the process of completing your life story was helpful?

INCLUSION CRITERIA

Staff participatory action research group

During 2011-12 The Trust recruited around 25 staff to run the DCS. This staff group was comprised of multi-professional staff and support staff, and the range of professions included nursing, occupational therapy, social work, psychology, medicine physiotherapy, nutritional advisers and associate practitioners. A representative sample from these groups will be included in the study.

Inclusion Criteria:

- Employment specifically within DCS
- Undertaken in-house preparation for working in DCS including person-centred care planning
- Both male and female staff
- Age range from 20-65

Interviews with the person and carers

Inclusion Criteria:

- Age inclusive (i.e. sample will include people who have younger onset dementia)
- Those newly referred to the DCS following diagnosis and assessment by the memory assessment service
- Trust profiling data will be utilised by the key workers to ensure the sample is representative by including people who have different forms of dementia and who have differing social profiles. The sample may be extended from 30 to ensure saturation of thematic categories
- The person is able and willing to give informed consent
- Both male and female participants
- Age range from 40-85

EXCLUSION CRITERIA

Staff participatory action research group

Exclusion Criteria:

- Temporary, bank or agency staff
- Unwilling/unable to commit to attending all of the PAGs

Interviews with the person and carers

Exclusion Criteria:

- People assessed by the memory clinic, but not accessing DCS on a regular basis
- People with behaviours that challenge and require in-patient or residential care (it would be unethical and possibly ineffective to engage with a group who are currently in severe distress)
- People with more advanced dementia (similarly, it would be unethical or potentially distressing for the person)

CONSENT PROCEDURES

The person who has dementia and carers:

As previously mentioned, only people who are able and willing to give informed consent will be invited to participate in this research study. That said, addressing ethical principles including informed consent when involving the person with dementia in research still presents a number of challenges. These include obtaining meaningful, continuous consent from the respondents, ensuring a positive research outcome for them and preventing any personal distress. Dementia can be a lonely and isolating experience and so it is crucial that research helps to counterbalance social exclusion by ensuring the person is involved in studies that document their perception of care processes. Accordingly this project seeks their views on the use of life story work. In consequence this raises a number of ethical considerations mainly because of the memory difficulties and cognitive decline associated with dementia. To alleviate these potential problems research of a similar design has adopted a multi-process, reflexive and layered approach combined with person-centred strategies to establish principles of good ethical practice (Reid et al. 2001; Dewing, 2002 and Ellins et al. 2012). This study will reflect such a philosophy by utilising the following strategies for the person who has dementia and carers:

- Key workers within the Dementia Care Service (DCS) will be asked to circulate a letter of invitation to people attending the DCS (who meet the inclusion criteria). The letter will include written information about the study and explain why it is being conducted. Potential participants will be asked to return an expression of interest form to the Chief Investigator (CI) who will make contact by phone with the person and their carer to explain the purpose of the research and make arrangements for an interview.
- A further explanation will be given and written consent obtained just before the interview commences (carers will be present during this process). Participants will be informed of their right to withdraw from the study at any time, without having to provide a reason and without affecting their care or treatment. Verbal consent will also be recorded at the beginning of each interview.
- Each interview will be recorded and will last approximately one hour. People using the DCS and their carers will be interviewed together; the decision to conjointly interview people and their carers reflects the reality of life experiences in dementia care. Some of those using the service may need support during the interviews; as previously mentioned the carer will be

present to support and contribute to this process. The CI will adopt an approach of ‘memory difficulties’ rather than a diagnosis of dementia (unless the person is fully aware of their diagnosis) to the interviews.
- Those participating will be given assurances that their confidentiality, privacy and anonymity will be protected. The respondents and their carer will be advised that the data will be kept on a computer which will be password protected and can only be accessed by the CI and project supervisor. Once the research report is completed the data will be erased. Assurances will also be given that no individual will be identifiable in the report and that all respondents will be sent a summary of the research report (or the full report if requested).
- People with dementia and carers will be members of the project team which will monitor the ethical processes. Representatives from the Alzheimer’s society and carers have acted as advisors to this project by providing advice, guidance and support to the project team. This has ensured the rights of the person who has dementia have been protected through independent advice and guidance. This ethical framework has also been peer reviewed and scrutinised by experienced research colleagues and clinical experts.
- Provision will be made for the appointment of consultees. This corresponds with the requirements of the Mental Capacity Act (2005) Code of Practice. The consultees will be the person’s main carer or family member who might consider it not to be in the person’s best interests to participate in the study (this may occur between obtaining initial interest and conducting the interview). In such a situation the interview would not be conducted.

Practitioners:

A similar process will be followed for staff participating in the study (by way of the participatory action research group):

- Approval will be sought from the Local Research Ethics committee, The Trust’s research and development group and the University of Essex’s research ethics forum.
- The clinical team manager will help identify suitable participants for the project and will circulate a letter of invitation to the practitioners (who meet the inclusion criteria). The letter will include written information about the study and explain why it is being conducted. Potential participants will be asked to return an expression of interest form to the Chief Investigator (CI) who will make contact by phone with them to explain the purpose of the research and make arrangements for group attendance.
- A further explanation will be given and written consent obtained before the PAG commences. Participants will be informed of their right to withdraw from the study at any time, without having to provide a reason and without affecting their role or status. Verbal consent will also be recorded at the beginning of each PAG.
- Every PAG will be recorded and will last approximately one hour. The agenda for each PAG will be set by the group but may include opportunities for person and carer involvement, the strategies used for involvement and service

development potential. The PAG will meet 6 times, be sensitively facilitated and have 8 participants.

- Those participating will be given assurances that their confidentiality, privacy and anonymity will be protected. They will also be asked to respect the confidentiality of anything which takes place in the group. The respondents will be advised that the data will be kept on a computer which will be password protected and can only be accessed by the CI and project supervisor. Once the research report is completed the data will be erased. Assurances will also be given that no individual will be identifiable in the report and that all respondents will be sent a summary of the research report (or the full report if requested).

In addition to the above, the following consent processes will be adopted with both the person who has dementia and carers and practitioners:

- The research process and hence ethical principles will be monitored by the partnership project management team who require six-monthly progress reports. This ethical framework has also been peer reviewed and scrutinised by experienced research colleagues and clinical experts.
- The CI's own professional background in mental health nursing, dementia care and training and as a mental health academic will assist in sensitively facilitating the interviews and in dealing with any problems the research may evoke. The CI will be the sole researcher and so will be a continuous point of contact for all participants for the duration of the study. He has previously undertaken qualitative research that utilised semi-structured interviews and focus groups (including interviewing carers and older adults) and is experienced in principles of informed consent and maintaining confidentiality.
- The CI is currently undertaking a PhD and so is supervised by two experienced academics and clinical experts. A model of 'ongoing consent' will be adopted by utilising regular discussion, debriefs and reflection on the research process. The CI will discuss the consent issues that arise from the focus groups within the supervisory process.
- The research information sheet, letter of invitation and consent forms will be written in plain language in a large font with a minimum of information whilst ensuring all essential information is provided.
- The CI has been appointed as researcher for the project and so will not be concurrently undertaking a clinical role. Thus no professional role conflicts are anticipated.

DATA ANALYSIS

Qualitative analysis of the PAGs and interview transcripts will use Miles & Huberman's (1994) analytical structure:

a) Data reduction

- Transcribed data from interviews and PAGs will be inputted into a software qualitative data analysis programme (MAXQDA).
- Analysis will commence only when all data has been collected.
- Emergent themes will be identified from the data.

- Each theme will be expanded and made complete.

b) Data display

- Data will be reported with reference to the informants' accounts through which the veracity of the emergent themes will be demonstrated.
- Data will be displayed in a manner that is readable and comprehensible to both professional and lay audiences and reports accurately the findings in context.

c) Conclusion drawing and verification

Throughout data analysis an iterative approach to rigour will be employed. This will include:

- Credibility – informants' group will all be invited to comment on data analysis and emergent themes.
- Confirmability – sources of data are repeatedly sampled during the research and from various sources
- Meaning-in-context – data is not reported without reference to the context from which it emerged.
- Recurrent patterning – themes will only be considered viable when they are observable within different data sets.
- Saturation – data will be concluded when either (a) no new data is forthcoming or (b) when the agreed sample size has been attained. If saturation has not occurred at (b) this will be reported in the findings.
- Transferability – the richness of the meaning-in-context data will enable the research to be transferred to a similar location. Some of the findings, particularly monitoring tools, will be utilisable in a broader range of locations (Leininger 1995).

Expected Outputs of Research
The study will:

1. Support the development and implementation of life story work within a dementia service. The methods used for this will be available for use within the NHS and wider health care community.
2. Provide a model of service redesign which facilitates the introduction of good practice in dementia care.
3. Develop good practice guidelines associated with life story work. These will be defined, written and disseminated locally and will also be available to the NHS and wider health and social care community.
4. Provide indicative research evidence and unique evaluative data to support the value and usefulness of life story work in dementia care.

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APPENDIX FIVE:
THE PROCESS UNDERTAKEN TO IDENTIFY THE STUDY THEMES

The coding processes undertaken to identify the study themes followed the procedure outlined below:

1. Miles & Huberman’s (1994) stage of ‘Data reduction.’

The data transcript quotes were randomly inputted into a word document and initial codes then assigned and emergent themes identified. This process correlates with Bryman’s (2004) coding framework whereby the initial two stages require the researcher to read through the entire transcript, make notes within the document on analytic ideas and to identify potential significant themes.

2. Miles & Huberman’s (1994) stage of ‘Data display.’

Further analysis and coding of the data were then undertaken with additional ‘chunks’ of text identified and added to the sub-codes. Many codes were initially identified, but these were then subsumed into others when duplication was identified. Bryman (2004) describes this stage as ‘Researcher interpretation’ to identify ‘interconnections between codes’.

3. Miles & Huberman’s (1994) stage of ‘Conclusion drawing and verification.’

The above process was repeated for each code and sub-code which then formed the basis of the principal theme. The researcher then worked through every quotation included and described and summarised his interpretation in respect of the meaning associated with each. This was then presented in the research findings in chapter four of this thesis. An overview and examples of this stage are included in the sections that follow.

4. The thematic overview was finalised as:

LIFE STORY WORK IS A			
MECHANISM FOR RESOLVING INFLEXIBLE PARADIGMS IN WORKING PRACTICE	MEANS OF BRINGING PEOPLE TOGETHER IN A COLLABORATIVE MANNER	STRATEGY FOR PROVIDING POST-DIAGNOSTIC SUPPORT	FRAMEWORK FOR MANAGING BOUNDARIES BETWEEN STAFF AND SERVICE USERS

LIFE STORY WORK IS A MECHANISM FOR RESOLVING INFLEXIBLE PARADIGMS IN WORKING PRACTICE	
Overarching code (1): **SHIFTING PARADIGMS – A NEW WAY OF WORKING** • LSW enabled paradigm change for the person who has dementia and the carer, team, organisation and staff • LSW prompted clinicians to think differently about how LSW should/could be used and how it impacted on a person's care	**AN EXAMPLE OF HOW CODES WERE ASSOCIATED WITH AND ASSIGNED FROM THE QUOTES:** **Overarching code (1): LSW SHIFTING PARADIGMS – A NEW WAY OF WORKING** "There needs to be a more cohesive plan about what we use that information for, and how it then influences someone's care and how we're interpreting that information" (PA-PAR Group 6) "That the information that we're using is used for a very specific purpose rather than it just being information that we're gathering" (xx-PAR Group 2) "It's (PAR) allowed us that space to sort of explore what we can do and to create something. That in itself is quite empowering within the team" (xx-interview) "I think with a constantly evolving team there is the danger that things get lost. I think it's really important to spend a bit of time to think about how we embed it so that it becomes fundamental to the work that we do, both here and in the wards or some of the other services that they're also using" (F1-PAR Meeting 3) "I think it's important that that's (LSW) introduced at the information meetings and given that opportunity, but it needs to be part of every other thing as well that's done. That there is that opportunity to create a life story and be involved in the research" (xx-PAR Meeting 1) "That the information that we're using is used for a very specific purpose rather than it just being information that we're gathering" (xx-PAR Group 2) "It feels like the research project having happened, has driven things forward within the Trust as well, because I know you were saying about the (Trust) LSW group that xx attends" (xx-interview)

	"One thing that I'm thinking about at the moment is that we've inadvertently tapped into the support that's needed for people after discharge; I mean, almost providing a service that's not necessarily there in a consistent way after diagnosis" (MO-PAR Meeting 6) "So you've got little prompts as well within the home, which is one thing that we kind of take away from people when we bring them in (to the Centre)" (xx-interview).
Overarching code (2): **BRINGING ABOUT CHANGE** • LSW empowered staff to bring about change because they had acquired new knowledge and skills and professional confidence	
Code: **SERVICE JOURNEY** Sub-code: MOVING ON! • LSW informed the person's care journey in the present and in the longer term Sub-code: SERVICE JOURNEY • LSW provided the personal support and named contact required instead of the central service • LSW identified how experiences of the service journey included a need to adjust to a diagnosis • LSW highlighted the variety of support accessed including a dementia café Sub-code: LIVING IN THE PRESENT-DEMENTIA & LSW HAS GIVEN ME A NEW LIFE • LSW enabled the person with dementia to re-evaluate and appreciate their life achievements and enjoy life more in present Sub-code: MAKING SENSE • LSW helped explain behaviours observed in and statements	

made by the person with dementia Sub-code: PLANNING AHEAD • LSW helped some people to plan ahead in terms of their own care, end of life and funeral • LSW enabled some staff to welcome the opportunity to use LSW to implement a new therapeutic approach Sub-code: SUPPORT • LSW promoted carer awareness of the support available in primary care • LSW demonstrated that the Individual support sessions were helpful in attaining meaningful LSW outcomes • LSW showed that the LSW book supported longer-term care and prompted personal memory • LSW helped support dissemination of a person’s life to wider family and acted as a memento	
Code: **RESISTANCE <-> FACILITATION - STAFF RECORDING OF WORK** Sub-code: MISSING THE POINT – SHIFT TO OTHER SERVICE • The clinical team ‘missed the point’ of LSW by stating it would have been more successfully implemented elsewhere	
Code: **TEAM DYNAMICS** Sub-code: TEAM OR PEOPLE NOT INTERESTED = COMPETING DEMANDS • LSW was considered to be an additional burden to all of the other services being delivered, making it difficult to get people or other staff involved • LSW was not seen as a routine intervention by the clinicians	
Code: **ORGANISATIONAL CHANGE** Sub-code: WHAT IS RELEVANT / WORKING IT OUT • LSW was considered to be complex by the staff, and this	

promoted a critical review of current practice Sub-code: SUPPORTIVE: • LSW helped staff explain to managers the problems encountered in practice, and this enabled the managers to understand these difficulties Sub-code: SERVICE / DEMANDS VERSUS PCC • LSW was considered to be an exemplar of PCC yet service, contracting and team demands in respect of therapies took priority Sub-code: QUALITY TO ENGAGEMENT IN PAR (DISEMPOWERED) • The therapies offered were determined by contracts and the commissioners, these were given priority and this disempowered staff. The commissioned therapies took up most of the staff time, and so new therapies such as LSW were resisted Sub-code: WHO IS IN CONTROL • The impact of resources, senior management, service priorities meant the staff felt they had little control in respect of their own decision making about LSW	
Code: **SKILLS DEFICIT** Sub-code: WORKING TOGETHER • Working together on LSW required all parties to reflect on their roles, skills and experience and the interactions and some people reconstructed or modified these Sub-code: PROFESSIONAL DISCOMFORT • LSW prompted staff to reflect on the professional discomfort caused by implementing it and the effects of using it such as what the future holds for the person • Staff were worried if they had the skills to deal with the emotional issues that developed	

Code: **PERSONHOOD – IDENTITY** Sub-code: GETTING TO KNOW THE PERSON • Dementia created communication difficulties, but LSW helped with this and enabled everyone to know the person and their life achievements/wishes • PAR is a person-centred way of undertaking research and so helped with communication between all parties	
Code: **IDENTITY – LSW IS ABOUT DIFFERENCE. PERSONALISED** Sub-code: BEING DIFFERENT – PERSONALISE – PERSONAL IDENTITY • The approaches used/selected by the person were very different and seemed to reflect their personal story, personality and life skills	

LIFE STORY WORK IS A MEANS OF BRINGING PEOPLE TOGETHER IN A COLLABORATIVE MANNER	
Overarching code: **LSW BRINGS PEOPLE TOGETHER** • LSW created different meanings for all involved in the process (the person who has dementia, carer, team, organisation and staff)	
Code: **WHAT LSW MEANS TO ME** • LSW provoked different meanings for all involved including visualising reminiscence, prompting happy memories, enabling living in the present, helping to cope with change, informing future care, regular use of the LSW ‘book’, realisation it is also a therapeutic process and reflection on essential relationships	
Code: **OWNERSHIP-WHOSE STORY IS IT?** • LSW highlighted that it is the person’s story so they should be enabled to compile this as they wish and without pressure to complete it (from staff, family, the project deadlines etc.). That said some people did find a deadline useful to work to	**AN EXAMPLE OF HOW CODES WERE ASSOCIATED WITH AND ASSIGNED FROM THE QUOTES:** **Sub-code: OWNERSHIP-WHOSE STORY IS IT?** “It’s got to be right for them at the right time, they’ve got to have done a substantial part of the life story work, they’ve got to have been through all three sessions. And I think some people don’t want to get involved in research. So I think there’s five or six factors that does slow it (referrals for LSW) down a bit” (CI in xx-interview) “So the sessions were sufficient, it was, because H did that for me if you understand me? Otherwise, I might still be working on it” (Interview 3) “Another theme was you talked about difficulties of patient carers to see the benefits of life story work in advance. Some didn’t seem to be able to grasp what it meant, what it actually firmly looked like. There was no firm template for it, which there shouldn’t be, but it’s hard for people to know what it is and how it will help them” (PA-PAR Group 7) “We used the first session as kind of an introduction and beginning to think about how you could do it. I think some people initially really wanted a more structured, ‘This is what you do’ but when we started exploring it and explaining that actually, having a more flexible approach meant that it would reflect who we are better. I

	think that's just a different perspective. Actually, when they started, I think it was quite good that it was a group because when they started talking about things, they could see that there were different things that actually were important to them" (xx-PAR Group Meeting 1) "Sometimes you have to be a historian as well because people can't necessarily explain to you their experiences of significant events that may have happened in the world around them. So I end up spending quite a lot of time researching to actually try and understand what that experience might have been like, so you can try and understand, because someone may place themselves back at that particular point in time" (F1-PAR Meeting 3)
Code: **LSW IS A NATURAL PROCESS** • EXPECTATIONS: LSW was considered to be a natural process in terms of personal interactions • CAPTURING THE MOMENT: LSW utilised a variety of approaches to recreate or capture certain or memorable moments from a person's life. Such re-creation was enjoyable for all involved	
Code: **BUILDING RELATIONSHIPS – CONNECTING – FRIENDSHIP** • BUILDING RAPPORT: LSW was considered to be a good starting point or way to build rapport between the person who has dementia, carer, family, staff etc • VALUING LSW – SENSE OF SHARING DEVELOPING: LSW was valued by the PAR group, and this initiated a sense of sharing and collaboration within the group • FAMILY INVOLVED – BRINGS PEOPLE TOGETHER - LSW brought the family together and often revealed feelings previously unknown - LSW developed meaningful and reciprocal relationships between staff and person, friends, carers and family; the home environment helps with this • BUILDING RELATIONSHIPS – FRIENDSHIP CONNECTING - LSW was felt to be critical to 'getting to know' each other	

and in building (new) relationships (between all involved in LSW) • SHARED MOMENTS - The LSW events reflected on recreated key memories and shared moments and further positive reflections on those moments	
Code: **LSW IS COMPLEX** • LSW was used by people for many different purposes, e.g. to remember the person after they've passed away • People needed to be 'in the right place' emotionally to undertake LSW. • People used different approaches to LSW, this is understandable, and so staff must be flexible, but not all clinicians recognised this • LSW was considered to be the basis of individualised care	

<table>
<tr><th colspan="2">LIFE STORY WORK IS A STRATEGY FOR PROVIDING POST-DIAGNOSTIC SUPPORT</th></tr>
<tr>
<td>Overarching code: GIVE US TIME – DIAGNOSIS
• Too much information was provided/given to people after diagnosis, everyone needed less information and over a more extended period of time
• LSW demonstrated it was challenging to do soon after diagnosis because there was so much going on
• LSW highlighted that carers are thrown into the caring role</td>
<td>AN EXAMPLE OF HOW CODES WERE ASSOCIATED WITH AND ASSIGNED FROM THE QUOTES:
Overarching code: GIVE US TIME – DIAGNOSIS
“Some people do go into denial. I met a gentleman when I first started when I did an information meeting, and he was determined there was nothing wrong with him. He wouldn’t have wanted to share anything about himself probably there and then, because he was in denial” (xx-interview)
“I actually thought I might be lynched. It probably came from that place actually, being angry about the diagnosis and maybe having the first opportunity through this (LSW), to actually talk about the diagnosis” (xx-PAR Meeting 1)
“One thing that I’m thinking about at the moment is that we’ve inadvertently tapped into the support that’s needed for people after discharge; I mean, almost providing a service that’s not necessarily there in a consistent way after diagnosis” (MO-PAR Meeting 6)
“Some people don’t like being called carers or caregivers because again they don’t necessarily feel it’s a choice that they’ve been given. Some people think it’s something that they’ve been thrown into and are again maybe struggling with that” (FI-PAR Meeting 3)
“I wonder if there’s a way of making it seem less of a chore on top of everything else that’s going on or whether there’s a way to make that easier” (F1-PAR Meeting 3)
“It’s got to be right for them at the right time, they’ve got to have done a substantial part of the life story work, they’ve got to have been through all three sessions. And I think some people don’t want to get involved in research. So I think there’s five or six factors that does slow it (referrals for LSW) down a bit” (CI in xx-interview)
“Certainly, some people that I’ve explained it to, it’s a case of, ‘Oh yes, life story.’ Then it’s a case of, ‘Oh there’s actually some research going on at the moment.’ Then it’s a case of, ‘No, I don’t want to be involved in that thanks.’ Very definite</td>
</tr>
</table>

	opinions, where research is concerned" (xx-PAR Meeting 1)
Code: **SENSITIVITY** • LSW demonstrated that people grieve through the process of doing a life story	
Code: **I DON'T WANT TO BE RESEARCHED** • LSW showed that some staff and people with dementia do not want to become involved in the research study even though they were interested in LSW	
Code: **METHODS OF LOOKING BACK – NO RUSH – REGRET** • LSW highlighted that having dementia meant some people focused on the present in a positive way • LSW showed that having a diagnosis may result in regret at the loss of abilities • LSW enabled people to reminisce about significant events in their life • LSW demonstrated that online resources such as the 'Forget me not' web-based life story pages enabled the inputting of key information and facts about the person's life story • LSW showed that it takes time, there is 'no rush', and it is never complete	
Code: **ANOTHER STONE IN RUCKSACK** • LSW protected staff from being overloaded because they also had other significant responsibilities. It also protected people with dementia from becoming overwhelmed by being subjected to too many services and allowed the diagnosis to settle in • LSW helped people adjust to a diagnosis and enabled people to cope with the demands post-diagnosis	

LIFE STORY WORK IS A FRAMEWORK FOR MANAGING BOUNDARIES BETWEEN STAFF AND SERVICE USERS	
Overarching code: **BOUNDARIES** (PERSONAL – PROFESSIONAL - ORGANISATIONAL – STRUCTURAL) • LSW showed that it is a framework for managing many boundaries	**AN EXAMPLE OF HOW CODES WERE ASSOCIATED WITH AND ASSIGNED FROM THE QUOTES:** **Overarching code: BOUNDARIES (PERSONAL – PROFESSIONAL - ORGANISATIONAL – STRUCTURAL)** “She was always on time. She never did the I’m running late, or this is my angst of the day. You had no idea how to work that, what would one call it, that file. So she has a lovely manner” (Interview 1) “But it maybe be quite useful for yourself to actually have those boundaries where you’re actually saying, Okay, we have an hour. Make them clear that there’s an hour” (xx-PAR Group 2) “Offering people guidelines and allowing them to do it because it’s their life story, it’s not us writing it for them. So I think it is about having a variety of tools (and templates) that you can offer and giving the guidelines for it” (IE2-PAR Group 8) “I just think the book is more easily accessible than any other media. If you have got a DVD, and you haven’t got a player no one is going to get to see it, but you have always got that book, it is there. They can access it better as well obviously further on in their journey” (XX-PAR Group 0) “It was nice to have H visit the house because you didn’t really want to go anywhere. We’d have been willing to, but it was nice to have her come to the house” (Interview 1) “That was too personal, so we decided not to talk about that” (Interview 2) “I think it’s something that to start with we have been giving a bit of a health warning so that people are prepared for that. So, that it doesn’t feel comfortable to start down this line and not actually say to people, by the way, there is a risk. You know, we all have nice memories and some difficult experiences and when you reflect on your life both of those are going to be there in the room” (xx-PAR Group 2)

	"I wouldn't show this to everybody because I think this is very personal, and there are things here that I don't really want, especially the letter, my daughter's letter, that is very personal to me and to close family. I wouldn't say, oh, here, read the book, and give it to every Tom, Dick, and Harry – this is for me" (Interview 4) "I think we were too prescriptive when we set the service up, you know, we will offer you this and I think we probably wrongly had the vision that everybody would have this fantastic book of, you know, their life story, which I think, with hindsight, was too prescriptive. But I do think that the practitioners use the principles of life story work, that you know that's going to help relieve that sort of agitation or, you know, upset" (IE2-PAR Meeting 8) "I worry about going on about the future too much and scaring them. That's my biggest worry. I'm like; Your life can be well enough, really promoting it, and then I'm like; Yes, but this could help in the future if you go into a care home or hospital or whatever" (F2-PAR Meeting 3)
Code: **DON'T WANT TO TALK ABOUT THAT** • LSW showed there were some personal issues people did not wish to explore. • LSW demonstrated there is a hidden area for staff too, e.g. their own life story.	
Code: **PERSONAL BOUNDARIES BECOME BREACHED / MOVED IN DEMENTIA** • LSW highlighted that dementia has an effect on personal boundaries	
Code: **BOUNDARYING LSW** • LSW showed that staff arriving on/keeping to time and having a professional manner was important • Keeping to a structured LSW approach is important • LSW demonstrated that thinking about if personal information should be included is important • LSW highlighted that meeting at home is important	

APPENDIX SIX:
PARTICIPANT INFORMATION SHEET: PERSON WITH DEMENTIA

PARTICIPANT INFORMATION SHEET

Project title: The use of life story work in an age inclusive dementia service: a participatory action research study

Introduction

You are being invited to take part in a research study. The researcher is undertaking this study for a PhD in Health Studies at the University of Essex.

Before you decide whether to participate it is important for you to understand why the research is being done and what it will involve.

Please read this information carefully and discuss it with others if you wish. Feel free to contact the researcher if there is anything that is not clear or you would like more information about. Please take time to decide whether or not you wish to take part.

What is the purpose of the study?

When you first met a member of the care team from the service they assessed your needs and worked with you to develop your life story. The purpose of this study is to try to understand more about how life story work can be improved. This type of research is important because we want to continually improve dementia care services.

If you agree to take part you will be interviewed and this will last between 30-60 minutes. If you wish you can be interviewed in your own home.

The life story work being used for this research is the established template approach to developing a life story book. After your initial meeting to introduce you to life story work you will be provided with three extra support sessions to help you produce your life story book. Your partner or carer will be invited to attend all of the meetings.

Why have I been asked to participate?

You have been asked to contribute to this study because you have been supported by the dementia care service at the service. Other people will also be invited to contribute to the research.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part please keep this information sheet and complete the attached expression of interest sheet and hand it to your care worker or return to the researcher. Before you are interviewed you will be asked to sign a consent form.

If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the support or treatment you receive.

What will happen to me if I take part?

After December 2013 you will be contacted by the researcher who will arrange a suitable date and time for the interview. These interviews will be conducted with both you and your partner or relative present.

At the interview you will be asked questions about your involvement in life story work and the discussion will be recorded.

What are the possible disadvantages and risks of taking part?

Whilst we do not believe there will be any disadvantages and risks to you when taking part in this research, if you do feel or appear distressed in any way the researcher will ensure support is provided to you by your service key worker. You will be supported at all times during the interview and the researcher is experienced in conducting this type of interview. If you were to reveal anything untoward to the researcher such as poor care practices, neglect or any safeguarding concerns then the researcher will have to bring these to the attention of the team leader at the service.

What are the possible benefits of taking part?

We hope that the information we obtain from this study will improve life story work at the service.

Will my taking part in this study be kept confidential?

The information you share with us will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised. The information will be stored on a computer for two years and password protected which only the researcher and the project supervisor will have access to.

What will happen to the results of the research study?

We would like to share the results by publishing a research report and by possibly undertaking a larger-scale study in the future.

When the research is completed we will send you a summary by post.

You will not be identified in any report/publication and all information collected will be erased once the research report is completed.

Who is organising and funding the research?

The project is being funded by The Trust.

Who has reviewed the study?

This study has been reviewed by the NRES Committee the Trust's Research & Development Group and the Research Governance and Planning Manager at the University.

Contact for Further Information
Steve Wood

Steve Wood, PhD Student, The Trust.

Project Supervisor: Dr MK, The Trust.

Independent Advice
If you would like independent advice about taking part in research please contact: the Alzheimer's Society Local Branch.

Thank you for taking the time to read through this information sheet. If you do wish to participate please complete the expression of interest form and hand to your care worker or return to the researcher.

APPENDIX SEVEN:
PARTICIPANT INFORMATION SHEET: CARERS

PARTICIPANT INFORMATION SHEET

Project title: The use of life story work in an age inclusive dementia service: a participatory action research study

Introduction

You are being invited to take part in a research study. The researcher is undertaking this study for a PhD in Health Studies at the University of Essex.

Before you decide whether to participate it is important for you to understand why the research is being done and what it will involve.

Please read this information carefully and discuss it with others if you wish. Feel free to contact the researcher if there is anything that is not clear or you would like more information about. Please take time to decide whether or not you wish to take part.

What is the purpose of the study?

When you first met a member of the care team with your partner or relative from the service they assessed their needs and worked with you both to develop their life story. The purpose of this study is to try to understand more about how life story work can be improved. This type of research is important because we want to continually improve dementia care services.

If you agree to take part you will be interviewed and this will last between 30-60 minutes. If you wish you can be interviewed in your own home.

The life story work being used for this research is the established template approach to developing a life story book. After your initial meeting to introduce your partner or relative to life story work they will be provided with three extra support sessions to help produce their life story book. You will also be invited to attend these three meetings.

Why have I been asked to participate?

You have been asked to contribute to this study because you have been supporting someone who has been helped by the dementia care service. Other carers will also be invited to contribute to the research.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part please keep this information sheet and complete the attached expression of interest sheet and hand it to the care worker or return to the researcher. Before you are interviewed you will be asked to sign a consent form.

If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the support or treatment your partner or relative receives.

What will happen to me if I take part?

After December 2013 you will be contacted by the researcher who will arrange a suitable date and time for the interview. These interviews will be conducted with you and your partner or relative present.

At the interview you will be asked questions about your involvement in the life story work and the discussion will be recorded.

What are the possible disadvantages and risks of taking part?

Whilst we do not believe there will be any disadvantages and risks to you when taking part in this research, if you do feel or appear distressed in any way the researcher will ensure support is provided to you by the service key worker. You will be supported at all times during the interview and the researcher is experienced in conducting this type of interview. If you were to reveal anything untoward to the researcher such as poor care practices or any safeguarding concerns then the researcher will have to bring these to the attention of the team leader at the service.

What are the possible benefits of taking part?

We hope that the information we obtain from this study will improve life story work at the service.

Will my taking part in this study be kept confidential?

The information you share with us will be kept strictly confidential. Any information about you will have your name and address removed so that you cannot be recognised. The information will be stored on a computer for two years and password protected which only the researcher and the project supervisor will have access to.

What will happen to the results of the research study?

We would like to share the results by publishing a research report and by possibly undertaking a larger-scale study in the future.

When the research is completed we will send you a summary by post.

You will not be identified in any report/publication and all information collected will be erased once the research report is completed.

Who is organising and funding the research?

The project is being funded by The Trust.

Who has reviewed the study?

This study has been reviewed by the NRES Committee the Trust’s Research & Development Group and the Research Governance and Planning Manager at the University.

Contact for Further Information
Steve Wood

Steve Wood, PhD Student, The Trust.

Project Supervisor: Dr MK, The Trust.

Independent Advice
If you would like independent advice about taking part in research please contact: the Alzheimer’s Society Local Branch.

Thank you for taking the time to read through this information sheet. If you do wish to participate please complete the expression of interest form and hand to your care worker or return to the researcher.

APPENDIX EIGHT:
EXPRESSION OF INTEREST FORM: PERSON WITH DEMENTIA

Expression of interest in participating in the research study ‘The use of life story work in an age inclusive dementia service: a participatory action research study’.

I hereby confirm my expression of interest in participating in this research to share my views on the use of life story work.

Name...

Signature...

Address..…..
....
....

Phone Number......................................

Mobile...

Email..

Please hand this form to your care worker or return to the researcher

Thank you,

Steve Wood, PhD Student, The Trust.

APPENDIX NINE:
EXPRESSION OF INTEREST FORM: CARERS

Expression of interest in participating in the research study ‘The use of life story work in an age inclusive dementia service: a participatory action research study’.

I hereby confirm my expression of interest in participating in this research to share my views on the use of life story work.

Name...

Signature...

Address..…...
....
....

Phone Number......................................

Mobile...

Email..

Please hand this form to your care worker or return to the researcher

Thank you,

Steve Wood, PhD Student, The Trust.

APPENDIX TEN:
PARTICIPATION CONSENT FORM: PERSON WITH DEMENTIA

RESEARCH PARTICIPANT CONSENT FORM

Project title: The use of life story work in an age inclusive dementia service: a participatory action research study

Name of Researcher: Steve Wood

Name of Participant:

Please initial all of the boxes below

I have read the Participant Information Sheet version number 2 dated 11.10.2013 and the nature and purpose of the research project has been explained to me. I understand and agree to take part.

☐

I understand the purpose of the research project and my involvement in it.

☐

I understand that my participation is voluntary and I may withdraw from the research project at any stage and that this will not affect my status or treatment now or in the future.

☐

I understand that while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

☐

I understand that I will be audio recorded during the interview.

☐

I understand that data will be stored on a computer which will be pass word protected but will then be erased once the research report is completed.

☐

I consent to being contacted about the results of the study.

☐

I understand that I may contact the researcher if I require further information about the research, and that I may contact the project supervisor, if I wish to make a complaint relating to my involvement in the research.

☐

I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Essex, 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 records.

☐

Signed …………………………………………………………
(Research participant)

Print name……………………………………………………

Date …………………………………

Signed …………………………………………………………
(Person obtaining consent)

Print name……………………………………………………

Date …………………………………

Contact details:
Steve Wood, PhD Student, The Trust.

Project Supervisor:
Dr MK.

APPENDIX ELEVEN:
PARTICIPATION CONSENT FORM: CARERS

RESEARCH PARTICIPANT CONSENT FORM

Project title: The use of life story work in an age inclusive dementia service: a participatory action research study

Name of Researcher: Steve Wood

Name of Participant:

Please initial all of the boxes below

I have read the Participant Information Sheet version number 2 dated 11.10.2013 and the nature and purpose of the research project has been explained to me. I understand and agree to take part.

☐

I understand the purpose of the research project and my involvement in it.

☐

I understand that my participation is voluntary and I may withdraw from the research project at any stage and that this will not affect the status or treatment of my partner or relative now or in the future.

☐

I understand that while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

☐

I understand that I will be audio recorded during the interview.

☐

I understand that data will be stored on a computer which will be pass word protected but will then be erased once the research report is completed.

☐

I consent to being contacted about the results of the study.

☐

I understand that I may contact the researcher if I require further information about the research, and that I may contact the project supervisor, if I wish to make a complaint relating to my involvement in the research.

☐

I understand that data collected during the study, may be looked at by individuals from the University of Essex, 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 records.

☐

Signed ……………………………………………………………
(Research participant)

Print name…………………………………………………………

Date …………………………………

Signed ……………………………………………………………
(Person obtaining consent)

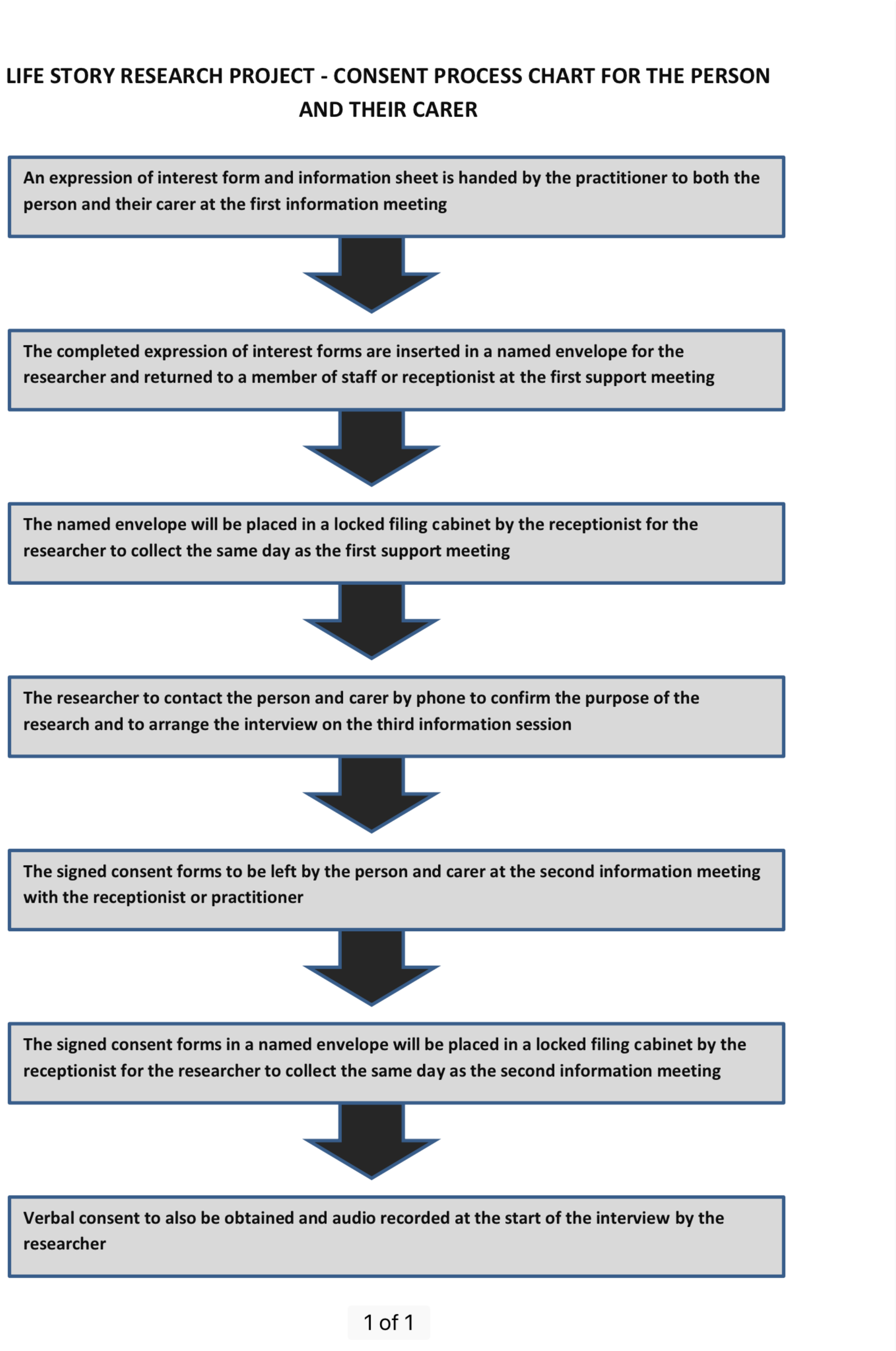
Print name…………………………………………………………

Date …………………………………

Contact details:
Steve Wood, PhD Student, The Trust.

Project Supervisor:
Dr MK.

APPENDIX TWELVE:
CONSENT PROCESS CHART FOR PERSON AND THEIR CARER



LIFE STORY RESEARCH PROJECT - CONSENT PROCESS CHART FOR THE PERSON AND THEIR CARER

An expression of interest form and information sheet is handed by the practitioner to both the person and their carer at the first information meeting

The completed expression of interest forms are inserted in a named envelope for the researcher and returned to a member of staff or receptionist at the first support meeting

The named envelope will be placed in a locked filing cabinet by the receptionist for the researcher to collect the same day as the first support meeting

The researcher to contact the person and carer by phone to confirm the purpose of the research and to arrange the interview on the third information session

The signed consent forms to be left by the person and carer at the second information meeting with the receptionist or practitioner

The signed consent forms in a named envelope will be placed in a locked filing cabinet by the receptionist for the researcher to collect the same day as the second information meeting

Verbal consent to also be obtained and audio recorded at the start of the interview by the researcher

APPENDIX THIRTEEN:
PARTICIPANT INFORMATION SHEET: CLINICIAN

PARTICIPANT INFORMATION SHEET
(For Practitioners)

Research project title:
The use of life story work in an age inclusive dementia service: a participatory action research study

Introduction

You are being invited to take part in a research study. The researcher is undertaking this study for a PhD in Health Studies at the University of Essex.

Before you decide whether to participate it is important that the purpose of the research is explained and what it will involve.

Please read this information carefully and discuss it with other practitioners if you wish. Feel free to contact the researcher if there is anything that is not clear or you would like more information about. Please take time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of this study is to try to understand more about how life story work can be enhanced and embedded in practice. This type of research helps meet the requirements of the National dementia strategy and to continually improve dementia care.

If you agree to take part you will become a member of a participatory action research group (PAG). The group will plan the research project and evaluate opportunities for person and carer involvement, the strategies used for life story work and the service development potential of life story work. Each meeting will last 60 minutes and the group will meet 6 times. The groups will take place at the service.

Why have I been asked to participate?

You have been asked to contribute to this study because you are a member of the dementia care service.

Other team members will also be invited to contribute to the research.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part please keep this information sheet and complete the attached expression of interest sheet and return to the researcher. Before the first PAG you will be asked to sign a consent form.

If you do decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your role in any way.

What will happen to me if I take part?

After December 2013 you will be contacted by the researcher who will arrange a suitable date and time for the first PAG.

At the PAG you will be facilitated to discuss your views on and experiences of life story work and the discussion will be audio recorded.

What are the possible disadvantages and risks of taking part?

We do not believe there will be any disadvantages and risks to you when taking part in this research. The groups will be sensitively facilitated and we are experienced in conducting this type of data collection. If you were to reveal anything untoward to the researcher such as poor care practices, neglect or any safeguarding concerns then the researcher will have to bring these to the attention of the team at the service or Trust managers.

What are the possible benefits of taking part?

We hope that the information we obtain from this study will enhance life story work at the service.

Will my taking part in this study be kept confidential?

The information you share with us will be kept strictly confidential. Any information about you will have your name removed so that you cannot be recognised. The information will be stored on a computer for two years and password protected which only the researcher and supervisor will have access to.

What will happen to the results of the research study?

We would like to share the results by publishing a research report and by possibly undertaking a larger-scale study in the future.

When the research is completed we will send you a summary by post.

You will not be identified in any report/publication and all information collected will be erased once the research report is completed.

Who is organising and funding the research?

The project is being funded by the Trust.

Who has reviewed the study?

This study has been reviewed by the NRES Committee, the Trust's Research & Development Group and the Research Governance and Planning Manager at the University.

Contact for Further Information
Steve Wood

Steve Wood, PhD Student, The Trust.

Project Supervisor: Dr MK.

Thank you for taking the time to read through this information sheet. If you do wish to participate please complete the expression of interest form and return to the researcher.

APPENDIX FOURTEEN:
EXPRESSION OF INTEREST FORM: CLINICIAN

Expression of interest in participating in the research study ‘The use of life story work in an age inclusive dementia service: a participatory action research study’.

I hereby confirm my expression of interest in participating in this research as a member of the participatory action research group.

Name...

Signature...

Address...
....
....

Phone Number.......................................

Mobile...

Email..

<u>Please return this form to the researcher</u>

Thank you,

Steve Wood, PhD Student, The Trust.

APPENDIX FIFTEEN:
PARTICIPATION CONSENT FORM: CLINICIAN

RESEARCH PARTICIPANT CONSENT FORM

Project title: The use of life story work in an age inclusive dementia service: a participatory action research study

Name of Researcher: Steve Wood

Name of Participant:

Please initial all of the boxes below

I have read the Participant Information Sheet version number 2 dated 11.10.2013 and the nature and purpose of the research project has been explained to me. I understand and agree to take part.

☐

I understand the purpose of the research project and my involvement in it.

☐

I understand that my participation is voluntary and I may withdraw from the research project at any stage and that this will not affect my status or role now or in the future.

☐

I understand that while information gained during the study may be published, I will not be identified and my personal results will remain confidential.

☐

I understand that I will be audio recorded during the participatory action research groups.

☐

I understand that data will be stored on a computer which will be pass word protected but will then be erased once the research report is completed.

☐

I consent to being contacted about the results of the study.

☐

I understand that I may contact the researcher if I require further information about the research, and that I may contact the project supervisor, if I wish to make a complaint relating to my involvement in the research.

☐

I understand that data collected during the study, may be looked at by individuals from the University of Essex, 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 records.

☐

Signed ……………………………………………………………
(Research participant)

Print name………………………………………………………

Date …………………………………

Signed ………………………………………………………
(Person obtaining consent)

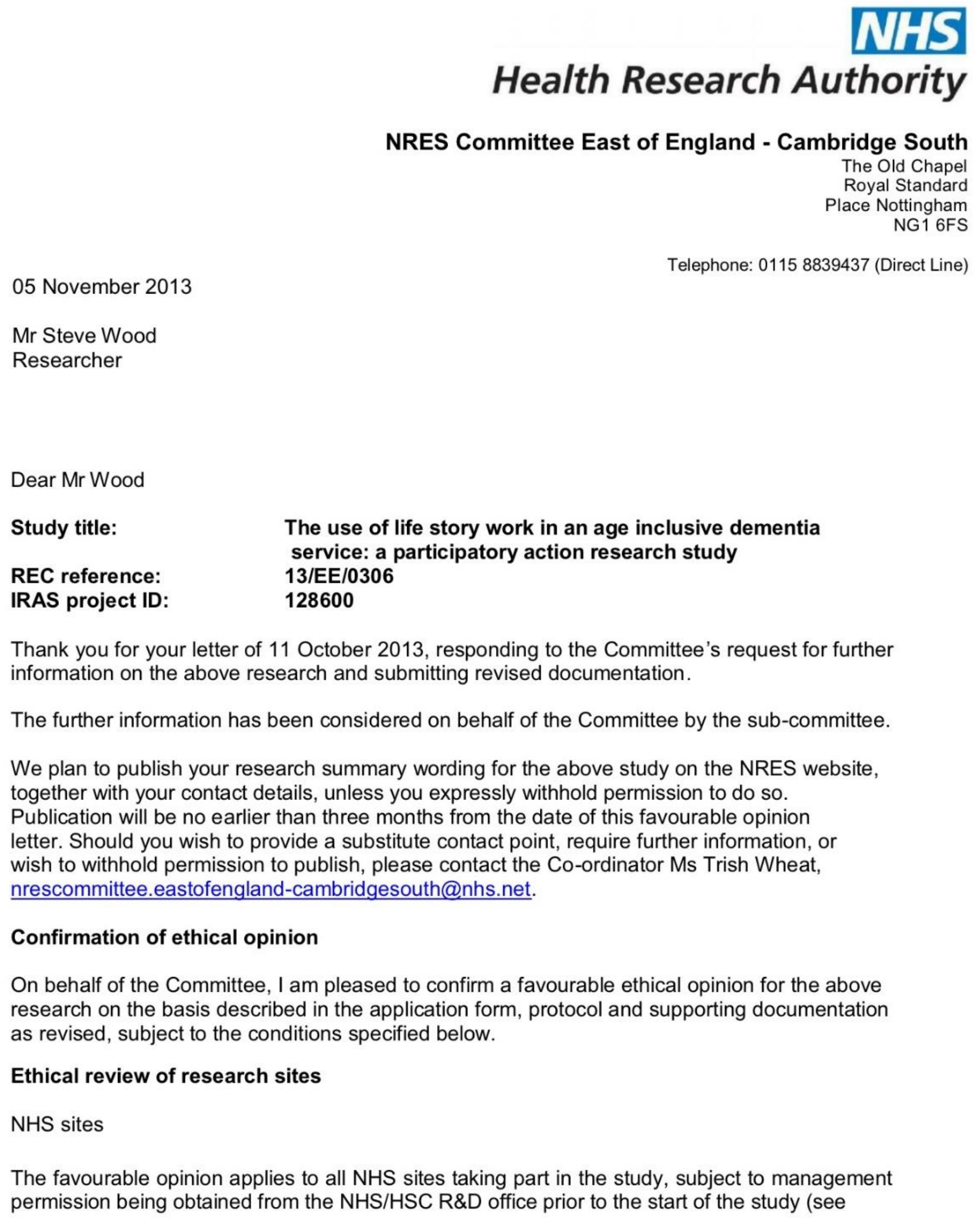
Print name……………………………………………………

Date …………………………………

Contact details:
Steve Wood, PhD Student, The Trust.

Project Supervisor:
Dr MK.

APPENDIX SIXTEEN:
NHS HEALTH RESEARCH AUTHORITY CONFIRMATION OF STUDY APPROVAL (1) – 05.11.2013



NHS
Health Research Authority

NRES Committee East of England - Cambridge South
The Old Chapel
Royal Standard
Place Nottingham
NG1 6FS

Telephone: 0115 8839437 (Direct Line)

05 November 2013

Mr Steve Wood
Researcher

Dear Mr Wood

Study title:	**The use of life story work in an age inclusive dementia service: a participatory action research study**
REC reference:	**13/EE/0306**
IRAS project ID:	**128600**

Thank you for your letter of 11 October 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the sub-committee.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Ms Trish Wheat, nrescommittee.eastofengland-cambridgesouth@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Additional conditions:-

1. In all Consent Forms, in the 1st point, the version number and date should be inserted of the corresponding Participant Information Sheets i.e. it should state 'I have read the Participant Information Sheet version number ? dated ? and the nature and purpose…etc'.

2. A mandatory statement should also be inserted in all Consent Forms that states 'I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from the University of Essex, 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 records.' *Where review of medical notes will not be looked at, reference to this should be removed.*

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which can be made available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

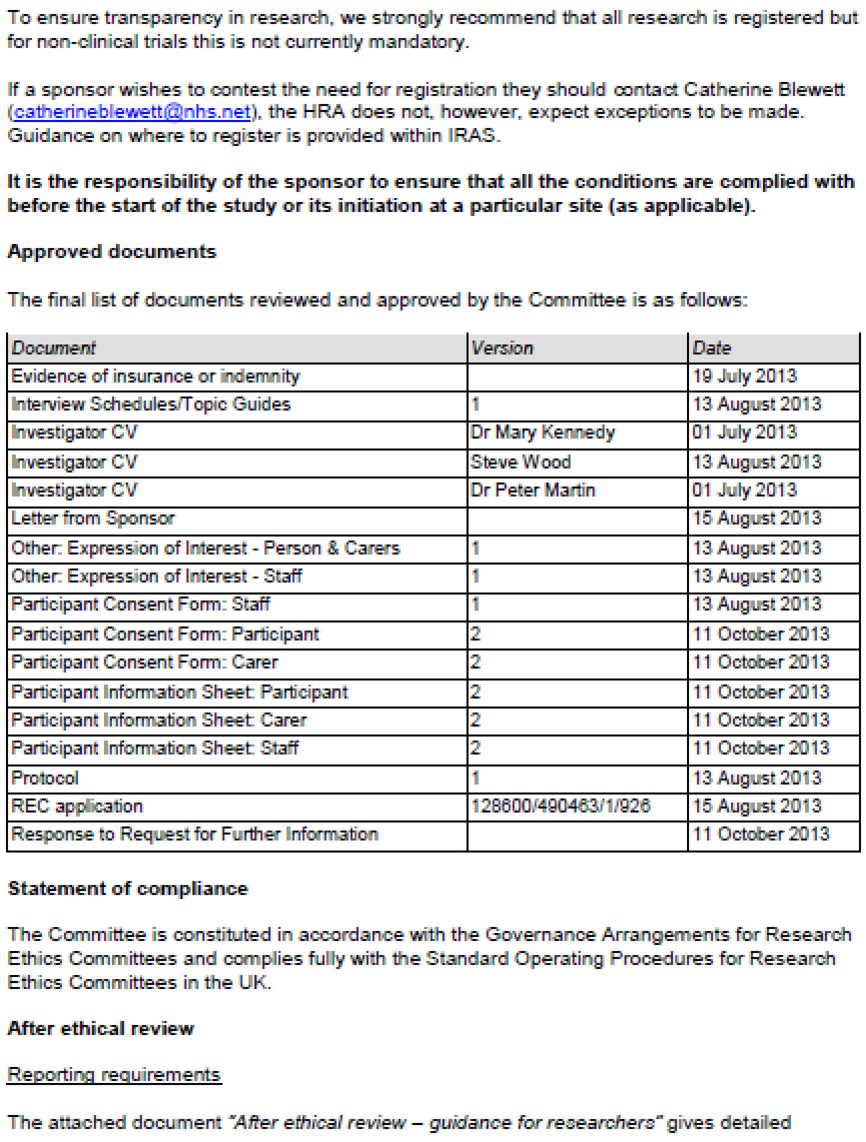
Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).



To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Evidence of insurance or indemnity		19 July 2013
Interview Schedules/Topic Guides	1	13 August 2013
Investigator CV	Dr Mary Kennedy	01 July 2013
Investigator CV	Steve Wood	13 August 2013
Investigator CV	Dr Peter Martin	01 July 2013
Letter from Sponsor		15 August 2013
Other: Expression of Interest - Person & Carers	1	13 August 2013
Other: Expression of Interest - Staff	1	13 August 2013
Participant Consent Form: Staff	1	13 August 2013
Participant Consent Form: Participant	2	11 October 2013
Participant Consent Form: Carer	2	11 October 2013
Participant Information Sheet: Participant	2	11 October 2013
Participant Information Sheet: Carer	2	11 October 2013
Participant Information Sheet: Staff	2	11 October 2013
Protocol	1	13 August 2013
REC application	128600/490463/1/926	15 August 2013
Response to Request for Further Information		11 October 2013

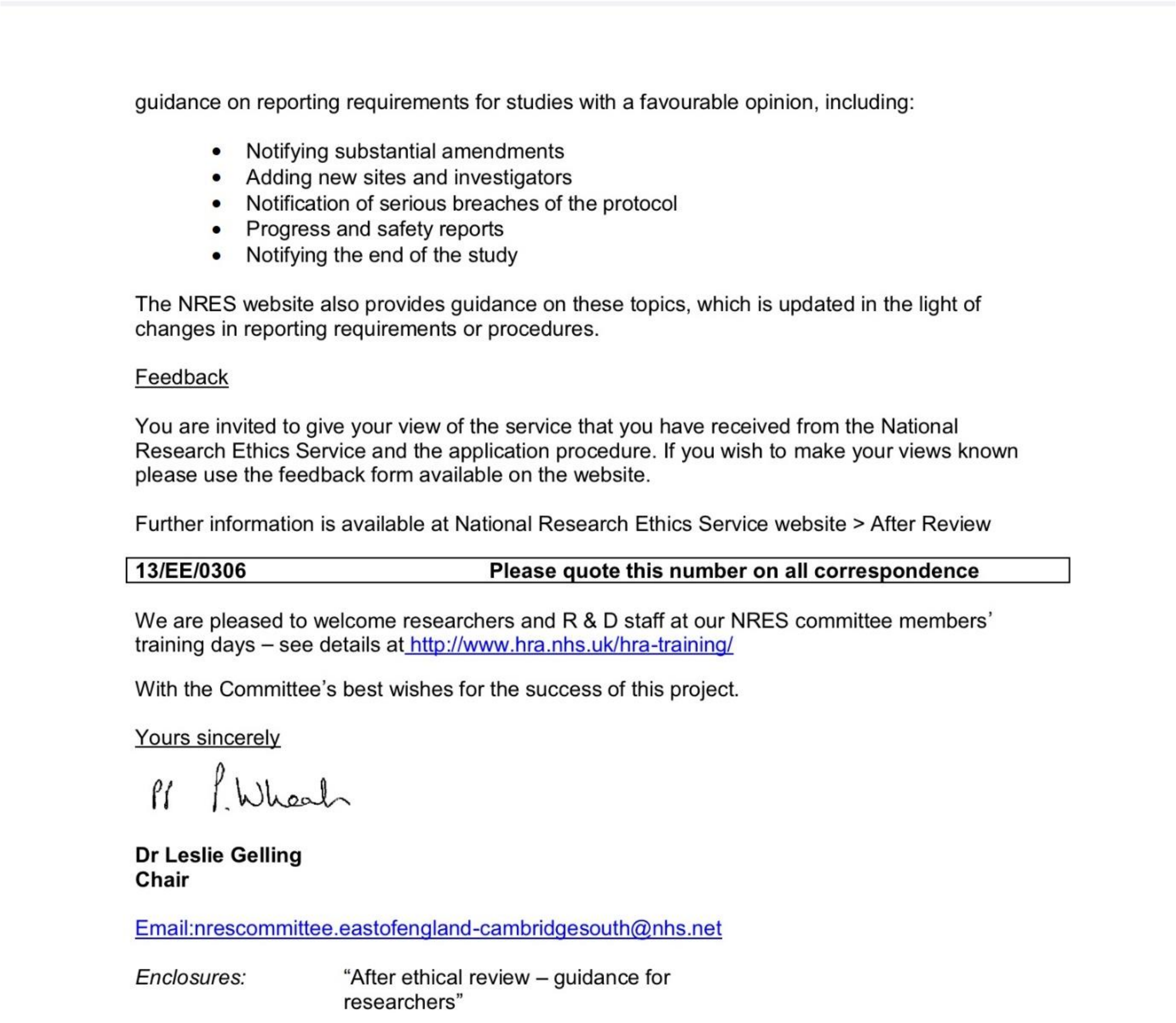
Statement of compliance

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

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed



guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/EE/0306 Please quote this number on all correspondence

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

With the Committee's best wishes for the success of this project.

Yours sincerely

pp P. Wheal

Dr Leslie Gelling
Chair

Email:nrescommittee.eastofengland-cambridgesouth@nhs.net

Enclosures: "After ethical review – guidance for researchers"

APPENDIX SEVENTEEN: NHS HEALTH RESEARCH AUTHORITY CONFIRMATION OF STUDY APPROVAL (2) – 21.11.2013

Health Research Authority

NRES Committee East of England - Cambridge South
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839437 (Direct Line)

21 November 2013

Mr Steve Wood
Researcher

Dear Mr Wood

Study title:	**The use of life story work in an age inclusive dementia service: a participatory action research study**
REC reference:	**13/EE/0306**
IRAS project ID:	**128600**

Thank you for your email correspondence of 11 November 2013. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 05 November 2013

Documents received

The documents received were as follows:

Document	*Version*	*Date*	
Participant Consent Form: Carer	3	06 November 2013	
Participant Consent Form: Participant	3	06 November 2013	
Participant Consent Form: Staff	2	06 November 2013	

Approved documents

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

Document	*Version*	*Date*	

Evidence of insurance or indemnity		19 July 2013	
Interview Schedules/Topic Guides	1	13 August 2013	
Investigator CV	Dr MK	01 July 2013	
Investigator CV	Steve Wood	13 August 2013	
Investigator CV	Dr PM	01 July 2013	
Letter from Sponsor		15 August 2013	
Other: Expression of Interest - Person & Carers	1	13 August 2013	
Other: Expression of Interest - Staff	1	13 August 2013	
Participant Consent Form: Carer	3	06 November 2013	
Participant Consent Form: Participant	3	06 November 2013	
Participant Consent Form: Staff	2	06 November 2013	
Participant Information Sheet: Participant	2	11 October 2013	
Participant Information Sheet: Carer	2	11 October 2013	
Participant Information Sheet: Staff	2	11 October 2013	
Protocol	1	13 August 2013	
REC application	128600/490463/1/926	15 August 2013	
Response to Request for Further Information		11 October 2013	

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.

13/EE/0306 **Please quote this number on all correspondence**

Yours sincerely

P. Wheat

Ms Trish Wheat
REC Manager

E-mail: nrescommittee.eastofengland-cambridgesouth@nhs.net
Copy to: *The University & The Trust*

APPENDIX EIGHTEEN:
UNIVERSITY OF ESSEX CONFIRMATION OF STUDY APPROVAL 02.12.2013

University of Essex

School of Health and
Human Sciences
T 01206 872854
F 01206 873765
E hhs@essex.ac.uk

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom
T 01206 873333
F 01206 873598

www.essex.ac.uk

02 December 2013

MR S.C. WOOD

Dear Steve,

Re: Ethical Approval Application (Ref 12059)

Further to your application for ethical approval, please find enclosed a copy of your application which has now been approved by Dr Wayne Wilson on behalf of the Faculty Ethics Committee.

Yours sincerely,

Mel Wiltshire
Ethics Administrator
School of Health and Human Sciences

cc. Sarah Manning-Press, REO
Peter Martin, Supervisor

APPENDIX NINETEEN: UNIVERSITY OF ESSEX CO-SPONSORSHIP CONFIRMATION LETTER 15.08.2013

University of Essex

Research and Enterprise Office
T 01206 872922
F 01206 873894
E reo@essex.ac.uk

www.essex.ac.uk/reo

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom
T 01206 873333
F 01206 873598

www.essex.ac.uk

15 August 2013

Ms Trish Wheat
Co-ordinator
NRES Committee East of England – Cambridge South
The Old Chapel
Royal Standard Court
Nottingham
NG1 6FS

Dear Ms Wheat

The use of life story work in an age inclusive dementia service: a participatory action research study (REC 13/EE/0306)

I am pleased to confirm that the University of Essex will act as Co-sponsor, together with North Essex Partnership University NHS Foundation Trust, under the Department of Health Research Governance Framework for Health and Social Care for the following research project undertaken by one of our postgraduate students:

Chief Investigator:	Mr Steve Wood
Department:	School of Health and Human Sciences
Project Title:	The use of life story work in an age inclusive dementia service: a participatory action research study
Academic Supervisor:	Dr Peter Martin
Trust Supervisor:	Dr Mary Kennedy

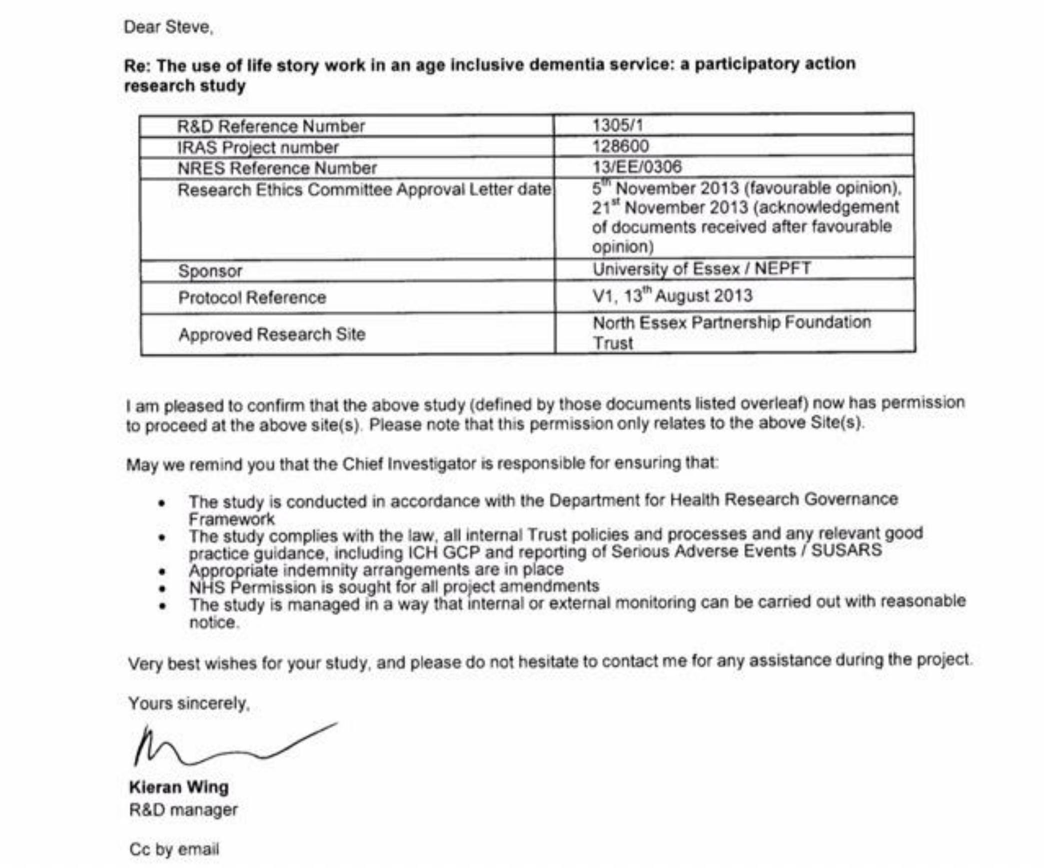
For avoidance of doubt the University of Essex will not act as Sponsor for Clinical Trials of Medicinal Products which fall under The Medicines for Human Use (Clinical Trials) Regulations 2004.

Yours sincerely

Sarah Manning-Press
Research Governance and Planning Manager

THE QUEEN'S

APPENDIX TWENTY:
NHS TRUST CONFIRMATION OF STUDY APPROVAL
27.11.2013



Dear Steve,

Re: The use of life story work in an age inclusive dementia service: a participatory action research study

R&D Reference Number	1305/1
IRAS Project number	128600
NRES Reference Number	13/EE/0306
Research Ethics Committee Approval Letter date	5th November 2013 (favourable opinion), 21st November 2013 (acknowledgement of documents received after favourable opinion)
Sponsor	University of Essex / NEPFT
Protocol Reference	V1, 13th August 2013
Approved Research Site	North Essex Partnership Foundation Trust

I am pleased to confirm that the above study (defined by those documents listed overleaf) now has permission to proceed at the above site(s). Please note that this permission only relates to the above Site(s).

May we remind you that the Chief Investigator is responsible for ensuring that:

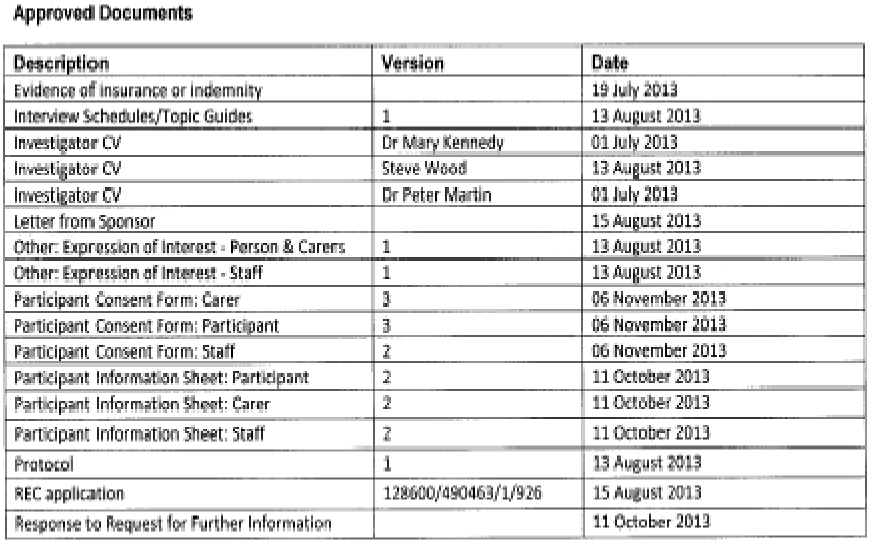
- The study is conducted in accordance with the Department for Health Research Governance Framework
- The study complies with the law, all internal Trust policies and processes and any relevant good practice guidance, including ICH GCP and reporting of Serious Adverse Events / SUSARS
- Appropriate indemnity arrangements are in place
- NHS Permission is sought for all project amendments
- The study is managed in a way that internal or external monitoring can be carried out with reasonable notice.

Very best wishes for your study, and please do not hesitate to contact me for any assistance during the project.

Yours sincerely,

Kieran Wing
R&D manager

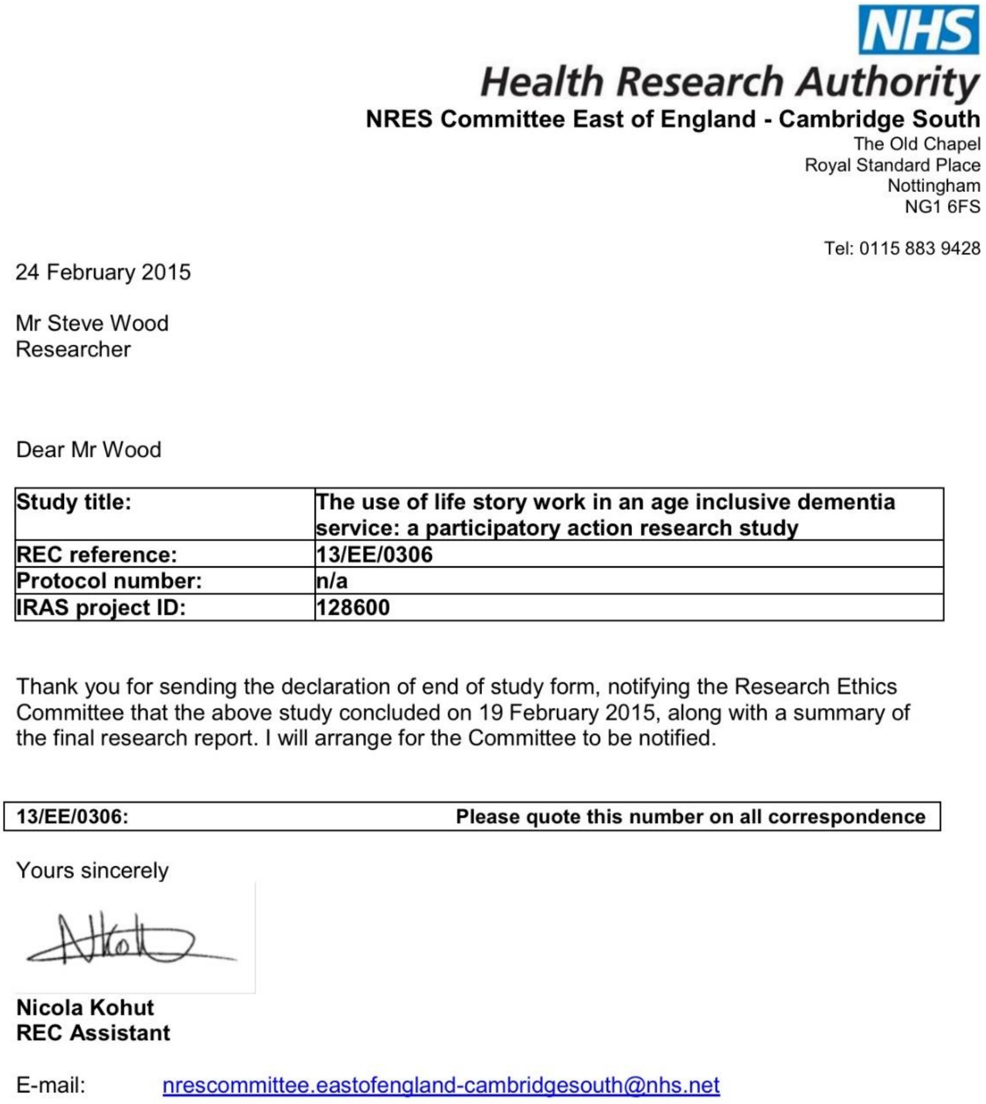
Cc by email



Approved Documents

Description	Version	Date
Evidence of insurance or indemnity		19 July 2013
Interview Schedules/Topic Guides	1	13 August 2013
Investigator CV	Dr Mary Kennedy	01 July 2013
Investigator CV	Steve Wood	13 August 2013
Investigator CV	Dr Peter Martin	01 July 2013
Letter from Sponsor		15 August 2013
Other: Expression of Interest - Person & Carers	1	13 August 2013
Other: Expression of Interest - Staff	1	13 August 2013
Participant Consent Form: Carer	3	06 November 2013
Participant Consent Form: Participant	3	06 November 2013
Participant Consent Form: Staff	2	06 November 2013
Participant Information Sheet: Participant	2	11 October 2013
Participant Information Sheet: Carer	2	11 October 2013
Participant Information Sheet: Staff	2	11 October 2013
Protocol	1	13 August 2013
REC application	128600/490463/1/926	15 August 2013
Response to Request for Further Information		11 October 2013

APPENDIX TWENTY-ONE: NHS HEALTH RESEARCH AUTHORITY ACKNOWLEDGEMENT OF END OF STUDY 24.02.2015.



NHS
Health Research Authority
NRES Committee East of England - Cambridge South
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Tel: 0115 883 9428

24 February 2015

Mr Steve Wood
Researcher

Dear Mr Wood

Study title:	**The use of life story work in an age inclusive dementia service: a participatory action research study**
REC reference:	**13/EE/0306**
Protocol number:	**n/a**
IRAS project ID:	**128600**

Thank you for sending the declaration of end of study form, notifying the Research Ethics Committee that the above study concluded on 19 February 2015, along with a summary of the final research report. I will arrange for the Committee to be notified.

13/EE/0306: **Please quote this number on all correspondence**

Yours sincerely

Nicola Kohut
REC Assistant

E-mail: nrescommittee.eastofengland-cambridgesouth@nhs.net

APPENDIX TWENTY-TWO:
INTERVIEW SCHEDULE: PERSON WITH DEMENTIA AND CARERS

SCHEDULE FOR PERSON AND CARER INTERVIEWS

Project title: The use of life story work in an age inclusive dementia service: a participatory action research study

Qualitative interviews will seek the views and perspectives of the person and carers in relation to the use of life story work within the Dementia care service. The data generated will reflect the uniqueness of each individual experience and will be exploratory in nature. Therefore, in line with the proposed qualitative methodology, semi-structured interviews based on broad areas of inquiry will be used to guide the interviews.

The objectives of the interviews are to investigate:

1. Perceived opportunities for people and carers to be involved in developing their life story
2. Evidence of involvement in life story work and the information given to support this
3. Perceived benefits and challenges of being involved in life story work

The topic guide for the interviews will be developed by the participatory action research group but is likely to include the following:

- In what ways have you been involved in developing your life story?
- Are there other ways in which you would have liked to have been involved?
- Are there other methods that could have been used?
- Did you find the group and support sessions useful?
- Could you explain to me whether you felt the process of completing your life story was helpful?