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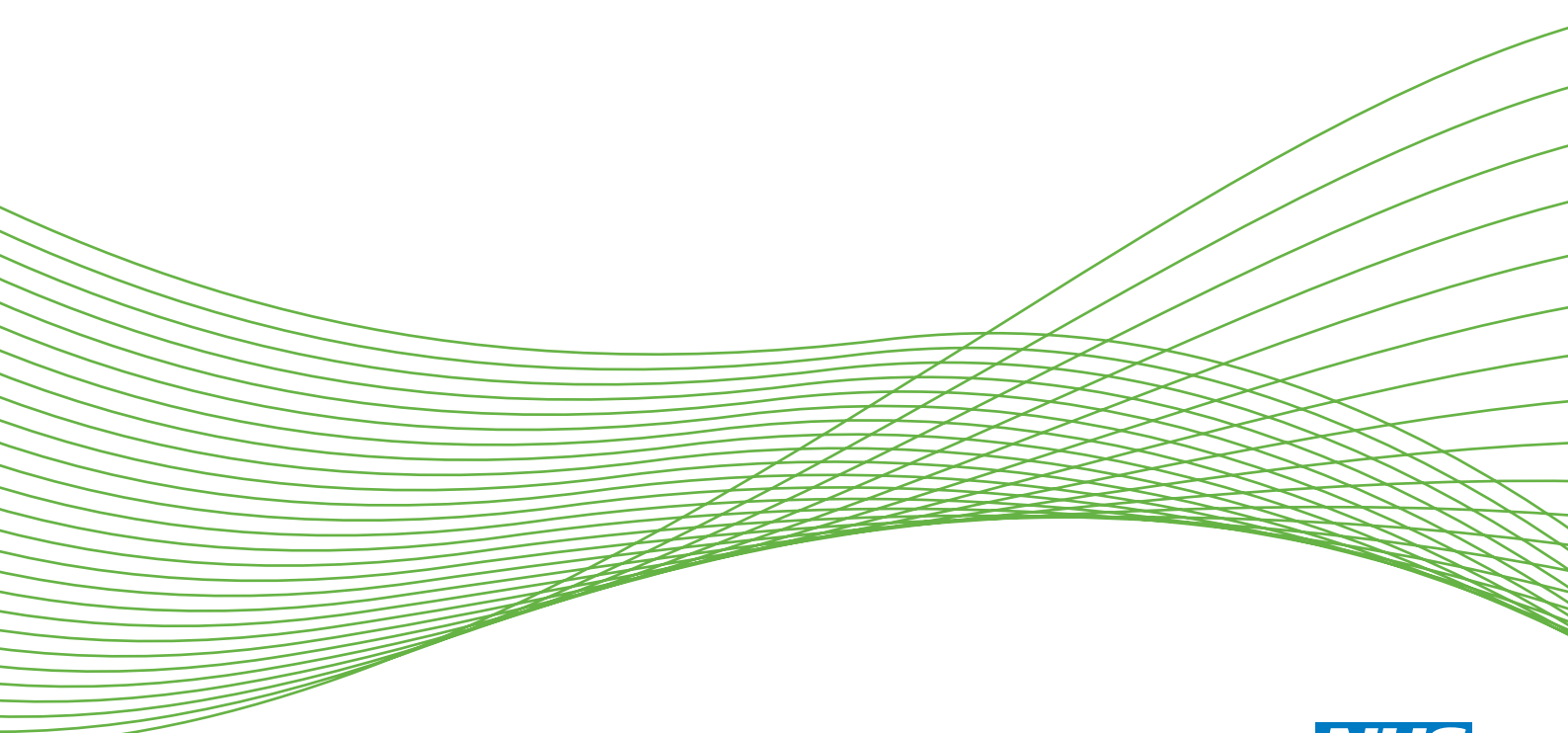
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## Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care

*Kate Gridley, Jenni Brooks, Yvonne Birks, Kate Baxter and Gillian Parker*



***National Institute for  
Health Research***



# Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care

Kate Gridley, Jenni Brooks, Yvonne Birks, Kate Baxter and Gillian Parker\*

Social Policy Research Unit, University of York, York, UK

\*Corresponding author

**Declared competing interests of authors:** none

**Disclaimer:** This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

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# Abstract

## Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care

Kate Gridley, Jenni Brooks, Yvonne Birks, Kate Baxter and Gillian Parker\*

Social Policy Research Unit, University of York, York, UK

\*Corresponding author [gillian.parker@york.ac.uk](mailto:gillian.parker@york.ac.uk)

**Background:** Improving dementia care quality is an urgent priority nationally and internationally. Life story work (LSW) is an intervention that aims to improve individual outcomes and care for people with dementia and their carers. LSW gathers information and artefacts about the person, their history and interests, and produces a tangible output: the 'life story'.

**Objective:** To establish whether or not full evaluation of LSW was feasible.

**Design:** Mixed-methods feasibility study.

**Methods:** In-depth interviews and focus groups explored experiences of LSW and best practice with people with dementia, family members and dementia care staff. A systematic review explored best practice and theories of change for LSW. These stages helped to identify the outcomes and resources to explore in the feasibility study. A representative sample survey of health and social care dementia care providers in England established LSW practice in different settings. A survey of a self-selected sample of family members of people with dementia explored how LSW is experienced. Two small outcome studies (stepped-wedge study in six care homes and pre-test post-test study in inpatient specialist dementia care wards) explored the feasibility of full evaluation of LSW in these settings.

**Settings:** Survey: generalist and specialist care homes; NHS dementia care settings; and community dementia services. Feasibility study: care homes and NHS inpatient dementia care wards.

**Participants:** NHS and social care services, people with dementia, family carers, care home staff and NHS staff.

**Interventions:** LSW.

**Main outcome measures:** Spread of LSW and good practice, quality of life (QoL) for the person with dementia and carers, relationships between people with dementia and family carers, staff attitudes about dementia, staff burnout, resource use and costs.

**Review methods:** Narrative review and synthesis, following Centre for Review and Dissemination guidelines.

**Results:** Good practice in LSW is identifiable, as are theories of change about how it might affect given outcomes. Indicators of best practice were produced. LSW is spreading but practice and use vary between care settings and are not always in line with identified good practice. Two different models of LSW are evident; these are likely to be appropriate at different stages of the dementia journey. The feasibility study showed some positive changes in staff attitudes towards dementia and, for some people with dementia, improvements in QoL. These may be attributable to LSW but these potential benefits require full evaluation. The feasibility work established the likely costs of LSW and highlighted the challenges of future evaluation in care homes and inpatient dementia care settings.

**Limitations:** There was insufficient evidence in the literature to allow estimation of outcome size. We did not carry out planned Markov chain modelling to inform decisions about carrying out future evaluation because of the dearth of outcome data in the literature; low levels of data return for people with dementia in the hospital settings; lack of detected effect for most people with dementia; and questions about implementation in the research settings.

**Conclusions:** LSW is used across different health and social care settings in England, but in different ways, not all of which reflect 'good practice'. This large, complex study identified a wide range of challenges for future research, but also the possibility that LSW may help to improve care staff attitudes towards dementia and QoL for some people with dementia.

**Future work:** Full evaluation of LSW as an intervention to improve staff attitudes and care is feasible with researchers based in or very close to care settings to ensure high-quality data collection.

**Funding:** The National Institute for Health Research Health Services and Delivery Research programme.

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# List of abbreviations

A&E	accident and emergency	MRC	Medical Research Council
ADQ	Approaches to Dementia Questionnaire	OT	occupational therapist
CBI	Copenhagen Burnout Inventory	OTTI	occupational therapy technical instructor
CDS	community dementia support service	PDQ	Personhood in Dementia Questionnaire
CES	Carer Experience Scale	PRN	pro re nata ('as required')
CIC	community interest company	QCPR	Scale for the Quality of the Current Relationship in Caregiving
DVD	digital versatile disc	QoL	quality of life
GP	general practitioner	QoL-AD	Quality of Life – Alzheimer's Disease
IPA	inpatient dementia assessment service	SCH	dementia-specialist long-term care home
IW	intervention ward	SCREC	Social Care Research Ethics Committee
LSW	life story work		
MAS	memory assessment service		
MeSH	medical subject heading		



## Plain English summary

Life story work (LSW) is used to support people with dementia to communicate their life stories. Until now there have been no large-scale, rigorous studies of LSW to see whether or not it works and why.

This research involved:

1. searching for existing evidence
2. asking people with dementia, their carers and professionals about LSW and how to do it well
3. two surveys (of service providers and family carers) to find out where LSW is being done and how
4. two small studies to measure the costs and outcomes of LSW, and to see how feasible LSW is to introduce.

We involved people with dementia on our advisory group and worked with partner organisations to make sure we included as many people with dementia as possible in the research.

We identified what good practice might look like and found that many services now use LSW, but not always to inform care. We found some improvements in staff attitudes towards people with dementia in care homes and some improvements in quality of life for some people with dementia, although we had only small numbers in the study.

The cost of delivering LSW was relatively small, and staff felt that doing LSW encouraged interactions with family and helped staff to get to know the person with dementia.

We therefore think that LSW has potential to help people with dementia and that a full study is needed to judge whether or not this is really so.



# Scientific summary

## Background

Dementia is a growing health problem internationally. With an imminent cure unlikely, providing good-quality and cost-effective care, over a long period of need, will remain a major challenge for health and other care providers. Improving the quality of care in general hospitals, living well with dementia in care homes, reducing the use of antipsychotic medication and improving health outcomes through improving care outcomes are priority policy objectives for dementia.

Listening to people with dementia and understanding their rich and varied histories is seen as essential to good care. 'Life story work' (LSW) is used increasingly for this, which 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 has been used in health and social care settings for nearly three decades. Since the 1990s, there has been growing interest in its potential to deliver person-centred care for people with dementia.

Despite LSW's increased use in the NHS and elsewhere, its outcomes for people with dementia, family carers and staff, its costs and its impact on care quality remain unevaluated.

## Objectives

The aim of the project was:

- to carry out the development and initial feasibility stages of evaluation of a complex intervention – LSW – for people with dementia.

The research questions were:

1. How might LSW improve outcomes for people with dementia, carers, staff and wider health and social care systems?
2. How cost-effective could this be?
3. Is formal evaluation of LSW feasible?

## Methods

We used a mixed-methods design in two stages to explore the feasibility of formal evaluation of LSW in health and social care settings.

### ***Stage 1a: a systematic review of the existing literature to produce a narrative synthesis of good practice and of theories of change***

Searches were designed to identify any type of study about LSW published in or after 1984. Algorithms guided the selection of publications for relevance and for review by three team members. One team member was responsible for data extraction and analysis but discussed progress with other team members and the project advisory groups throughout. Narrative synthesis and mind-mapping were the predominant approaches to analysis.

### ***Stage 1b: qualitative focus groups and individual interviews with people with dementia***

These elucidated the outcomes people wished to see from LSW and the routes through which they felt those outcomes might be reached. A framework approach was used to analyse the material.

### ***Stages 2a and b: two national surveys carried out via electronic survey software***

One survey was of a representative sample of health and social care settings, and the other was of family carers of people with dementia, drawn from a third-sector support organisation for carers. Both surveys drew on findings from stage 1 and discussion with our advisory groups. The national survey of health and social care settings was also used to estimate the spread of LSW.

Analysis was largely descriptive and bivariate.

### ***Stage 2c: feasibility study***

We carried out two small feasibility studies to test data-gathering processes and instruments. One study used a stepped-wedge design to introduce LSW in six care homes and the other study used a pre-test post-test design in three NHS assessment units that already used LSW and one that did not. In both settings, we also aimed to examine the potential size of outcomes from and costs of using LSW to inform the design of a full evaluation.

Measures mapped onto outcomes identified in stage 1 (where these were available) covering:

- quality of life (QoL) for the person with dementia (assessed by the person him- or herself, where possible, and by a family carer or other proxy)
- the quality of relationships between people with dementia and family carers (assessed by the person with dementia him- or herself, where possible, and the carer)
- the experiences of family carers
- staff attitudes towards dementia care and staff burnout.

We tested different ways of identifying, collecting and measuring relevant resource inputs. We then valued these using local or national unit costs to establish the costs of LSW.

### ***Public and patient involvement***

The project was informed throughout by the involvement of people with dementia, family carers and staff working in dementia care. This was done through an advisory group, supported by virtual advisory groups of people with dementia and family carers. These groups met throughout the project and advised on the contents of the survey, the findings of the review and the qualitative work, and the choice of outcome measures for the feasibility study. They also commented on the findings.

## **Results**

### ***Stages 1a and b***

We identified 657 studies from our reviews, of which 55 were included in the review; 47 were used in the good practice review and 18 were used in the theories of change review.

Twenty-five people with dementia, 21 family carers and 27 professionals and care staff participated in a total of 10 focus groups or interviews.

Material from the review and from the qualitative work was used to produce good practice 'learning points' and to elucidate the routes through which LSW was felt to achieve given outcomes. The good

practice learning points are an outcome of the project in their own right but they also informed questionnaire development for the surveys in stage 2.

The qualitative work identified QoL, both for the person with dementia and for family members/carers, and relationships between them, as outcomes.

The review identified outcomes that might eventually *lead* to improved QoL. These included an increased sense of self-worth for the person with dementia, improved psychological well-being, reduction in behaviour that challenges and improved 'coping' for the family carer. Improvements in the care environment were also important in the review, reflecting the professional orientation of the publications included. There was sufficient commonality in the outcomes and the hypothesised routes between LSW and achievement of these to inform stage 2.

### Stage 2: surveys

Response rates varied across the health and social care settings, from 32% from generalist care homes to 70% in NHS specialist assessment units. Overall, we had a return of 58% (307 responses).

Life story work has spread relatively widely, particularly in hospital assessment settings, although to a lesser extent in care homes.

Services varied widely in the type of LSW they did, the overall objectives of LSW (including the involvement of the person with dementia), whether LSW was past or forward looking and how LSW was used. These differences probably reflect the different places in which services were located on the dementia care pathway.

The day-to-day use of the life story product was not as high as might be hoped. Doing LSW is one thing; using it to inform and improve care is clearly another.

The service survey emphasised the role of carers in LSW, and the carers' survey confirmed this. Carers reported heavy involvement, and, in some cases, had led the LSW. However, although they played an important part in services' LSW, carers were unlikely to be offered training to do it. Again, the reported *actual* use of the life story by care staff, and even by the person with dementia and carers, was lower than might be expected.

### Stage 2: feasibility study process

Recruitment and retention was challenging, being most difficult for people with dementia in the NHS assessment settings, and most difficult for staff in care homes. The recruitment and retention of family carers was somewhat more successful. Staff turnover, differing priorities and continuity of management in the care settings all influenced the success of recruitment of people with dementia, over and above any issues of their capacity to consent. Fifty-one staff, 39 people with dementia and 31 carers were recruited in care homes. Twelve people with dementia, 10 carers and varying numbers of staff participated in the NHS settings.

### Stage 2: feasibility study outcomes

Even after successful recruitment, gathering data was difficult. Completion rates for outcome measures were best overall for family carers in care homes (up to 61% at final follow-up) and worst for people with dementia in hospital wards (none at final follow-up). Completion of measures by staff in care homes was disappointing, given the commitment of the care home provider to the study.

However, there was useful learning for future research. We observed fatigue effects in the completion of outcome measures over time, the competing demands of the routines in care settings and the inability of conventional outcome measures to capture 'in-the-moment' benefits for people with dementia. The measures also missed how LSW was used, in particular for the de-escalation of behaviour that challenges in hospital settings.



We observed some changes in our outcome measures from baseline to follow-up and these were significant for staff attitudes towards dementia in care homes, for self-reported QoL (DEMQOL) between baseline and final follow-up for 12 people with dementia in care homes who were able to complete the measure, and for the experiences of carers.

The first change may be an effect of LSW, as we saw evidence of it in both measures of staff attitudes. Whether the change was due to the training associated with implementing LSW or to LSW itself is not clear.

The people with dementia able to complete DEMQOL might have been less cognitively impaired than others in the study, meaning that we cannot extrapolate this finding to everyone.

Carers' experience scores worsened in the care homes but improved in the hospital setting. We are not sure that LSW caused either effect. People with dementia in the care homes were often approaching the end of their lives; for carers of people in hospital it was often the case that the person with dementia had been admitted in a crisis, but, during his or her stay, was stabilised and assessed and had his or her future care planned (in some cases meaning admission to long-term care).

### **Stage 2: collecting resource-use data**

The collection of resource-use data in all settings was time-consuming and complicated. In all cases, data collection was better when assisted by the presence of a researcher.

### **Stage 2: resource use outcomes**

The cost of delivering the LSW training in care homes ranged from £950 to £1581 and the average cost of creating and using LSW products for a resident in the care homes was £37.42 spread over 16 weeks. If all costs were additional, resource implications would be relatively small at an individual resident level but could be substantial if extrapolated to all residents.

Life story work was a part of routine care in the hospital intervention wards, so there were no initial training costs. The average cost of creating and using LSW products was £68.21 per patient over 3 weeks. The more intensive activity may be attributable to staff attempting to complete life story products before patients are discharged, or to staff having dedicated time for this activity.

The most frequently used services in care homes were visits to the care home by the general practitioner (GP) and the district nurse. Care home staff accompanied residents to these consultations on at least 25% of occasions, which potentially adds to overall costs. Visits by the GP showed some reduction at follow-up compared with baseline, but visits by the district nurse did not.

The resources with the highest monetary values per use were an inpatient stay on a general medical ward, an accident and emergency attendance by ambulance, an outpatient appointment and a GP visit to a care home. Because of their relatively high cost, these events are more likely than other types of input to affect total costs. Over a larger number of residents in a full evaluation, differences in the costs of this type of activity might be substantial.

Care home use by participants of prescribed medication for anxiety and depression was low. Only two homes provided home-wide data on antipsychotic prescribing. In one, prescribing was low; in the other (the specialist dementia care home), 12 residents were prescribed antipsychotics, all but one on a continuous basis. Overall, however, for study participants in care homes, the use of antipsychotic or other drugs was not a big driver of costs. The small numbers of participants in the hospital settings make it impossible to judge from individual patient data how extensively antipsychotic drugs were used. Ward-level data suggest antipsychotic prescribing cost up to £1350 per ward over 6 months.

Although never intended to be robust enough to demonstrate change, this feasibility work does suggest a possible reduction in service use and adverse events and indicates the main drivers of costs.

## ***Stage 2: participants' experiences of life story work as part of the research project***

Carers in particular were unsure of the benefits of LSW, particularly for people in whom the dementia had progressed, which sometimes led to reluctance to get involved, feeling that LSW would have no effect. People with dementia in the study enjoyed looking at their life story books, and staff were more certain of a positive effect, particularly in facilitating interactions and encouraging staff to get to know the person.

Staff were positive about collecting life story information but had some scepticism about the need for a physical life story product, particularly as this was considered time-consuming to make. LSW was easier when one person or a small team took the lead; when this was the case, all staff members were encouraged to collect information, but only the core team or lead person had responsibility for making a product.

Although some aspects of LSW can be beneficial for people with dementia, it is unclear whether this is attributable to the presence of a physical life story product, or to the act of spending time with someone, learning about their life. Although the latter may occur without LSW, LSW can be a mechanism for this learning, and a physical life story product may facilitate interactions and enhance relationships with family members and staff.

## **Conclusions**

### ***Implications for health care***

Stage 1 of our work was based on in-depth qualitative research and a systematic review of the literature. This found consistent messages about good practice in doing LSW. The survey of health and social care services showed that not all services follow these practices. We have drawn together good practice learning points and will disseminate these widely to health and social care audiences.

Stage 2 was intentionally exploratory. Although we did observe effects in this stage of the work, particularly in relation to staff attitudes in care homes, it is clearly not right at this stage to draw out implications for health and social care providers.

### ***Recommendations for research***

Our work means that we now have a clear idea of the challenges and benefits of attempting to establish evaluation of this complex intervention in care settings that are themselves complex and often complicated. In order of priority, there is a need for:

1. Formal evaluation of LSW as a method of changing staff attitudes about dementia, and particularly in care homes. This should compare LSW against more general training input about dementia.
2. Qualitative research that explores the motivation and 'emotional intelligence' of care staff, recognising that delivering person-centred care for people with dementia requires particular qualities of both.
3. Methodological development in assessing QoL for people with dementia 'in the moment'.

## **Funding**

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# Chapter 1 Introduction

Dementia is a major and growing health concern across the world. With an imminent cure unlikely, providing good-quality and cost-effective care, over what is often a long period of need, is, and will remain, a major challenge for health and other care providers. The Department of Health (DH) has outlined improved quality of care in general hospitals, living well with dementia in care homes, and reduced use of antipsychotic medication as priority objectives for dementia.<sup>1</sup> Quality outcomes for people with dementia in the National Institute for Health and Care Excellence Quality Standards<sup>2</sup> similarly focus on improving health outcomes through improving care processes, and two quality statements emphasise the importance of understanding people with dementia via their life stories and biographies.

Listening to people with dementia and understanding that they have rich and varied histories is essential to good care.<sup>3</sup> 'Life story work' (LSW) is used increasingly for this and involves gathering information and artefacts about the person, their history and interests, and producing a picture book or other tangible output – the 'life story' – including storyboards and multimedia resources.<sup>4</sup> LSW has been used in health and social care settings for nearly three decades, with children,<sup>5</sup> people with learning disabilities<sup>6</sup> and older people.<sup>7</sup> Since the 1990s, there has been growing interest in its potential to deliver person-centred care for people with dementia.<sup>8,9</sup>

The approach is distinct from reminiscence and 'biographical work' in dementia care, because it emphasises using the life story in day-to-day care to improve communication, relationships and understanding of the individual's past life, and in its orientation to the future. Life stories, as tangible products, are owned and held by people with dementia and can travel with them to smooth the transition to other settings, for example into acute medical care or from home to long-term care. This makes life stories distinct from biographical 'work' in care settings<sup>10</sup> or the simple logging of life history details in care records.

Two systematic reviews have explored LSW in dementia care and both suggest that the approach has considerable potential. The first<sup>11</sup> reviewed LSW with a range of user groups and reviewed four qualitative studies focused specifically on dementia. These studies suggested that life stories can help staff to understand the person they are caring for in the context of their past, which in turn can help to explain their present behaviours. Staff valued life story books as care planning and assessment resources, but there was little reporting of patients' and carers' views. The review's authors noted an absence of attempts to present conflicting evidence about the value of life stories in practice. The second review identified 28 studies of LSW with people with dementia in institutional settings.<sup>12</sup> All interventions contained some features important for achieving an enhanced sense of identity among residents. However, the focus of the studies tended to be the impact of the life story reminiscence process, generally conducted by researchers or therapists for limited periods, rather than the routine daily use of life stories. The authors concluded that there is still much to learn about how best to deliver LSW to people with dementia and that more attention should be paid to developing a sound theoretical framework.

Subsequent studies have suggested that life stories help staff to see clients with dementia as individuals, help family carers to uphold relatives' personhood and enable those with dementia to be heard and recognised as people with unique stories. However, these studies have been very small in scale<sup>13,14</sup> or remain unpublished (Cohen K, Johnson D, Kaiser P, Dolan A, Lancaster University, 2008, unpublished report).

The use of life histories (sic) has been advocated in the DH Dementia Commissioning Pack<sup>15</sup> and this, in turn, refers to a Commission for Social Care Inspection report that commended the use of life histories in care planning.<sup>16</sup> However, LSW for people with dementia is under-researched, with little evidence about the most cost-effective ways to implement it in different settings or with different user groups. To date, there have been no large-scale, methodologically rigorous studies of the impact of LSW on outcomes for people with dementia, carers and staff, or any attempt to establish its costs. More basically, unlike reminiscence therapy,<sup>17</sup> the mechanisms that might make LSW effective, or the contexts in which these might apply, have not been articulated; there is, thus, no developed theory of change that underpins its use. Finally, although descriptive accounts and practice-based knowledge show LSW being used in different ways in different dementia care settings, we have no systematic knowledge about who is using it, where, how, with what effect and at what financial cost.

Despite LSW's use in dementia care settings in the NHS and elsewhere, its outcomes for people with dementia, their carers and staff, its costs and its impact on care quality remain unevaluated. With current moves towards embedding LSW in dementia care, robust evaluation of the technique, its outcomes and costs, and how it can best be applied is urgently needed. We need to understand how LSW might improve interactions and relationships between staff, carers and people with dementia in a range of health and long-term care settings; affect service users' and carers' quality of life (QoL) and other individual outcomes; and reduce the use of antipsychotic drugs for behavioural 'problems'. There is also a need to establish the likely costs and benefits of implementing LSW more widely in health and long-term care settings.

As LSW is a complex intervention, formal evaluation must be preceded by development and feasibility/pilot stage research, as recommended in the most recent Medical Research Council (MRC) guidance.<sup>18</sup> Our project was, therefore, planned to provide theoretical underpinnings for LSW, explore good practice in its use, establish where and how it is used in health and social care settings in England, outline its possible costs and benefits in such settings and establish the feasibility of formal evaluation.

The work was designed to generate a robust theory of change and a good practice framework to underpin growing use of LSW in dementia care for the NHS management community to use. We hoped that elucidating LSW's potential outcomes, impact on care quality and costs might inform commissioning decisions about where and how best to use it. Future formal evaluation of LSW, building on our work, would, further, provide robust, generalisable evidence of effectiveness and costs.

The formally stated aim of the project was to carry out the development and initial feasibility stages of evaluation of a complex intervention – LSW – for people with dementia.

The objectives were to:

1. develop a theoretical model of LSW (including its potential outcomes) and establish core elements of good practice in using and applying the approach
2. benchmark the current use of LSW in dementia services in England against good practice
3. scope the potential effects and costs of using LSW in specialist inpatient and long-term care settings
4. explore the feasibility of formal evaluation of LSW in health and long-term care settings
5. disseminate findings to providers, planners, commissioners and users of dementia services.

The research questions were:

1. How might LSW improve outcomes for people with dementia, carers, staff and wider health and social care systems?
2. How cost-effective could this be?
3. Is formal evaluation of LSW feasible?

## Overview of design and methods

Each main chapter describes in detail the design and methods used to address the research questions. Here, we provide a brief overview of the rationale for our choices.

Medical Research Council guidance points to the special challenges that evaluation of complex interventions poses for evaluators.<sup>18</sup> The guidance suggests that before formal evaluation of effectiveness and costs, understanding of the existing evidence base, a developed theory of change, process and outcome modelling, and a clear understanding of the feasibility of formal evaluation must be in place. These elements were not in place for LSW when we wrote our proposal. We thus focused on the development and initial feasibility work required before full evaluation in two main stages: (1) reviewing the evidence base and identifying and developing theory and components of good practice; and (2) data collection to support modelling of processes and outcomes and judgement about the feasibility of full evaluation. A mixed-methods approach was used throughout. *Table 1* sets out how each objective was addressed by the project methods.

We also planned a dissemination phase, including with a short film, produced with the advice of people with dementia, and a four-page plain English summary.

**TABLE 1** Overview of project objectives and methods

Objective	Methods
1: Develop a theoretical model of LSW, including its potential outcomes, and establish core elements of good practice in using and applying the approach	<p>A systematic review of literature (stage 1a) published in or after 1984 on LSW with people with dementia to identify reported outcomes and their sizes, underlying theories of change and any reported elements of good practice in creating and using life stories</p> <p>A qualitative study (stage 1b) using focus groups with people with early-stage dementia, carers and professionals, who have experience of LSW to ascertain what outcomes are experienced or expected, for whom, under what circumstances and by which causal routes; as well as participants' views about core elements of good practice in LSW</p>
2: Benchmark the current use of LSW in dementia services in England against good practice	A survey of health and social care providers of dementia services (stage 2a) and of informal carers (stage 2b) to establish how LSW is used in different care settings. Good practice elements identified in stage 1 will influence the survey content, enabling us to benchmark use against good practice
3: Scope the potential effects and costs of using LSW in specialist inpatient and long-term care settings	<p>Two small-scale feasibility studies (stage 2c) – one with a stepped-wedge design in care homes, the other with a pre-test post-test design in a NHS assessment unit – to examine the potential size of outcomes from and costs of using LSW in these settings. Relevant resource inputs will be identified, measured and then valued using local or national unit costs to establish the costs of LSW relative to other approaches</p> <p>Using these preliminary data, and assuming that we have observed any effects, we will create a probability tree for effectiveness of LSW in relation to outcomes and then a Markov model of effectiveness and cost-effectiveness of LSW (stage 2d). This will help to assess whether or not future, formal evaluation of LSW would be worthwhile</p>
4: Explore the feasibility of formal evaluation of LSW in health and long-term care settings	In addition to producing data on potential costs and outcomes of LSW, these small-scale studies (stage 2c) will provide valuable learning on the practical feasibility of formal evaluation of LSW in different settings and for two different designs

## Outline of the report

*Chapter 2* reports the literature review that we used to explore good practice in LSW and to develop a theory of change, while *Chapter 3* reports the qualitative work with people with dementia, family carers and professionals that addressed the same issues through empirical exploration. In *Chapter 4* we explain how we used the findings in *Chapters 2* and *3* to identify outcomes for the feasibility study and how we chose instruments to measure them. The two national surveys of the use of LSW in health and social care settings and the experiences of carers of LSW are reported in *Chapter 5*. *Chapter 6* reports our in-depth exploration of the feasibility of formal evaluation, while *Chapters 7* and *8* report the outcomes and costs measured in the feasibility study. *Chapter 9* reports the qualitative work carried out at the end of the study to explore the experiences of those who had been involved in it. The final chapter contains discussion of our results and conclusions.

## Chapter 2 Review of the literature

An important element of the initial development stage of our research was a review of the existing literature to inform the development of a theoretical model of LSW, including its potential outcomes, and to establish core elements of good practice in using and applying the approach (project stage 1a, objective 1). The main research questions here were:

- What outcomes and of what size have been reported for LSW?
- What underlying theories of change for LSW are articulated in the literature?
- What elements of good practice in creating and using life stories are reported in the literature?

We proposed to undertake the review following Centre for Reviews and Dissemination guidance,<sup>19</sup> using a narrative synthesis<sup>20</sup> of the extracted material, and a 'realist' approach<sup>21</sup> – establishing what types and size of outcomes were reported, for whom, under what circumstances (including good practice components), and by which (implicit or explicit) causal routes. We further proposed synthesising evidence by the type of LSW used and the characteristics of participants and care settings.

### Search strategy

The literature searches involved electronic searching of a range of databases covering the fields of health, mental health, nursing and social care (see *Appendix 1, Table 8*; all tables for this chapter can be found in *Appendix 1*). The search strategies were devised using a combination of subject indexing terms (when available), such as medical subject headings (MeSHs) in MEDLINE, and free-text search terms in the title and abstract. The search terms were identified through discussion within the research team and by scanning background literature.

The search strategies focused on the retrieval of published studies and 'grey literature' (dissertations, reports, etc.) in which interventions were described explicitly as life story/life history/life review or life narrative within the title/abstract. Related terms such as oral history/biography/reminiscence were not searched, in order to reduce the retrieval of irrelevant studies. The decisions to restrict the searches in this way were made after the inclusion of these wider terms was piloted. The results of the broader search were compared with those from the more focused search and a decision was taken to use the more specific terms only.

The search strategies used to identify studies are included in *Appendix 2*. The searches were not limited by date, but were limited to English-language results only.

The results were loaded into EndNote bibliographic software (Thomson Reuters, CA, USA) and deduplicated using several algorithms.

The reference lists of all included review articles were searched for apparently relevant additional studies.

### Inclusion and exclusion criteria

As with most reviews of complex interventions, it is good practice to finesse the inclusion and exclusion criteria for selection for relevance after the first phase of searching.<sup>22</sup> However, we had developed some initial inclusion and exclusion criteria based on our existing knowledge of this literature, which we outlined in our proposal. These were:

- inclusion: any published account of LSW or life stories that is also about one of the dementias and refers to outcomes; any care setting, including own home; any country (UK and non-UK); any empirical study type; any theoretical account, including guidance and training documents.
- exclusion: opinion pieces, letters; published before 1984; not English language.



Once the project started, we further developed the inclusion and exclusion criteria in consultation with the project steering group and our project advisers. They were finalised through an iterative process during the early stages of searching and were as follows.

### *Inclusion criteria*

#### **Types of participants**

Studies that included, and papers that were about, people with dementia or Alzheimer's disease (including 'confusion' or 'memory problems').

#### **Phenomena of interest**

Studies that evaluated or that elucidated the theoretical underpinnings of LSW with people with dementia.

#### **Types of outcomes**

Any outcomes reported.

#### **Study designs**

Any study design, qualitative or quantitative.

#### **Date**

Studies published in or after 1984.

### *Exclusion criteria*

- Literature on LSW outside the dementia/Alzheimer's context.
- Opinion pieces and letters.
- Studies not in English.

### *Selection of studies for relevance*

We first went through the identified studies to assess their relevance to the aims and objectives of the review, using titles and, when available, abstracts. We developed a simple algorithm to help us in this (see *Appendix 3*). Two researchers (KG and GMP) worked individually and then as a pair to agreement about relevant studies.

We obtained full copies of the studies selected for relevance and read them before making a final decision about inclusion for review. Again, we developed guidelines for this process to ensure consistency across the team (see *Appendix 4*). Three members of the team (KG, GMP and YB) worked individually and then in pairs to agreement about relevant studies. When we could not reach agreement in pairs, the third member of the review team arbitrated.

### *Assessment of methodological quality*

Given the limited literature on LSW and the largely scoping and qualitative nature of our research questions, we did not include or exclude papers based on their methodological quality.

### *Data extraction*

The focus of data extraction was on outcomes that authors reported as arising, actually or potentially, from LSW, for whom these outcomes arose, explicit or implicit theoretical assumptions about causation, and any information on changes in outcomes.

We also extracted details of the type of LSW described, participants, the care setting, study design and any data or discussion related to good practice in creating and using life stories.

## Data extraction headings

Data extraction headings were developed after the first reading of the included studies and were discussed both in the research team and with the project steering group. The headings were then used to create data extraction forms in Microsoft Excel® (Microsoft Corporation, Redmond, WA, USA).

For the best practice part of the review, the final data extraction headings in relation to 'doing' LSW were format of the LSW, contents to include, contents to exclude or avoid, style of the LSW product, which people with dementia should do LSW, who should be involved in doing LSW, when LSW should be done, and ethical issues. Headings for organisational 'best practice' issues were the culture of care, leadership and management support for LSW, resources and time, support for staff doing LSW, training and preparation for staff/volunteers doing LSW, and incentives.

For the theory of change review, we were interested in any causal links that authors argued – either explicitly or implicitly – existed between doing LSW and outcomes (whether for people with dementia, family members or care staff).

For this part of the review, then, the data extraction headings were type of LSW (as defined by analysis of the first stage of the review – see *Results, Good practice in life story work*), argued causal links between LSW and outcomes, types of primary outcomes, types of intermediate or process outcomes, and contextual influences and factors that might affect outcomes.

All data extraction for both parts of the review was carried out by one researcher (GMP). The progress and initial findings of the extraction process were shared with other members of the team and with the project steering group.

## Data synthesis

All findings were analysed qualitatively and, when possible, metasynthesised. This involved aggregating or synthesising conclusions from the reviewed publications to generate a set of statements that represented that aggregation. The aim of meta-synthesis was to produce a single comprehensive set of synthesised findings. For the theory of change analysis we also used mind-mapping software in the first stages of analysis.

## Results

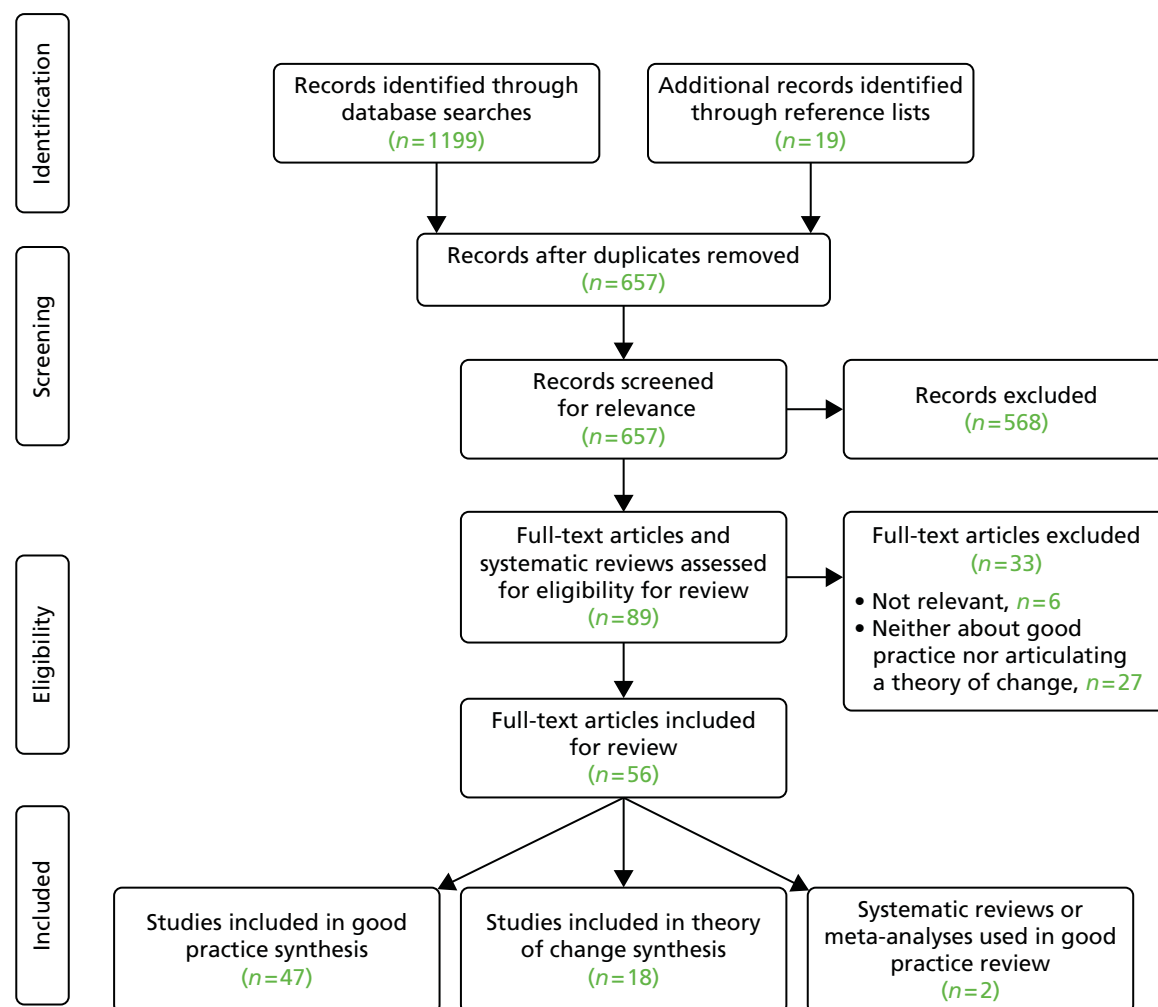
### Numbers of papers identified

The electronic searches identified 1199 records (see *Appendix 1, Table 9*). Following deduplication, 638 records were available to be assessed for relevance. A further 19 studies were identified at a later stage from the reference lists of papers included for review.

The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) diagram (*Figure 1*) shows the process through which the identified studies<sup>7,9–11,14,17,24–104</sup> were reduced to a final selection of 56 papers; of these, 47 were used in the good practice review and 18 were used in the theory of change review (see *Appendix 1, Table 10*).

Two of the six existing systematic reviews or meta-analyses<sup>11,105</sup> also provided material for the good practice review (see *Appendix 1, Table 11*).

Details of the types of primary studies included in the two reviews are in *Table 12* (see *Appendix 1*).



**FIGURE 1** Flow diagram for selection for relevance and review (PRISMA 2009<sup>23</sup>).

As *Figure 1* and the tables show, the majority of selected papers contributed to the good practice review, but few articulated any explicit or implicit explanation of why LSW might lead to better outcomes for people with dementia, their family members or care staff.

### **Good practice in life story work**

In this part of the review we first identified which selected publications contained any ‘how to do it’ material about LSW, so that we could focus on what authors believed was good practice in relation to LSW. We looked for publications that said anything about one or more of the following issues: format of a life story, contents to include in a life story, contents to be excluded or avoided, style to be used, who should be involved in LSW, when LSW should be done, and ethical issues. We also looked for publications that said anything about the organisational context to support LSW. The issues here were culture of the care setting, leadership and management support, resources and time commitment, support for staff in settings where LSW was being done, training or preparation for staff or volunteers doing LSW, and ‘incentives’ that might encourage LSW to be undertaken.

The literature we included in this part of the review revealed a number of distinct models of LSW and ideas about best practice within them. We have tentatively labelled these as follows: narrative approaches; biographical or chronological approaches; care-focused approaches; and care-focused approaches with a narrative orientation. We deal with these approaches in separate sections below, exploring first what characterises each approach and then what the publications say about what should be done (the LSW

product), when, by whom, how and with what type of involvement of which people. We then move on to discuss how each approach deals with issues around what should not be included in a life story, dealing with distress and consent to use.

We deal with the organisational context for LSW in a final subsection of this part of the chapter.

### *Narrative approaches to life story work*

#### **What is a narrative approach to life story work?**

Publications in this category were those that most frequently talked about LSW as a process tantamount to writing a novel. Thus, LSW was not about documenting 'objective facts' but rather about the personal interpretation of facts<sup>24</sup> and identifying the strength of the person living with dementia and the wisdom that they had accumulated during life.<sup>25</sup> As a result, the main issue in doing a life story was not accuracy, but capturing the emotions that accompanied that story, engaging with the person and hearing what they had to say about their identity and feelings.<sup>25,26</sup> Similarly, it was felt that there was no one way to 'do' LSW or to decide what content it should have; rather, it should be regarded as a process whereby doing one element of LSW might lead to another.<sup>27,28</sup>

Given this narrative approach, it was not surprising that the person living with dementia was seen as being firmly at the centre of the work<sup>29</sup> or as the virtual director (of a filmed life story).<sup>30</sup> LSW was a process, not just a form to be filled in,<sup>29</sup> and the story produced, via a dignified and respectful process, enhanced a person-centred approach.<sup>28</sup> Some also felt that a narrative approach produced a life story that was easier to read and engage with, both for the person living with dementia and for those who lived and worked with them.<sup>28,31</sup> Further, a narrative could be a living thing that recorded not just the past but also the present.<sup>29,30</sup>

Even in the description of an entirely carer-led life story process, a distinction was made between 'social histories', typically gathered in nursing homes, and the attempt in LSW to illuminate as well as report on a life.<sup>32-34</sup> These papers did talk about capturing facts, but also about communicating the essence of the person living with dementia and what made them unique.

#### **Good practice in narrative approaches to life story work**

Fourteen of the papers that represented a narrative approach also included details about how best to do LSW, although three of these were about the same intervention. There was a high degree of consistency about what this approach should contain and the process it should follow.

The strongest common message was that the LSW process should focus on feelings, opinions, meaning and emotions<sup>25,28,31</sup> and reflect the themes, topics or objects that are most important to the person living with dementia.<sup>31,35,36</sup> This means that the person living with dementia should choose the topics and material to be included and the way in which these are presented.<sup>35,36</sup> This orientation was reflected in some commentators' views that carers could be involved with creating a life story, but only with the permission of the person living with dementia.<sup>29,36</sup>

As outlined above, we did find accounts of a strongly narrative approach to LSW that was entirely carer led, but, even here, it was argued that the emphasis should be on key themes that illustrated the person's life rather than a list of facts about them.<sup>32-34</sup>

Several writers also talked about the importance of the life story not just being about the past but also being a 'living' or continually evolving account. It should thus be able to include current hopes and future wishes,<sup>26,29</sup> record aspects of current life,<sup>30</sup> add new stories and ideas and allow 'editing of the past' to match the current viewpoint of the person living with dementia.<sup>24,31</sup>

The emphasis on meanings and emotions underlines a need for a high degree of emotional intelligence in the person facilitating the life story production. One paper emphasised that the person who helps the person with dementia to create the life story needs to be 'emotionally present', prepared to be the 'validating witness' for the story, and receptive, open and non-judgemental about the story being told.<sup>27</sup> This recognised that whatever story is being told, it is of consequence to the teller and has been shared at an emotional cost. Others talked more generally about the importance of building strong rapport and a trusting relationship, without which nothing can happen.<sup>30,35</sup>

However, this emphasis on feelings and meaning may bring up issues that the life story process cannot resolve, in and of itself. One writer clearly states that LSW should not try to resolve either past or present problems; it is not therapy, even if it might be therapeutic. The issues of material that should not be included in a life story, and with whom the life story might be shared, are thus important too. Some researchers acknowledge that, although people with dementia are likely to express a wide range of preferences in relation to sharing and privacy,<sup>25</sup> the process might reveal issues that should never be revealed to anyone else without 'express permission'.<sup>27</sup> This means that the person to whom the life story belongs must be able to choose how much of it they want to share with others.<sup>24</sup>

When the process is carer led, carers themselves should choose to tell only the stories that they believe the person with dementia would tell, and keep private those they would keep private,<sup>32-34</sup> thereby viewing the process in the same way that they would view surrogate decision-making.<sup>34</sup> By contrast, two descriptions of a narrative approach argued that, although carers could be involved in LSW, this should be only with the permission of the person living with dementia.<sup>29,36</sup> Although some papers included clear statements about ownership of the LSW, one gave a somewhat confused account, reflecting the experience that if ownership is not properly negotiated at the start of the process, then problems and conflict may emerge later.<sup>30</sup>

The issue of what material should and should not be included and/or shared in a life story was also related in some writers' accounts of which people living with dementia should or should not be offered the opportunity to do LSW. Some publications advocating a narrative approach stated that LSW could be done regardless of the stage or type of dementia<sup>26,37</sup> – which may be true – or that it should be started as early as possible.<sup>31</sup> However, it is necessary to select carefully those to whom LSW is offered,<sup>38</sup> taking into account both personal preference and the likelihood of causing distress.<sup>26,36</sup>

### ***Biographical or chronological approaches to life story work***

#### **What is a biographical or chronological approach to life story work?**

The approach evident here is distinct from a narrative approach in its emphasis on a relatively ordered, chronological recording of the life of the person living with dementia. Writers thus talked about a final product that follows the life course, from birth to the current day, with material that is displayed or recorded chronologically, even if it is not necessarily gathered systematically.<sup>39-42</sup> There is thus an emphasis on remembering and memories,<sup>43</sup> on lists of topics to be addressed<sup>39</sup> and on timelines,<sup>41</sup> rather than on feelings and meaning. Perhaps as a corollary to this more structured approach, there is less reference here to validation of the life portrayed (Gibson and Carson<sup>39</sup> being a notable exception).

#### **Good practice in biographical or chronological approaches to life story work**

The more structured underlying approach here gives rise to a more directive feel to recommendations about how life stories should be recorded. Books, albums, workbooks and topic-based templates are recommended or described,<sup>39-41,43</sup> while timelines and visual and auditory 'prompts' and triggers to memory are suggested as useful adjuncts.<sup>41,42,44</sup> There are also recommendations about ensuring that books and albums are attractive<sup>40,41</sup> and immediately recognisable as belonging to the person living with dementia.<sup>40</sup>

The involvement of the person living with dementia does not seem as central in these approaches as in the narrative ones. In two of the models described, the person's memories are recorded and transcribed by others, based on audio-taped 'life review' sessions<sup>43</sup> or weekly, one-to-one reminiscence sessions in which a member of care staff acts as an 'amanuensis'.<sup>39</sup> One account suggests that a life story can be constructed based on what the 'helper' already knows about the person living with dementia, but points out that both the process and the end product are more meaningful if the person is included in the process.<sup>41</sup> This seems a much weaker commitment to the centrality of the person living with dementia than was evident in the descriptions of narrative approaches.

The role of family members or carers in LSW is also more evident here, with suggestions that they can encourage or facilitate the involvement of the person living with dementia<sup>40,43</sup> or indeed that they are 'integral' to the process.<sup>44</sup> One account reported that, although family members had been initially reluctant to discuss the past with their relative, fearing that they would cause distress, they had actually managed to have meaningful and pleasant discussions while doing LSW.<sup>40</sup>

One publication in this group (in which the production of a life story was tied in to 'life review') was clear that LSW was best done with people who were in the early stages of dementia and with those who were interested and had the cognitive, emotional and physical capacity to participate in life review activities.<sup>43</sup> By contrast, the authors who described an evaluation of a video photo show approach to LSW felt that it worked best for people with moderate to severe dementia, because they were less likely than people with lower levels of impairment to lose interest while watching the video on multiple occasions.<sup>42</sup>

The only other practical recommendation that emerged from this set of publications was the importance of using statements rather than questions in the final LSW product; this was in relation to a video-based life story, but might well also apply to text- or audio-based products.

The publications in this group were, overall, less reflective than those in the narrative group about how to deal with 'difficult' material. Some accounts simply suggested that the person might not want to discuss some things and that LSW should 'avoid' some types of memories or topics and concentrate on enjoyable memories;<sup>41,42</sup> most did not refer to the possibility of difficult issues arising at all. There was, similarly, little routine acknowledgement of issues of privacy or confidentiality. The single publication in the whole review that was specifically about people living with dementia who were lesbian or gay<sup>45</sup> talked about the person needing to feel comfortable with the level of detail included in their 'autobiography' and that LSW could raise issues of privacy and confidentiality. However, only one description of LSW in this subgroup talked specifically about issues of consent and future use, which, it was suggested, should be logged and recorded in the life story, and, in the case of consent (or assent), should be assured on a continuing basis.<sup>39</sup> Perhaps in implicit recognition of the possibility of having to deal with 'difficult' issues, two papers did suggest that untrained staff, or volunteers (even if trained), should not do LSW.<sup>39,43</sup>

### **Care-focused approaches to life story work**

#### **What is a care-focused approach to life story work?**

We defined a third group of publications about LSW based on their strong focus on practical advice about LSW done in care settings or by care staff. They are distinct from the other two groups described above by their emphasis on 'how to do it' and a generally lower level of reflection on 'why' and 'what for' questions about doing LSW. Indeed, only four of the publications in this section reflected on what LSW might be. One discussed the role of LSW as a device for 'cognitive stimulation', with the aim of maximising independence, engagement and well-being.<sup>46</sup> Another spoke of LSW as an opportunity to focus on 'memory windows' for people living with severe dementia and to identify specific and personally relevant triggers to memory.<sup>47</sup> A third publication spoke of the importance of seeing a life story as an 'interactive tool-box' for the person living with dementia, family and care staff, and not just as a source of information.<sup>48</sup> A single publication referred to the need for an holistic approach to underpin LSW.<sup>49</sup>



### Good practice in care-focused approaches to life story work

Many different life story formats were referred to in these publications: books, collages, photo albums, videos, digital versatile discs (DVDs), boxes of items, and albums with both text and relevant artefacts. As this might suggest, many writers argued that there should be no rigid approach to the LSW 'product': that the chosen format should be discussed and agreed with the person living with dementia;<sup>49</sup> that life story 'albums' should be as individual as the person they were about;<sup>48</sup> that it was important to avoid a 'story book' format and to include belongings and photographs;<sup>50</sup> that any artefacts included should be personally meaningful and significant for the person living with dementia;<sup>46</sup> and that the topics in life stories should also follow no rigid format.<sup>51</sup>

Although these papers that were advocating a wide range of formats underlined the person-centred decision-making that should determine choice, others suggested that choice was more likely to be or should be determined by the stage of dementia<sup>51</sup> or the care setting.<sup>52</sup> Thus, collages were suggested as more appropriate vehicles for life stories in continuing care settings.<sup>52</sup> Further, in contrast to the laissez-faire approach to format, two publications suggested the use of topic lists or templates for creating a life story.<sup>53,54</sup>

There seems to be more emphasis in the publications in this group on other people being involved in collecting and recording information than just the person living with dementia and a life story worker. Thus, one publication states clearly that family members compiled the life story books;<sup>51</sup> others state that staff recorded memories prompted in reminiscence sessions,<sup>54</sup> typed up notes about memories and added photos to them<sup>54</sup> or found or added photos and sensory objects related to the 'main themes' addressed during LSW. Two writers, however, do underline the importance of ensuring that information recorded by staff, and its use, should then be agreed with the person living with dementia.<sup>49,55</sup> One of these further states that it is the role of the care worker not to 'steer' the person living with dementia but to value their reflections and negotiate where in the life story content should be placed.<sup>55</sup>

The role of family members is more prominent in this group of publications, although not all writers agree about their role. Views included that mentioned above – that family members should actually compile the life story – and an assertion that the life story should *belong* to the carer when the family member is living with dementia.<sup>7</sup> Some writers suggest that staff should gather family members' and friends' recollections<sup>7,47,54</sup> and that they could provide photos or other supplementary material.<sup>46,47,54</sup> Only one paper suggested that the person living with dementia should be asked to give their permission before staff talked to family members and carers.<sup>55</sup> Overall, then, publications in this section see family member or carer involvement in LSW as unproblematic. Indeed, one suggests that staff should ensure that family members are happy with the life story's contents, but does not make the same suggestion about the person living with dementia.<sup>56</sup>

Perhaps because of the care-focused nature of these publications and, therefore, the possibility that they were targeted at care staff working with people living with later stages of dementia, some of them position LSW clearly within the routines and processes of the care setting. Thus, LSW is argued to start with assessment<sup>46,49</sup> and to draw on information about the person living with dementia drawn from files, from other staff members and from interactions and observations in the care setting.<sup>46,47,49</sup>

Only one publication in this group talked specifically about consent in relation to LSW and this emphasised that consent should be an ongoing and renegotiated process.<sup>54</sup> Another talked about the need to establish trust before any LSW was started.<sup>7</sup> Privacy and confidentiality were raised more often and particularly in relation to 'personal' information;<sup>7,55</sup> one paper reported LSW where 'sensitive' information about the person with dementia was collected from family members but not 'posted' in the life story itself.<sup>56</sup>

Responding to sensitive or difficult issues was also mentioned, with recommendations that staff helping people with dementia to do LSW should be aware of what type of material might provoke strong or upsetting emotions<sup>47,49,54</sup> and perhaps avoid or move away from such material.<sup>54,55</sup> By contrast, it was also important to acknowledge or empathise with strong feelings during LSW,<sup>49,55</sup> not least because not acknowledging 'difficult' things could be a barrier to understanding.<sup>56</sup> One publication went so far as to say that LSW could be a good vehicle for exploring feelings if staff had counselling skills.<sup>51</sup> Alone among all

the publications included in the good practice part of our review, a publication in this subsection raised the ethical issue of the loss of close personal communication that might be experienced by the person with dementia when LSW was completed.<sup>55</sup>

## Hybrid approaches to life story work

### What is a hybrid approach to life story work?

A small number of publications (five, reporting four different types of LSW<sup>9,57–60</sup>) were hybrids, in that they were mainly about LSW in care settings but included some narrative elements in the description of how LSW should be carried out. These publications were least likely of all those reviewed here so far to articulate a view about what LSW actually *is*. What characterised them as having elements of a narrative approach, however, was their emphasis on the centrality of the person living with dementia. They argued that a life story should reflect the issues and events of most importance to the person living with dementia,<sup>9,57</sup> that it should use the words of the person living with dementia<sup>58</sup> and that it should be written in the first person.<sup>59</sup>

### Good practice in hybrid approaches to life story work

Although publications in this group emphasised that there was no single format that LSW might use, in effect all were predominantly about life story books.<sup>9,57–59</sup> One publication emphasised the importance of making the life story product attractive to hold and look at, involving the person living with dementia in the choice of colours and design, and using high-quality materials to avoid any association with ‘childish’ activity.<sup>58</sup>

The two publications related to life review suggested recording life review sessions to guide the process of creating the life story,<sup>57</sup> using the Haight Life Review and Experiencing Form as a framework for the LSW process.<sup>60</sup> For others, objects and photographs could be ‘starting points’ for the reminiscing that informed LSW and served as illustrations for the book.<sup>9,58</sup> When such ‘starting points’ were absent, however, one publication suggested that finding alternatives or taking new photographs might stand in their stead.<sup>60</sup> Illustration might also be more useful than text in the later stages of dementia.

The authors in this section also pointed out that a life story did not have to be chronological, could include current information and details, should be kept up to date and could be edited to add new material.<sup>9,58,59</sup> However, one publication warned against the ‘diary/log of outings’ approach to keeping a life story up to date.<sup>59</sup> The life review-based publications did not talk about these sorts of issues, presumably because once a life review is finished it is considered complete.

Several authors acknowledged that LSW was not for everyone, whether because of personality or stage of dementia. Some people simply might not want to reminisce.<sup>9</sup> At later stages of dementia it might be difficult to do LSW,<sup>9,58,59</sup> particularly if the work relied on life review;<sup>58</sup> and in later stages people needed a product that they could look at rather than being involved in producing it themselves.<sup>58</sup> Overall, then, it was better to do LSW earlier rather than later.<sup>9</sup>

Despite what appeared to be a commitment to the centrality of the person living with dementia, the publications in this group took different views about who should be involved in LSW and when. Those that saw the life story as a product of life review work were consistent in their view about family carer involvement. While acknowledging that family carers could contribute material to LSW, they argued that carers could not and should not direct the contents of a life story book, and that any involvement in the book should be *after* life review work was complete, and then only with the permission of the person living with dementia.<sup>57</sup> As a result, staff and participants carried out LSW.<sup>60</sup> There was also a suggestion that family carers should do their own life story at the same time as the person living with dementia.<sup>57</sup> By contrast, other publications suggested that carers could provide material for LSW, after it had been fully explained to them, and that when people living with dementia were too severely affected to do LSW themselves, then carers could contribute.<sup>9</sup> One also felt that templates were useful for LSW



because they provided questions and prompts for staff and family members not experienced in LSW,<sup>58</sup> suggesting that family members might themselves be doing the LSW with the person living with dementia.

Despite this divergence of views about who could be involved in doing LSW, most publications in this section were clear that the life story product was the property of the person living with dementia,<sup>9,57,58</sup> although they were less likely to deal with access issues. One suggested that during the process of gaining consent for doing LSW, the person living with dementia should be shown an example of a life story book and be given clear examples of who might see and use the book once produced.<sup>9</sup> Another said that the person living with dementia should guide the current use, access to and future use of the book.<sup>57</sup>

Only one publication in this hybrid group specifically mentioned issues of what and what not to include in the life story product, stating that the boundaries of what should be included or not should be provided by the person living with dementia *and their carer* and then respected during LSW.<sup>9</sup> Further, this publication warned that perceptions of an invasion of privacy might be more evident when a 'task model' of LSW was predominant.

Only two publications<sup>9,59</sup> dealt with what to do if difficult issues came up during LSW. They counselled against ignoring expressions of emotion and underlined the importance of skilled listening, but also acknowledged that staff involved in LSW were not there to resolve problems and 'make things better'.<sup>9</sup> One also talked about the importance of not letting the person with dementia get 'trapped' in negative memories.<sup>59</sup>

### **Organisational issues around life story work**

In this final section of the good practice review, we turn to what the documents said about how LSW should be organised or presented within the settings in which it was being carried out. We identified several themes here: the culture of care in the organisation; leadership and management support for LSW; the resources or time required for doing LSW; the support provided to staff involved in the setting where LSW was being carried out; and training or preparation for staff and/or volunteers doing LSW in partnership with people living with dementia. Thirty-five of the 47 publications reviewed here said something about one or more of these themes.<sup>7,9-11,14,25,26,31-34,36-40,43-45,49,50,52,54-56,58-66,70</sup>

#### **The culture of care**

The publications that talked about the culture of care in the LSW setting were all agreed that, in order to be successfully adopted and carried out, LSW had to be embedded in and 'match' the culture or service philosophy of the care setting.<sup>10,14,32,34,40,60</sup> If LSW was being proposed from 'outside', then it was important to examine the culture of care implementation to ensure that this matched.

To assist the proper embedding of LSW, the care setting itself had to have an overall culture of person-centred care<sup>14,33,40</sup> and also to believe in the importance of partnership between care staff and families.<sup>14,33,34</sup> One publication said that without these cultural underpinnings it was more difficult to secure staff commitment to doing LSW.<sup>34</sup>

Furthermore, LSW had to be an integral part of everyday care and not an additional 'task',<sup>10,40</sup> or one that was 'assigned' to some staff and not seen as a team responsibility.<sup>32,40</sup>

#### **Leadership and management support**

Active support from the leaders, senior managers or owners of care settings was clearly seen as crucial to the successful implementation of LSW,<sup>7,11,32,34,36,39,40,44,50,52,61,62</sup> and without this support it would probably be difficult to secure staff and/or team participation.<sup>34,52,59,60</sup>

The appropriate commitment of leaders and managers was needed to ensure that LSW was implemented as part of a well-thought-out strategy,<sup>11</sup> accompanied by facilitation and supervision for staff doing LSW<sup>14</sup> as well as policies and guidelines about how LSW was to be carried out and how its products were to be used.<sup>40,63</sup>

One particularly important study in this group specifically explored the factors that influenced implementation and argued that 'Consistent, convinced leadership, careful prioritisation of resources and competent management (particularly over small details such as staff rosters) are all essential if lasting improvements are to be made'.<sup>39</sup>

### **Resources and time needed for life story work**

The major issue identified here was the time needed for doing LSW well.

Some publications talked about the *actual* amount of time or number of 'sessions' that needed to be dedicated to doing LSW: a minimum of 2 hours per week per person,<sup>39</sup> 50 hours over 6 months for each person,<sup>54</sup> a minimum of six one-to-one sessions with the person living with dementia.<sup>26</sup> Others just acknowledged that LSW is time-consuming<sup>40,58</sup> and that time has to be spent getting to know, or building trust with, the person living with dementia before starting LSW,<sup>7,11</sup> a particular issue for those who might be working with lesbian or gay people living with dementia.<sup>45</sup>

However, the length of each LSW session will be influenced by the attention span, motivation and emotional state of the person living with dementia at any given session.<sup>55</sup> It is thus presumably difficult to predict with any accuracy how long it will take to complete LSW for any given individual.

Much discussion revolved around a lack of dedicated resources or time as the biggest obstacle both to doing LSW and then to using its products in care.<sup>7,10,11,34,39,44,49,52,56,59,60</sup> As a corollary, adequate and dedicated resources and staff time were seen as the *sine qua non* for successful LSW to take place.<sup>7,26,36,39,54,58,59</sup>

All of the comments above suggest that LSW is seen as something separate from the normal routines of care. However, one writer argued strongly that LSW should be a part of ongoing, interactive 'joint production', and not a 'task' to be completed in a given place at a given time.<sup>9</sup> The *use* of life story products should also be built into everyday routines.<sup>59</sup>

Practical resources are also necessary to support LSW; laptops or PCs, scanners and digital cameras are essential,<sup>26</sup> as are the skills in using them.<sup>52</sup> Somewhere quiet or private to do the work is also necessary, but often surprisingly hard to find in care settings.<sup>26,39</sup>

Some publications talked about the need for trained facilitators, project workers or co-ordinators to support LSW,<sup>7,52,54,63,64</sup> again suggesting that LSW is seen as something rather separate from everyday care.

### **Support for staff carrying out life story work**

Related to the issue of resources and time was the theme of the nature of support offered to staff involved in doing LSW. Here, training for LSW was the main concern,<sup>7,40,58–60,65</sup> to enable staff to both do LSW and use its products. Only two publications, however,<sup>54,65</sup> suggested that staff might be encouraged to create their own life story.

Life story work training might not be enough in itself, however; staff might need help to develop their communication skills,<sup>40</sup> or support and encouragement to enable them to explore the stories of people living with dementia without feeling 'nosey' or 'intrusive'.<sup>60</sup> Appropriate supervision or mentorship should also be in place to support staff in setting appropriate professional boundaries and in case 'difficult' material is revealed while helping a person living with dementia to create their life story.<sup>11,14,37,63</sup>

Finally, there was a subtheme about the importance of a team approach to LSW. LSW should be developed as a mutually supportive team effort, even if not everyone is involved in actually doing it; it should not be left to a limited number of staff whose work might be 'sabotaged' by others who do not understand or respect the approach.<sup>39,52,56,60</sup> The role of a facilitator in developing LSW and supporting staff in this way was seen as crucial in one study that followed the implementation of LSW in a long-term care setting.<sup>52</sup>

### Training for life story work

Twenty-three of the included studies mentioned training as an issue in LSW. Most were clear that anyone doing LSW should be trained<sup>7,11,38-40,52,64,70</sup> or that trained facilitators or 'champions' were essential to good practice.<sup>32,33,39,52</sup> Training for 'other' staff, or at least ensuring that all staff understood LSW and could support its use in the care setting, was also recommended.<sup>7,31,39,52,59</sup>

Other publications placed less emphasis on the need for training, suggesting that LSW could be done with minimal training if it was accompanied by supportive supervision,<sup>66</sup> or that volunteers could 'graduate' from family LSW workshop groups to run groups themselves.<sup>33</sup> However, one publication cautioned against the use of volunteers in LSW because of their potential vulnerability and the possibility that 'difficult' issues might emerge during LSW,<sup>43</sup> while another – that had used an informal 'monitor' approach to rolling out LSW training to staff – had had to put in additional training to make this model work.<sup>7</sup>

In terms of suggestions about the content of training, publications fell into two main groups.

First, there were those that were mostly practical in orientation. These recommended that training should include information about dementia itself<sup>25</sup> and how to 'select' people with dementia to do LSW;<sup>38</sup> about the different ways in which LSW might be presented;<sup>25,38,54</sup> about technical support for LSW such as scanners and computers, library and internet resources;<sup>54,65</sup> and about the principles of capacity and consent.<sup>36</sup>

The second group of publications concentrated more on aspects of emotional intelligence in relation to LSW, where learning to deal with 'difficult' issues was predominant. This grouping included methods for recognising and dealing with difficult issues<sup>11,38,60</sup> and emotions;<sup>9</sup> developing communication skills and empathy;<sup>40</sup> learning how to maintain boundaries<sup>37</sup> or, by contrast, becoming willing to scrutinise interpersonal relationships with care home residents;<sup>60</sup> and learning to be sensitive to family members.<sup>56</sup> Producing one's own life story product<sup>54,65</sup> or reflecting on one's own life story more generally<sup>49</sup> and reflective practice learning<sup>39</sup> were possible routes to enhanced emotional intelligence in LSW practice with others, but could also be empowering for staff in their own right.<sup>65</sup>

## Underlying theories of change

One of the acknowledged weaknesses of much research that has tried to evaluate complex interventions in health and social care settings is that it has searched for improved outcomes without any pre-existing theory about why we might expect the particular intervention to affect the given outcome.<sup>18</sup> This is the case with LSW: there is enthusiasm for it as an approach and practitioners feel that they observe change when they use it, but it is difficult to pin down any underlying theory of change about why these changes might have occurred. There is, thus, the danger that evaluative research might choose the wrong outcomes to assess – both intermediate and final – and thus fail to demonstrate change.

This next part of our review work was, therefore, designed to develop a theory of change, based on the literature selected for review.

We gave an example of how we envisaged this work in our proposal:

*The results of one life story project<sup>57</sup> have been described thus: 'The group that participated in a dyadic life review (caregiver and care receiver) seemed to gain most from the intervention, particularly in their assessment of the care receiver's problem behaviours. Possibly . . . because they were enjoying the process simultaneously and were sharing an event again.'*

p. 171<sup>106</sup>

Here, the underlying theory seemed to be that the carers' assessment of the care receiver's problem behaviours improved (final outcome for family carer) because the dyadic life story process (LSW) was shared (implicit causal link) and was enjoyed (implicit causal link).

This generates a theory of change that can be expressed in a linear fashion:

Type of LSW → that was a shared process → that was enjoyed → changed carer's assessment of 'problem behaviours'.

As this example suggests, such theoretical models are often embedded in descriptive or discursive text, rather than articulated explicitly as a hypothesis to be tested.

## Analysis

In our analysis of the 16 papers that expressed an underlying theory,<sup>7,10,14,31,32,34,38,42,56,57,59,60,67–70</sup> we identified the causal links between LSW and the outcome or outcomes that the authors were arguing for LSW, as given in the example above. In some papers there was a single such theory; in others there were several. We first summarised these theories into our Excel spreadsheet using the data headings outlined above, and then mapped them all in a mind map. This was done twice: once for the theories articulated in the introductory sections of each paper (initial theories of change) and again for the theories articulated in the discussion and concluding sections of each paper (concluding theories of change). In both cases, we concentrated on theories that the authors themselves were arguing, not on theories that they were repeating or reviewing from others' publications.

After completing the initial mind-mapping, we synthesised the material using a set of overarching outcomes. Given that most of the papers had included some empirical work, we took the concluding theories of change as the basis for this final stage of analysis, assuming that these would be a more accurate reflection of the authors' views about LSW, its outcomes and the routes by which it achieved these outcomes.

## Theories of change

The initial mind-mapping generated complex and complicated pictures of both initial and concluding theories of change (see *Appendix 1* and *Boxes 1* and *2*). The 18 papers outlined 26 theories of change initially, but 47 in their conclusions.

As *Tables 7* and *8* show, some theories of change were relatively simple, with only one intermediate outcome between LSW and a final outcome. So, for example, concluding theory of change 3 was that LSW leads to interactions between care staff and family members, thus strengthening understanding of, and the relationship with, family members.

Others theories of change were much more complex, and sometimes argued two separate final outcomes from the same causal chain. For example, concluding theory of change 24 (final outcomes in bold) was:

24: [LSW] enables staff to gain fuller and more dynamic picture of person with dementia

24.1: which increases their knowledge of the person

**24.1.1: which enables them to find out more about person's needs and behaviour AND**

**24.1.2: which helps staff see person in context of whole life rather than in terms of their medical condition/physical needs AND**

24.1.3: which provides a talking point between staff and person with dementia

**24.1.3.1: which helps develop common bond between person with dementia and staff.**

Here we see two intermediate outcomes (24, leading to 24.1) that led to two final outcomes (24.1.1 and 24.1.2) and one further intermediate outcome (24.1.3), which itself led to an additional final outcome (24.1.3.1).

As is also clear from the tables, there were overarching final outcomes in the theories of change. Our next stage of analysis was to identify these outcomes and synthesise the causal links that the literature suggested led to them. In doing this, we confined the analysis to outcomes that at least four papers identified as resulting from LSW. Then, within each outcome, we confined analysis to theories of change in which at least two studies had argued that the same or similar causal links led to these outcomes. In total, we identified seven outcomes and 12 theories of change.

The overarching final outcomes for the person with dementia were:

1. LSW supports the self-worth and empowerment of people with dementia, for example increased sense of control, pride in their lives and opportunity for reciprocity.<sup>14,31,38,67</sup>
2. LSW affects a range of individual outcomes positively, for example anxiety, depression, agitation, mood and behaviour.<sup>10,31,38,42,56,57,59,60,67,68</sup>

Final outcomes in relation to the care setting were:


1. LSW improves relationships between care staff and the individual person with dementia.<sup>7,31,59,69</sup>
2. LSW leads to better care, for example more person-centred, individualised, less 'pathological' care on a one-to-one basis.<sup>10,14,31,32,38,59,60,69,70</sup>

For family members and carers, the final outcomes were:


1. LSW allows more effective engagement of family members/carers within the care setting, for example enhanced communication with staff and more meaningful involvement in care planning and delivery.<sup>7,10,32,67,69</sup>
2. LSW helps carers to cope better.<sup>32,34,42,57,67</sup>

The theories of change are summarised in *Figures 2–7*.


The identified final outcomes from this part of the review were subsequently used to inform discussion and the final choice of outcome measures for the feasibility study (see *Chapter 4*).

Study ID	First link	Second link	Final outcome
Batson, <sup>38</sup> Hagens <sup>31</sup>	Being listened to/ opportunity to share self with staff	Increased sense of control/power	Increased self-worth
Damianakis, <sup>79</sup> McKeown <sup>14</sup>	Being valued and recognised	Self-affirmation and pride	
			

**FIGURE 2** Theories of change for increased self-worth of the person with dementia.

Study ID	First link	Second link	Final outcome
Egan, <sup>56</sup> Kellett, <sup>10</sup> Hagens <sup>31</sup>	Increased staff knowledge of, and interaction with, person with dementia	Facilitates more person-centred or individualised care	Reduced 'negative' psychological and behavioural outcomes
Chapman, <sup>68</sup> Haight, <sup>57</sup> Gibson, <sup>60</sup> Yasuda <sup>42</sup>	Person with dementia is engaged in/enjoys the LSW process	–	
			

**FIGURE 3** Theories of change for improved individual outcomes for the person with dementia.

Study ID	First link	Second link	Final outcome
Murphy, <sup>59</sup> Clarke, <sup>7</sup> Hagens <sup>31</sup>	Get to know the person with dementia	Improve interaction and communication	Improve relationships between staff member and person with dementia
Chaudhury, <sup>70</sup> Clarke <sup>7</sup>		Understand current actions and behaviour	
			

**FIGURE 4** Theories of change for improving relationships between staff and the person with dementia.


Study ID	First link	Second link	Third link	Final outcome
Chaudhury, <sup>70</sup> Gibson, <sup>60</sup> Kellett, <sup>10</sup> McKeown, <sup>14</sup> Murphy <sup>59</sup>	Increases staff understanding of the person with dementia	Enables staff to 'see' the person with dementia/makes the person with dementia 'knowable'	Facilitates more person-centred or individualised care	Better care
Batson, <sup>38</sup> Buron, <sup>69</sup> Chaudhury, <sup>70</sup> Murphy, <sup>59</sup> Hagens <sup>31</sup>	Increases staff knowledge about the person with dementia	Improves 'fit' between care provided and person with dementia's needs/interests	Improves overall care environment	
Buron, <sup>69</sup> Chaudhury <sup>70</sup>	Increases staff knowledge about the person with dementia	Changes aspects of the 'job' and staff behaviour		
				

FIGURE 5 Theories of change for improving care.

Study ID	First link	Second link	Final outcome
Caron, <sup>32</sup> Damianakis, <sup>79</sup> Kellett <sup>10</sup>	[Carer-led or -focused LSW] improves recognition and empowerment of family member/carer in care setting	More inclusive relationship between family member/carer and care setting with care planning and delivery	More effective engagement with family members/carers in care setting
Chaudhury, <sup>70</sup> Chapman <sup>68</sup>	[Staff-led LSW] leads to more interaction and involvement with family members/carers	Care staff have more knowledge and understanding of family members/carers of people with dementia	

FIGURE 6 Theories of change for more effective engagement of family/members in care setting.


Study ID	First link	Second link	Final outcome
Caron, <sup>32</sup> Damianakis, <sup>79</sup> Hepburn <sup>34</sup>	Enables carer to remember past life of person with dementia	Changes family members'/carers' appraisal of person with dementia and their current condition	Enhances coping of various types
			

FIGURE 7 Theory of change for helping family members/carers to cope better.

# Chapter 3 Life story work outcomes, challenges and good practice: findings from the focus groups

## Introduction

The objective of this part of the study was to carry out a qualitative study of experiences of LSW, including people with dementia, family carers and professionals (objective 1). The overall aim was to develop a theoretical model of LSW, including its potential outcomes, and establish core elements of good practice in using and applying the approach.

Successful evaluation requires an understanding of *what* an intervention is intended to achieve and *how* different approaches to this intervention may determine different outcomes for different groups.<sup>107</sup> MRC guidance recommends drawing on existing evidence to develop a theoretical understanding of the likely process of change, but also suggests supplementing this with new primary research if there are gaps in the literature.<sup>18</sup> Earlier reviews of the literature on LSW concluded that more work was needed to develop a sound theoretical framework<sup>12</sup> and, in particular, emphasised that there had so far been only limited reporting of patients' and carers' views.<sup>11</sup> We know that people living with a condition can have very different views about outcomes from policy-makers and clinicians.<sup>108–110</sup> This stage of the study, therefore, aimed to collect primary qualitative data about outcomes and good practice from three different perspectives: people with dementia; family carers; and staff and professionals with experience of LSW.

## Aims

- To identify potential outcomes of LSW (to be measured in the feasibility study).
- To identify potential challenges or problems with LSW and possible solutions.
- To establish core elements of good practice.
- To use these findings, together with those from the review, to develop a theoretical model of LSW.

## Methods

Ten focus groups were held: four with people with dementia [organised and co-facilitated by Innovations in Dementia community interest company (CIC) and KG]; three with family carers (organised and co-facilitated by Uniting Carers and KG); and three with staff, professionals and volunteers with experience of LSW, recruited through the Life Story Network CIC and co-facilitated by KG and GMP. Research ethics approval for this stage of the project was obtained from the National Institute for Health Research (NIHR) Social Care Research Ethics Committee (SCREC) for England in October 2012 (Research Ethics Committee reference number 12/IEC08/0046).

### Focus groups with people with dementia

We originally planned to conduct three focus groups for each group, each with 5–10 participants. We added a fourth session with people with dementia to bring in a wider range of views and anticipating that groups of people with dementia may need to be smaller to accommodate communication and cognitive impairment. Focus groups with people with dementia were held in settings already known to and attended by participants, in order to maximise comfort and familiarity. This also meant that known and trusted group facilitators were on hand to help with the consent process and to support anyone who chose, on the day, not to take part.



## Recruitment

Recruitment was purposive and designed to include people with dementia from a range of community settings and experience of LSW. Stages of recruitment were:

1. Innovations in Dementia CIC approached some groups they already worked with, as well as new contacts, via group facilitators.
2. Innovations in Dementia then visited interested groups (usually with KG) to inform potential participants about the project, answer their questions and invite them to take part (see the information sheet in *Appendix 5*).
3. If the group, or a number of the group's members, were interested in taking part, a date was set for KG and Innovations in Dementia to return to conduct a focus group. Consent was taken at this stage (see below).
4. After the focus group, a further visit was planned to feedback to participants (and group facilitators).

Details of the people with dementia that took part are included in *Table 13* (see *Appendix 1*, where other tables for this chapter can be found). In total, 25 participants with dementia (15 female and 10 male) took part across four groups.

## Consent

Only people with the capacity to give informed consent were included in this stage of the project, as participation in a focus group requires an understanding of the concepts under discussion and the ability to express views. Group facilitators discussed capacity before the first visit from Innovations in Dementia to gauge whether or not at least some of the group members would have the capacity to consent. At the first visit, Innovations in Dementia and/or KG talked through the project information sheet with the group and answered any questions, and then revisited the information sheets with each individual on the day of the focus group before consent was given.

The use of written consent forms (see *Appendix 5*) was not straightforward, and in some cases presented an active barrier to participation. People with dementia who understood the premise of the research and expressed (verbally) that they were happy to take part sometimes struggled when presented with a lengthy consent form with a number of separate statements for them to agree to before signing. These statements are a SCREC requirement and must be included on all participant consent forms. However, asking people to agree or disagree to each of these and then sign, after they had already discussed each point (while talking through the information sheet) and indicated verbally an intention to proceed, was burdensome and fatigued some before the focus groups had even begun. Moreover, some people with dementia found it physically difficult to hold a pen and sign their names. Signing a document may also feel like a significant act for a person who is losing control over aspects of their life and we became concerned that this might be causing unnecessary worry for some of our participants. We decided therefore to build the facility for verbal consent with a witness into future consent processes with people with dementia, and received approval from SCREC to use these in the final stage of the project (see *Chapter 6*).

## Format of the sessions and topics covered

We had planned only to include people with dementia with experience of LSW in the focus groups. However, after further consideration we agreed to include people with a range of experience of LSW. This recognised that some people with dementia may have actively chosen *not* to undertake LSW, while others might not have come across the idea but still have views on recording and sharing aspects of their life. To understand good practice we needed to hear from the full range of potential LSW participants, not just from those who had successfully engaged in it.

To ensure that all participants understood what we meant by LSW, we produced four specimen life stories and took these to each session to share with the group. These were:

- a structured life story book, based on a template
- an unstructured life story folder, with photographs and text
- a life story box with objects, photographs and documents
- a digital life story accessible via a touchscreen tablet.

On the advice of our advisory group, we also encouraged participants to bring in their own life story products or an object or photograph that they would be happy to share with the group. The focus groups then began with a discussion of these specific products and artefacts before moving on to more general topics such as the outcomes of recording and sharing life stories and the best ways to do this (see *Appendix 6* for the topic guide). Sessions were co-facilitated by Innovations in Dementia and KG, with the existing group facilitators on hand in case participants required support from a familiar worker.

### **Focus groups with family carers**

We held three focus groups with family carers of people with dementia with experience of LSW, all recruited through the Dementia UK network Uniting Carers. Dementia UK hosted two focus groups in London and we held a third in York. Uniting Carers and KG co-facilitated all three groups.

### **Recruitment**

Carers were recruited through the Uniting Carers e-network as follows:

1. Invitations were circulated to the e-network of carers of people with dementia.
2. Interested carers contacted Uniting Carers who gave full information (see participant information sheet in *Appendix 5*) and answered carers' questions.
3. Dates for focus groups were confirmed by telephone or e-mail and participants confirmed attendance.
4. KG and Uniting Carers co-facilitated three focus groups. Consent was taken at this stage.
5. Feedback on the overall findings from this phase of the research was circulated to participants by e-mail and comments were requested.

*Table 14* (see *Appendix 1*) gives details of the focus groups held and the types of carers who took part. In total, 21 carers (16 female and 5 male) took part across three groups.

### **Consent**

Written consent was given on the day of the focus groups (see *Appendix 5*). All participants received the information sheet in advance and again on the day of the focus group and had the opportunity to ask questions.

### **Format of the sessions and topics covered**

Uniting Carers and KG jointly facilitated the focus groups with carers. Each began with an 'icebreaker' exercise and moved on to topics such as personal experiences of doing LSW, outcomes and challenges, and general views about good practice (see *Appendix 6* for the topic guide).

### **Focus groups with professionals**

Three focus groups were held with professionals from health and social care settings who had experience of doing LSW with people with dementia. The Life Story Network CIC helped to identify potential participants, as did other networks including DeNDRoN (Dementias and Neurodegeneration Network). Two focus groups were held in York and one was held in London. KG and GMP facilitated two groups together, and KG facilitated one alone.

## Recruitment

Professionals were recruited as follows:

1. Invitations were circulated to a number of e-networks including the Life Story Network, local DeNDRoNs and a dementia-training network.
2. Interested professionals contacted KG, who gave full information (see participant information sheet in *Appendix 5*) and answered questions.
3. Dates for focus groups were confirmed and participants confirmed attendance.
4. Three focus groups were facilitated by the research team. Consent was taken at this stage.
5. Feedback on the overall findings from this phase of the research was circulated to participants by e-mail and comments were requested.

*Table 15* (see *Appendix 1*) gives details of the focus groups held and the types of professionals who took part. In total, 27 participants (26 female and 1 male) took part across three groups.

## Consent

Written consent was given on the day of the focus groups (see *Appendix 5*). All participants had been given the information sheet in advance but received it again on the day of the focus group and had the opportunity to ask questions.

## Format of the sessions and topics covered

As well as the topics addressed with all groups, professionals were also asked about drivers of resource use in dementia care settings and what changes, if any, they would expect to see in these if LSW was carried out (see *Appendix 6* for the topic guide). This material was used specifically to inform data collection in the feasibility study (see *Chapter 6*).

## Analysis

All the focus groups were audio-recorded, with participants' permission. They were transcribed and analysed thematically using the Framework approach.<sup>111</sup> The aim was to produce a realist account<sup>21</sup> of what works, for whom and in what circumstances, from the perspectives of people with dementia, family carers and professionals.

## Findings

By adopting a 'realist' approach, we were interested in the types of outcomes experienced or expected by different groups, as well as any situations in which such outcomes might not be achieved. By exploring the circumstance in which positive outcomes are experienced, and considering what went wrong when experiences were less positive, we also gained a better understanding of good practice. First, the findings of this stage of the research are presented in terms of outcomes – for individuals with dementia, for interpersonal relationships and for better care. Second, we examine the challenges involved in doing LSW, and what these might tell us about good practice.

### *The outcomes of life story work*

#### Outcomes for people with dementia

It was clear that some people with dementia gained immense pleasure from talking about their memories. Reminiscence activities have been used in dementia care for some time<sup>8</sup> and LSW can involve a specific form of reminiscence: that which focuses on the individual's life history. In each focus group with people with dementia some participants told us they found it enjoyable to talk about memories. More specific to

LSW, some felt that it was important to *record* memories, so that they had them to look back on and could share them with others:

**Researcher:** *What are you going to use them [the life story books] for?*

**DF3R7:** *[Pause] For memories.*

**Researcher:** *For yourself?*

**DF3R7:** *For myself, and the family, they've all seen them. It's – I think it's nice just to have a look and think – I used to look like that once!*

However, the benefits of this tool for looking back, highlighting and sharing important memories seemed to go further than simply the 'comfort in recall' (as one participant put it).

We asked participants in the dementia groups to bring in objects or photographs of something from their lives to act as a starting point for the discussions. Most brought things that reminded them of people or achievements that they were proud of, such as their children's certificates or photographs from their wedding day. Highlighting and celebrating past achievements was clearly a priority and one that appeared to bring much pleasure. Moreover, each object or photograph came with a story.

The literature suggests that storytelling may be an important tool for all of us, allowing us to communicate and, in the process, reaffirm our identity.<sup>9,112</sup> Through storytelling we have the opportunity to review, construct and reconstruct our own identities, both in the eyes of other people and for ourselves. Yet people with dementia may find themselves increasingly left out of such conversations and storytelling,<sup>113</sup> as illustrated here:

**Researcher:** *So, do you talk about your life much?*

**DF4R1:** *No, not really. Not now. Used to at one time . . . I didn't mind. I haven't done for a long time now.*

**Researcher:** *And why's that?*

**DF4R1:** *'Cause nobody asked.*

Life story work might, therefore, offer a valuable opportunity for people with dementia to continue to make and remake their identity, helping them to communicate aspects of themselves. This benefit may be of particular significance to people with impaired speech, as life story products can give visual hooks from which to hang verbal and non-verbal communication. Another participant had limited speech but was able to indicate to the group that she had a book of photographs that she valued, as it helped her to communicate with her friends and family. However, she did not see this as something to share with a wider range of people (such as care home or hospital staff): it was a private book which she used to help communicate with those close to her.

Some participants were clear that the primary purpose of LSW for them was to review their past in order to help them have a better idea of who they are today and who they might be in the future:

*. . . in writing this, I can't say that I'm writing it for posterity or for my children . . . But it is important to me . . . because I've never really looked back at the whole of my life at any stage, and taken stock of what I've done and what I aim to do, . . . it does make you think about your life . . .*

**DF3R3**

In this way, LSW can cross over into life review;<sup>114</sup> indeed, life review and LSW are sometimes combined, with the suggestion that making a book might help sustain the benefits of life review.<sup>66,115</sup> Moreover, some of the professionals we spoke to suggested that simply listening to people and validating their feelings could potentially resolve issues that were bothering a person.

Finally, in addition to celebrating past achievements and helping people to understand or reassess who they are today in the context of their histories, LSW was seen as providing an opportunity for people with dementia to achieve something *today*. Some of the people with dementia we spoke to were clearly very proud of the life story books they had made, seeing the process not only as an enjoyable activity but as a personal challenge they were pleased to be able to meet.

Table 2 summarises the outcomes identified for individuals with dementia. All of these potential immediate outcomes may have the potential to feed into a larger outcome, that of improved QoL, which we have added here as an hypothesised outcome.

### Interpersonal relationships

Life story work tends to be a shared activity, and a number of potential outcomes were identified that went beyond the individual. Both family carers and staff suggested that LSW could bring people with dementia and others (extended family, other residents in care homes or those attending social clubs, as well as staff in these settings) together through the identification of common ground and interests. Some of the participants with dementia (although by no means all) said that they would be interested to see other people's life stories, and both carers and staff recounted examples of life stories acting as a catalyst for relationship building.

Improved understanding and the establishment of common ground may also be important to family carers themselves seeking to connect, or reconnect, with their loved ones, as one carer explained: 'I find it comforting, in a way, that we can still have some things in common . . .' (CF2R7). In some cases, engaging in LSW could lead to family members learning things about their loved ones that they never knew before and found interesting or were proud of:

*By . . . producing this album, I was getting to know her even more, and admiring her more as a person. So, for me, I think it probably had more beneficial – [laughs] and more impact for me than my mum.*

*CF1R3, son of person with dementia*

In other cases, however, families learnt of things that appeared to have been concealed for good reason and there was concern about how to deal with this information.

For some, LSW provided an opportunity for an enjoyable shared activity, and a wider range of topics for conversation. Indeed, there was a suggestion from the professional focus groups that LSW might attract a wider range of visitors to care homes and hospital wards by providing new triggers for conversation.

**TABLE 2** Focus group analysis: outcomes for individuals with dementia arising from LSW

Immediate outcomes	Overall (hypothesised) outcome
Enjoyment/pleasure	Overall QoL
For identity	
Person is listened to/has feelings validated	
Issues resolved	
Skills maintained/independence reaffirmed	

For some, however, the opportunities for conversation sparked by a life story were limited by the severity of the dementia and associated communication impairments. Nevertheless, there was a suggestion that LSW might still provide a 'way in' for the families and carers of people with limited speech:

*And that's when a life story book's quite good, because they can go in. There's no speech, but they can look at the photographs . . . I think that life story books can bring everybody in, and the children, and when she saw their faces, even though she didn't know their names, she'd go like that and smile.*

CF3R3

This could have benefits both for the person with dementia and for those around them. Even in situations when the value for the person with dementia was questioned, several family carers said that they themselves valued the life story products and the memories that the objects and images brought back.

We saw earlier that LSW might help people with dementia to express aspects of their identity to others. There was a suggestion in the focus groups that the benefits of this could go beyond the individual, challenging assumptions by helping others to understand better the person with dementia. As one woman with dementia put it:

*. . . the younger ones today ought to realise it, even though I'm 82, I still feel just like I did feel when, you know? . . . even though you're 83, you can still be falling in love . . . you don't have to be all glamorous and young.*

DF1R3

Improved understanding could have a number of benefits. Feeling understood, in itself, may be important to an individual's well-being. In addition to this, improved understanding may alter other people's attitudes and responses towards people with dementia. Tom Kitwood<sup>116,117</sup> highlighted the ways in which the actions and responses of caregivers could affect the well-being of people with dementia. It was suggested in the focus groups that staff may form negative perceptions of patients or residents from reading their medical histories before meeting them, which could in turn affect how they acted towards them. Learning about people's life stories might help to redress the balance, as this hospital occupational therapist (OT) explained:

*. . . staff receive a report about who's coming in. 'Oh, we've got somebody coming in that's done this, this, this, and this,' and it immediately triggers those . . . negative attitudes. But . . . when people have arrived with a life story . . . once people have had a chance to look at it . . . the attitudes change completely.*

PF1R1

A summary of the potential interpersonal outcomes identified in this section is given in *Table 3*. As with the individual outcomes, the result of any of these outcomes might be an improvement in QoL. However, these outcomes might lead to improved QoL not only for the person with dementia, but also for family carers and others involved such as wider family and friends.

**TABLE 3** Focus group analysis: interpersonal outcomes arising from LSW

Immediate outcomes	Overall outcomes
Highlights common ground	Improved relationships
Fosters understanding	Personhood recognised
Shared enjoyment	Overall QoL
Assumptions challenged	

## Outcomes for care

We saw above that LSW can provide a hook for conversations and non-verbal interaction, helping to identify common ground and build relationships. Participants in the professional and family carer focus groups, in particular, suggested that this outcome could have the additional effect of influencing the way care staff viewed the people they worked with, which in turn could improve the care they provide. As an OT explained:

*I think that process of helping people recognise the common ground . . . helps humanise people again.*  
PF3R10

It could be argued that people receiving care should not have to be 'humanised'; however, we know that receiving care can have a dehumanising effect and that people with dementia in particular can too often be viewed in terms of their disease first and their personhood second.<sup>3</sup> LSW was therefore seen by professionals and carers as a tool with the potential to remind care staff that the people they care for are *people* first (with equally important hopes, fears, achievements and relationships as those of the care staff themselves) and *the recipients of care* a distant second.

'Seeing the person' is an outcome in itself, implying respect and the recognition of shared humanity. In addition, it could help to personalise care, as this day centre manager suggested:

*LSW in itself is maybe the way to get to that person-centred care, because by . . . helping people see the person as an individual, you can move forward to then working with them as an individual . . .*  
PF1R3

Life story work should tell us not only what a person has done and achieved, but what they would like to do, what they value, and how they would like to spend their time and who with. Such information is crucial to person-centred care planning. It may also shed light on the reasons why a person with dementia reacts negatively to a certain situation or approach to care. There were numerous examples given in the focus groups of people acting in ways that confused or challenged care staff until they discovered, often through LSW, that there was a perfectly rational explanation for that behaviour:

*. . . one of the key factors is what somebody did for a living, what their daily routine was, you know. 'Go on, Fred, get back to bed, it's only 4 o'clock in the morning.' But if you were a bus driver . . . or a postman, you were up at that time and those are the memories that stay . . . it's about understanding the person, and then you can understand some of the behaviour, and it doesn't challenge then.*  
PF1R8

Once something is understandable, it may seem less problematic. However, information pertinent to problem solving will not always be included in a life story product, particularly if the LSW is led by the person with dementia him- or herself rather than by a member of staff or carer (see *Challenges and good practice, What is it for and how much control will I have?*).

Even where it is difficult to understand or manage a person's actions, LSW may still be a useful tool in helping to put people at ease without recourse to medication:

*He's rattling the doors, trying to get out, and you start talking about all his achievements, 'cause he's so proud of all his achievements through his life. And immediately, he comes down and PRN [pro re nata] medication [antipsychotic medication issued as and when required] isn't needed . . .*  
PF1R1



Similarly, some family members found that LSW helped to calm or orientate the person they cared for:

*I think it is useful for my husband, although we don't know how much he recognises . . . but it's about the familiarity of it . . . So it is all part of that comforting, assuring familiarity of having these things . . .*

CF3R4

This carer went on to explain, further, that, although she could not know for certain whether or not the photographs of their life together were meaningful to her husband, they certainly were meaningful to her.

One effect of staff getting to know and understanding the people they work with better could be that they themselves gain more satisfaction from their work. If LSW sheds light on the ways in which a staff member can meet the needs or desires of a person better, then it may be easier for them to deliver care in a way that elicits positive feedback for them. This in turn may motivate care staff to find new ways to further the person's well-being, as this extract indicates:

PF1R4: . . . the staff do get very excited when they learn new things about people and very encouraged, and, you know, it's good for them, too.

PF1R3: And they start connecting, as well, and go . . .

PF1R9: 'Oh, I'll have to bring that in because I was a horse rider and she was a horse rider.'

PF1R6: Yeah.

PF1R9: 'So I'll bring in my helmet' and finding things in common, that's really important . . .

This suggests that measuring job satisfaction or staff motivation could be one way to assess the effectiveness of LSW.

A final area of potential outcome related to people moving from one care setting to another. We heard above how LSW could challenge the negative assumptions of staff by revealing the person behind the dementia. This effect was felt to come from seeing not only who the person was, but also who they still were and what they could still achieve. In one hospital ward, for example, they took photographs of patients taking part in activities and sent these with the person when they were discharged:

*. . . those photographs went in the life story book [made on the ward and passed on] to the residential home or the nursing home. So the care staff didn't just see Joe Bloggs who needs X, Y, and Z, but Joe Bloggs that actually can still do a bit of this and can still do a little bit of that . . .*

PF2R2

Table 4 summarises the outcomes for care identified in this section, including outcomes for care staff.

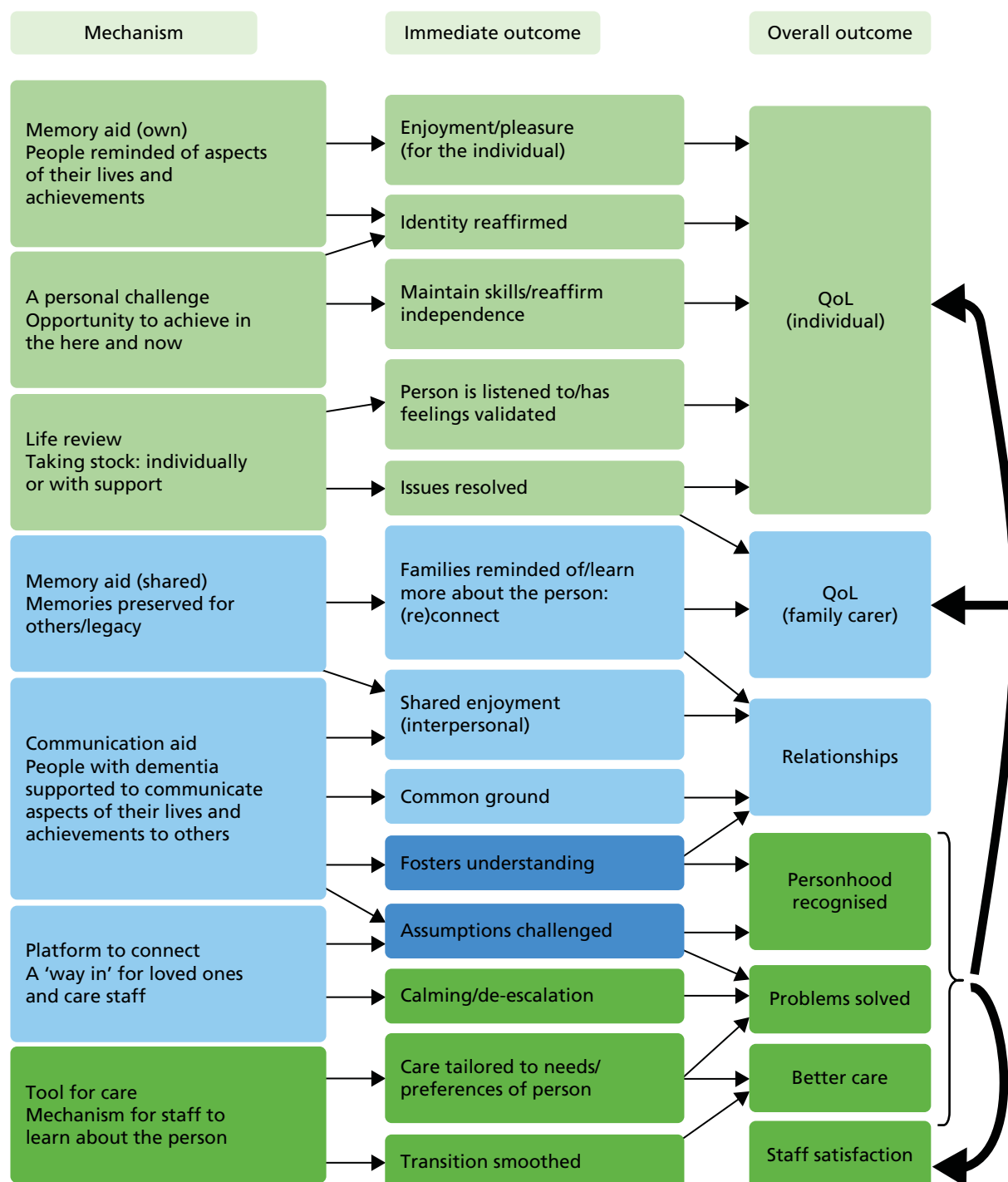
**TABLE 4** Focus group analysis: care-related outcomes arising from LSW

Immediate outcomes	Overall outcomes
Fosters understanding	Personhood recognised
Assumptions challenged	Better care
Care tailored to the needs/preferences of the individual	Behaviour no longer experienced as challenging (problems 'solved')
Calming/de-escalation	Improved staff satisfaction/motivation
Smother transition	



## Theory of change

As we have seen, LSW may have a variety of outcomes, arrived at via numerous different routes or mechanisms. *Figure 8* shows the various mechanisms, immediate outcomes and broader consequences (overall outcomes) identified through our focus groups.



**FIGURE 8** Mechanisms and outcomes of LSW.

## Challenges and good practice

We have outlined the ways in which our focus group participants felt LSW had been or could be beneficial. However, all of the groups agreed that LSW would not always give such benefits and that not everyone would necessarily experience benefits equally. We now look at the potential challenges associated with LSW, and what these tell us about good practice.

### Not everyone wants to engage in life story work

First, not everyone thinks LSW is for them. Some people simply did not see the point:

*I tend to just, sort of, say, 'Right, this is done' and it's done, and then move onto the next thing, rather than talking about it a lot.*

DF3R4

Others actively rejected the notion that reminiscence was a desirable thing: '... you say, "Mind your own bloody business" ... Sometimes you want to forget' (DF4R2). Similarly, some carers confirmed that people they cared for had not wanted to participate in LSW, with responses ranging from indifference to considerable distress:

*... my dad's not that interested in that sort of thing ...*

CF2R4 (daughter)

*He'd rather be on his allotment.*

CF2R2 (granddaughter)

*... a couple of times, people have tried to do LSW with him ... but it wasn't very successful ... he did ancestral research and he collected old postcards of Dover and so, everyone thought, oh, this is great, he – but he didn't want to go back. And very, very early on, he really didn't like looking at photographs, and particularly photographs of people who were dead ... a few months on, we had another helper from the Mental Health Team who wanted to have another crack at this, but it was just as bad.*

CF2R6 (wife)

Our advisers with dementia had suggested that some people might be reluctant to embark on LSW because of its focus on the past at the expense of the present and future. They were keen for people not to be 'set in stone' by a life story document. Some focus group participants also flagged this up as a risk. Professionals noted that a person may actively reject an activity which they used to enjoy because they are no longer able to engage in it proficiently. There was general agreement that it would be good practice to update life story products regularly and that the life story should not be given precedence over the current expressed preferences of an individual. However, in practice there were mixed views on the practicalities of this: who would update it/would there be time? One suggestion was to combine LSW with daily reporting, as this manager of a community day service had done:

*... [the life story includes] the important information that we need to report [such as medication use], but it also includes photographs of where we've taken the person. And we work with the person to compile this reporting, so they're involved and they don't feel like ... 'What's she saying about me?'. ... we encourage them [families] to include information in the book, as well ... we use a lot of scrapbooking techniques ...*

PF2R8

### Upsetting topics and the need for staff training

Professionals and carers pointed out that families might not want to engage in LSW because it could highlight the losses that they and the people they care for had experienced. Realising that a parent no longer recognises what were once favourite holiday destinations, for example, or even members of their

own family, is distressing. By contrast, this was not a strong theme among the people with dementia. However, this could be explained by a lack of insight or a perfectly understandable reluctance to imagine what it may feel like to struggle with greater memory loss as dementia progresses.

Even where differences in perception are not the issue, LSW still has the potential to cause upset, simply because delving back through people's personal histories can be emotional and there is always the possibility of stumbling on upsetting topics. Suggestions were made for avoiding such topics, but some argued that discussing emotional subjects is not necessarily a bad thing:

*PF1R1: But, you know, for that person to have the opportunity to have their feelings validated and acknowledged, and even if it means having to . . .*

*PF1R8: Having to cry and be upset.*

*PF1R1: . . . have those feelings again, can still be very . . .*

*PF1R8: Positive.*

*PF1R1: . . . beneficial to them.*

There were mixed views in the focus groups with people with dementia about whether or not they would choose to include upsetting memories in their life stories but our advisers with dementia reiterated that those wanting to discuss difficult issues should be supported to do so. However, staff facilitating LSW are unlikely to be psychological therapists and should not be expected to handle emotional issues unsupported. Training is essential, but support should also be on hand to help handle sensitive information (including potential safeguarding disclosures) and to judge when an onward referral is required:

*. . . closing the can of worms . . . for a Level 2 care staff, that could be an incredibly difficult feat to achieve . . . it's about leadership . . . and training . . . to make sure that staff feel that they're empowered and they've got the skills to be able to do it.*

*PF3R6*

### **What is it for and how much control will I have?**

Analysis of the outcomes that professionals, carers and people with dementia themselves hoped for indicates that people with dementia may have very different motives for embarking on LSW from, in particular, the professionals who work with them.

Professionals were concerned about recognising personhood and tailoring care to meet the needs of individuals. They also saw great potential for LSW to help 'problem solve', for example to help to understand and deal with behaviour that could be challenging. People with dementia, on the other hand, undertook LSW for personal reasons: to preserve memories, to share and enjoy with friends and family, to celebrate achievements or simply to prove to themselves that they could still do something like this. Even when asked directly if it might be useful for life story information to be shared more widely with care staff and professionals, there was a feeling from most that, while they had 'nothing to hide', this was not a priority for them personally:

*DF1R1: I might do one for myself, just for me, my life . . .*

*Researcher: And would you show it to people?*

*DF1R1: Yes, if they asked. Yeah, you know, I wouldn't go out and say, 'Look, look at this, look at this'. But if someone said, 'Oh, what are you doing?' I'd quite happily show it when I'd finished with it.*

**Researcher:** *If you were taking a book with you about you and your life into the respite home so that they knew a bit about you, what would you put in it?*

**DF2R1:** *Everything about myself I suppose, and so, I left school and so forth, up to the present time. I've got nothing to fear. I've got nothing to hide.*

**Researcher:** *But would you want them to know certain things about you?*

**DF2R1:** *Pass.*

Most of the people with dementia felt that some support from professionals to help make a life story could be helpful, especially for people who did not have family carers. However, they seemed unaware of the possible motives professionals might have for encouraging a person with dementia to do this. This is important, as people may choose to put very different information in a life story for their own personal use from the information they would put in something to be used by other people. Moreover, some people felt strongly that a life story should be 'a private thing' (DF2R4), or at least that they should be present when other people looked at it. Good ethical practice, therefore, means that professionals should make explicit the possible uses of the life story at the start of the process and check whether or not and with whom the person is happy to share it.

Similarly, professionals need to be aware that people select what information to share based on the image of themselves they would like to project or remember. Thus, the life story product may not tell staff everything they need to know in order to solve a problem or understand behaviour. One of our focus group participants, for example, spoke at length about some difficult times in her life before revealing that she had included none of these events in her life story book:

**DF3R6:** *None of that's in my book.*

**Researcher:** *What's in your book?*

**DF3R6:** *... this book, it tells all the nice bits, but [pause] I don't know why I did that. But that [referring to the story she had told] is the truth on it, and this [referring to the book] is also the truth ... I suppose it's part of me, so I should have put it in, but at the time I was doing this, I just wanted to look back at pictures, and I would still only have pictures of the nice things.*

Confidentiality and data protection were common topics in our focus groups. Some felt so strongly about data protection that life story books were locked away in staff offices: '... it boils down to confidentiality. We can't have them lying around in the lounge in case another patient picks them up or a relative sees them' (PF2R2). However, others argued this undermined the ownership of the life story by those whose life it was about and would make the achievement of certain individual and interpersonal benefits less likely. Instead, they suggested that consent be obtained (ideally from the individual, but if they lacked capacity then from a family member or other consultee) for information to be shared and that this should specify who was allowed to see what.

One suggestion to help care staff understand how it might feel for life story information to be shared with others (or, conversely, how it might feel to make a life story and then not have easy access to it) was to encourage staff to make their own life story products. Some participants felt that this had the potential to create greater equality between staff and service users and build relationships. Rather than information flowing in only one direction, people with dementia and their families could learn about the staff working with them. This would clearly be important to some people with dementia, as was illustrated by the participant who said, when we asked her if she would like staff to know more about her, 'I would like to know who you are [referring to the staff in the room]' (DF2R4).

### Is it ever 'too late'?

Carers and professionals discussed a range of approaches to making and using life stories. The extent to which the people they cared for were involved in the process depended to a large degree on the severity of their symptoms, which ranged from mild to severe. The people with dementia we spoke to, on the other hand, all had capacity to consent to take part in the focus groups and, as such, tended to have only mild to moderate symptoms. This group were, therefore, all able to take an active role in making a life story (usually with some degree of support) and most identified personal motives for doing so (see *Challenges and good practice, What is it for and how much control will I have?*).

The experiences of family carers, many of whom had cared for a person until his or her symptoms had become very severe, confirmed that a person's ability to take an active role in LSW could reduce over time. As a result, the motivations for doing LSW might change, along with the approaches that were most likely to give benefit. This carer, for example, initiated LSW with his mother to help her maintain her writing skills:

*... I did it initially for my mother to have practice in writing. The story was almost secondary ... there was a lot of confusion there. So I dictated it ... [But] there were things that she did contribute ...*

CF2R1

As her dementia progressed, the mother's ability to participate in making the life story deteriorated, but she did still seem to benefit from being reminded of its content:

*... this angel from Crossroads charity ... she took the book, took it out and read everything to my mother and my mother does respond ... I think what she remembers is a nice feeling.*

CF2R1

The outcomes of LSW in the later stages of dementia may be different from those achievable in earlier stages (more about stimulating a 'nice feeling' than offering people something they can actively engage in to review their life and share their memories), but such outcomes are no less important. Professionals agreed that LSW was best started early, when people are still able to express their views and take a lead in the process. However, they also felt that there could be numerous benefits (not only around problem solving, but also by raising opportunities to invoke a 'nice feeling') throughout the dementia journey and that it was thus never too late to get started.

### It is what you do with it that counts

Family carers felt that the outcomes of LSW depended largely on whether or not care staff took on board and used life story information when planning and delivering care. Unfortunately, many life story carers were doubtful that this happened and several gave examples of lovingly crafted life story documents packed with useful information that were ignored in care settings:

*... I put it in her bedroom, and I just, in my naivety, thought that they would share it ... She was given dreadful antipsychotic drugs to keep her sedated, and the input from the care home was, 'She has a condition,' and they ignored what I'd put together ... They didn't use it at all.*

CF3R7

*Well, I don't know if, as a carer, I, sort of, invested too much in the life story thing, thinking that the people who were helping me care for [husband] ... would pick these things out of this, which they haven't done, because they haven't had time ...*

CF2R6

It is not enough simply to produce a life story and expect it to make a difference, if the route to improvement is through the actions of busy staff who may not even realise that the life story product exists.

Some participants suggested making different versions for different uses or audiences: flash cards, a collage or a one-page summary of key information that would be easily accessible to staff, for example, *and* a more comprehensive book or digital product that the person with dementia might enjoy looking through, sharing and adding to him- or herself. The former might also be useful for transitions, for example if a person is admitted to hospital. There are several short templates available which have been designed specifically for this purpose. However, it is important to recognise that a one-page summary or a template detailing only key facts is not the same as a comprehensive life story and is unlikely to be something owned or designed by the person with dementia him- or herself.

A good practice approach to LSW would be tailored to the individual preferences of the person with dementia. Some participants were intrigued by the digital life story we had produced and felt that this was something they would like to pursue, whereas others were put off by the technology and preferred formats they were familiar with. Few of the participants with dementia who were interested in making a life story felt that a short written summary could take the place of something more comprehensive that they themselves had created.

### Organisational barriers to achieving outcomes

There was consensus among the professionals that LSW could benefit people with dementia and those who cared for them. However, they identified barriers to achieving benefits, many of which were organisational. The most common barrier discussed was lack of time, which professionals in all groups said posed a problem, if not for them then for their colleagues.

Lack of time seemed to be linked to low prioritisation, both by care staff and by their managers, so that those who viewed LSW as an optional extra struggled to find time for it once all the 'essential' work was complete:

*... we work with an excellent team ... But they're already overwhelmed with huge amounts of paperwork and that's where ... we're struggling to engage people ... it's another job, another thing to do ...*

*PF3R3 (OT with community team)*

Even when staff recognised that an investment of time in LSW could lead to benefits in the end, they felt pitted against a system that prioritised short-term targets over such longer-term gains:

*We've got incredibly strong targets at the moment, which is having a heavy impact on our therapeutic work with the patients, because it's more important that people are seen within a certain length of time ...*

*PF1R1 (OT on acute ward)*

In order to be successful, participants felt that LSW needed to be an integrated part of care rather than 'just another task'. Training was important but, crucially, needed to be coupled with a supportive management and organisational culture:

*... staff have been very good as well, taken it on board. I mean, the luxury I have is that when we're in a new care home, it becomes part of what we are and what we're doing, so they're coming into that. ... So, you know, they take the training very well and have done some fantastic work.*

*PF3R6 (care home manager)*

Another factor that influenced the successful take-up of LSW by staff was their perception of its purpose: was the aim to make a useful product, or was it the *process* of collecting and recording information that helped build relationships and inform care? Professionals reported colleagues' concerns that they did not have time to produce a glossy life story product. However, they themselves felt that collecting information and learning about the person behind the diagnosis was the most meaningful part of LSW, and argued that this could be undertaken concurrently with routine care (e.g. chatting to someone about their life while helping them dress). Nevertheless, focusing solely on the process could raise problems: if information is collected but never recorded or shared, how can it be used to improve care; and without a product to look through, will wider interpersonal benefits be realised?

An alternative solution to the problem of limited time was to encourage family carers to put life story documents together, which could then be used by care staff, wider family and people with dementia themselves. However, in this case staff would not be actively engaged in the collection of information from people with dementia, which was felt to be the most meaningful part of the process.

The focus groups arrived at no definitive solutions to these problems. However, we continued to grapple with them as a research team during the feasibility study, in which we observed different theory of change approaches to solving this dilemma (see *Chapter 6*).



## Chapter 4 Choice of outcome and costs measures

### Development phase

In *Chapter 2* we synthesised the literature on the expected outcomes of LSW and the processes by which these outcomes were thought to be achieved. Overarching final outcomes were identified for the person with dementia, the care setting and the people (family members and care staff) providing care. However, we knew from previous reviews that there had been only limited research into LSW that includes the views of people with dementia or carers<sup>14</sup> and that in general there was a dearth of sound quantitative and qualitative evidence.

We conducted additional primary research (in the form of qualitative focus groups) with 25 people with dementia, 21 family carers and 27 professionals, volunteers and care staff with experience of LSW. *Chapter 3* sets out the findings from this research, including the outcomes expected and/or experienced by participants. Learning from both the literature review and this primary research then informed the selection of outcome measures to be used in the feasibility study in care homes and acute settings which we now outline.

### Process of selection

A period of consultation preceded the selection of outcomes and outcome measurement tools. Findings from the literature review and the focus groups were discussed with both the project steering group and the advisory group; we liaised with the partner organisations that were to host the feasibility study; and we met with our specialist advisor, Professor Esme Moniz-Cook (lead author of the INTERDEM European consensus document on outcome measures for psychosocial intervention research in dementia care<sup>118</sup>). Outcomes to measure were selected in agreement with all those consulted. We then compiled and refined a list of available measures with Professor Moniz-Cook. All advisory and steering group members were asked to comment on the shortlist of outcome measures before it was finalised.

### Which outcomes to measure

There was general agreement that the primary overall outcome of interest for people with dementia should be QoL, albeit that this might be influenced by intermediate outcomes such as the maintenance of skills or feeling understood. Interpersonal outcomes may also influence QoL, and impact on relationships, in particular, was felt to be worth exploring as an outcome in its own right, along with impact on identity.

For family carers, QoL was again agreed to be the primary outcome, with impact on relationships and satisfaction with care also important.

Staff approaches to care, in terms of both person-centred care and perceptions of clients with dementia, might also have an impact on QoL. It seemed important to explore these care-related outcomes in their own right, to understand whether a change in QoL was due to individual outcomes or changes to care routines. We also hypothesised that improvements to care might influence staff burnout.

*Table 5* presents the outcomes that we agreed we would measure in the feasibility study.



TABLE 5 Outcomes to measure

Group affected	Outcome to measure
People with dementia	Well-being/QoL Relationships (person with dementia/carer) Identity
Family carers of people with dementia	Well-being/QoL Relationships (carer/person with dementia) Overall satisfaction with care
Staff	Perception of clients with dementia Person-centred approach to care Staff satisfaction and strain/burnout

## Selection of measurement tools

Measuring the QoL of people with dementia is notoriously challenging<sup>119</sup> because of the difficulties a person may experience in recall, time perception, communication and insight. Generalist health-related QoL measures are not considered valid for this group and, instead, a number of dementia-specific tools have been designed. Both the DEMQOL<sup>120</sup> and the Quality of Life – Alzheimer’s Disease (QoL-AD) measure<sup>121</sup> have been shown to be valid and reliable QoL measures for people with mild to moderate dementia.<sup>122</sup> There is less evidence of their successful use with people with severe dementia. However, we were reluctant to rely on observational measures such as QUALIDEM,<sup>123</sup> as these do not capture the voices of people with dementia. Instead, we chose to use both the self-report and proxy versions of QoL-AD and DEMQOL.

There is little precedent for quantitatively measuring the quality of relationships between carers and care recipients, particularly those with dementia. However, Professor Moniz-Cook suggested a scale [the Scale for the Quality of the Current Relationship in Caregiving (QCPR)] developed by Spruytte *et al.*<sup>124</sup> which, although not extensively tested, did have relevant subscales (measuring warmth, affection, conflict and criticism). The measurement of identity in dementia care is also a relatively underdeveloped subject. We collaborated with the School of Psychology, University of Leeds (see *Appendix 7*), who used the ‘I Am’ Fluency Task, developed from the Twenty Statements Task<sup>125</sup> and adapted for use with people with Alzheimer’s disease.<sup>126</sup>

Selection of a QoL measure for carers was more straightforward and was guided by agreement that the tool should measure care-related QoL rather than health-related QoL or carer burden. The Carer Experience Scale (CES)<sup>127</sup> was chosen, to be supplemented by qualitative data from in-depth interviews. In the study in acute settings, the intervention site also requested that we look at carer satisfaction with the service provided, and so the Carer or Family Member Satisfaction Questionnaire was used.<sup>128</sup>

We chose both the Approaches to Dementia Questionnaire (ADQ)<sup>129</sup> and the Personhood in Dementia Questionnaire (PDQ)<sup>130</sup> to measure staff approaches to care. The former had been used in a recent study of LSW<sup>131</sup> and the latter is a newer measure intended to operationalise Tom Kitwood’s definition of personhood. The customary choice for measuring staff burnout is the Maslach Burnout Inventory,<sup>132</sup> but we chose the Copenhagen Burnout Inventory (CBI) for its improved acceptability.<sup>133</sup> Data from staff measures were also supplemented by qualitative data from focus groups with staff involved in the feasibility study.

Table 6 shows the measurement tools selected for use against each outcome to be measured for each group affected (people with dementia, family carers and staff).

**TABLE 6** Quality of life outcome measurement tools

Group affected	Outcome identified	Measurement tool
People with dementia	Well-being/QoL	DEMQOL (family carer proxy and self-report); QoL-AD (family carer proxy and self-report) and field notes
	Relationships (person with dementia/carer)	QCPR
	Identity	'I am' Fluency Task (care homes study only)
Family carers of people with dementia	Well-being/QoL	CES and qualitative interviews
	Relationships (carer/person with dementia)	QCPR
	Overall satisfaction with care	Carer or Family Member Satisfaction Questionnaire (hospitals study only)
Staff	Perception of clients with dementia	ADQ
	Person-centredness of staff	PDQ
	Staff satisfaction and strain/burnout	CBI; staff focus groups

## Resource use and impact on health and social care providers

We also used the learning generated from the review (see *Chapter 2*) and the qualitative work (see *Chapter 3*) to inform the data collected in the health economics element of the feasibility study (see *Chapter 8*). This work identified the resources that were likely to be involved in implementing LSW in hospital and care home settings as well as potential areas for resource saving, both in relation to the individuals with dementia who were recruited to the study and for the ward or care home as a whole.

We then discussed these items with our project partners and advisory group, and with staff in the feasibility study sites, to ensure their face validity in the settings in which our project was operating. So, for example, the range of prescribed medication for care home residents that we included was agreed after consultation to reflect the types of medication that might be prescribed differently if LSW was having some type of effect on the person with dementia or the care environment.

We then used standard health economics literature to identify the most appropriate data to collect in order to identify resource use, and how to ascribe costs to these resources. We also operationalised possible areas of resource savings in order to identify the type of data we needed to collect. The areas of potential resource use and savings that we explored in this part of the study were thus:

- staff time (time spent with the person with dementia creating the life story and time spent creating the life story away from the person with dementia)
- use of other health and social care services by study individuals
- reported adverse events for study individuals reported
- reported challenging behaviour episodes for study individuals
- prescribed medication for study individuals
- staff sickness levels for the case site as a whole
- staff turnover for the case site as a whole
- prescribing rates for the case site as a whole
- number of adverse events for the case site as a whole.

Further detail about data collection methods and challenges is in *Chapter 8*.



## Chapter 5 Surveying life story work practice

We carried out two surveys to establish how LSW is used in health and social care settings and how people with dementia and their family carers experience it (project stages 2a and 2b, objective 2). We designed the questionnaire contents to reflect the good practice elements identified in stage 1, enabling us both to benchmark use of LSW in the health and care settings and to establish how it was used in which settings.

### Survey of health and social care providers

#### Methods

##### Sampling

Five parts of the health and social care pathway were the sampling frame for the survey: memory assessment services (MASSs), inpatient dementia assessment services (IPAs), community dementia support services (CDSs), generalist long-term care homes and dementia-specialist long-term care homes (SCHs). Given the different numbers of each of these types of services, we planned to use proportionate sampling to generate 100 services in each category.

We explored a range of sources of national information about services to identify the best sampling frames for the five categories (see *Appendix 1, Table 16*). It soon became clear that we could not easily judge whether or not identified organisations had the services we were interested in, before making direct contact with them. We therefore increased the initial sample size for each to 150. For some categories, there were fewer than 150 identified services and so we took a 100% sample for these. *Table 16* (see *Appendix 1*) shows how we generated the final sample and the stages of personal contact and filtering required.

We planned an electronic survey, and so we needed an e-mail contact for each service. We contacted all of them to identify the person best placed to complete the questionnaire. In some cases, organisations were unable or unwilling to provide an e-mail contact. We had a final sample of 567 services to which we could send the electronic survey.

##### Developing the questionnaire

We established benchmarks for good practice in LSW based on findings from stage 1 (see *Chapters 2 and 3*). This generated the domains to be covered in the questionnaire: knowledge and use of LSW; timing; type of records used; one-to-one or group work; people involved in LSW; use of LSW in the service; types of information included and excluded; temporal focus; access to the life story by different people; LSW policies and practice in the organisation; resources to support LSW; and the benefits and challenges of LSW. The questionnaire also asked for information about the service and basic sociodemographic information about the respondent.

Wherever possible, the question wording was the same as or as close as possible to that already used and tested in the questionnaire for carers (see *Survey of carers of people with dementia*).

The final draft was tested repeatedly within the research team and pre-piloted with members of the project advisory group. For final wording of the questionnaire, see *Appendix 8*.

##### Distributing the questionnaire

The link to the survey was e-mailed to the 567 service contacts in the first week of February 2014, with a message explaining the survey's purpose and how to contact the research team.

Mailing to the NHS-based organisations was problematic and caused significant delay to the distribution, with the e-mails to NHS services not finally sent until mid-March 2014.

### Challenges of using an electronic survey

Qualtrics (version 2013, Provo, UT, USA) is a high-quality, web-based service, with EU-based servers, making it ideal for designing, hosting and distributing research questionnaires. However, as well as the distribution problems, other challenges arose.

First, despite first contact with organisations to obtain e-mail addresses, some participants were puzzled about why they had received the survey link or how we had obtained their contact details. We sent a further e-mail explaining how we had identified them. If they responded that someone else was a more appropriate recipient, we reissued the survey to that other person.

Second, although most NHS staff have direct access to computers, this is rarely the case in social care settings, and particularly within care homes. A single e-mail address is often used for the whole care home, making it difficult to target the person who could respond to the questionnaire.

Third, e-mail addresses given were often inaccurate and bounced, requiring further personal contact with the organisation. Even after such contact, e-mail addresses were not always accurate.

Fourth, social care organisations can change significantly over short periods of time, which meant that details we were given in December 2013, when contacting the organisations personally, were no longer accurate in February 2014. Again, we used personal follow-up to deal with this. This revealed organisations that had changed e-mail provider, had closed or were no longer contracted to provide relevant dementia services, or where the nominated member of staff no longer worked there.

### Response rate

Several NHS services had multiple sites, all doing LSW. In some, the service returned a questionnaire for each. In others they returned a single questionnaire but informed us that the answers applied to all the sites, in which case we replicated the responses given to all the sites. This increased the number of 'returned' questionnaires by eight.

Given the technical challenges of getting the survey to NHS organisations and the structural challenges of systems in flux, we adopted a rigorous approach to follow-up in order to achieve the best response rate we could. Even so, the response rates for CDSs (52%) and generalist long-term care homes (32%) were not what we would have wished. However, we achieved good response rates from the MASs (64%), IPAs (70%) and SCHs (61%) (see *Appendix 1, Table 17*).

### Analysis

The data were downloaded from Qualtrics into IBM SPSS Statistics (version 22, IBM Corporation, Armonk, NY, USA) and cleaned. After initial frequency runs to ensure that the data were consistent, the first stage of analysis estimated the proportions of services across England carrying out LSW with people with dementia. We subsequently confined our analysis to services doing LSW currently, using bivariate approaches to explore which services were using 'good practice' approaches.

We used chi-squared statistics to evaluate differences between services, and examined adjusted standardised residuals to identify which cells in tables were contributing most to observed differences.

### Results

#### How many services are doing life story work?

The number of respondents who had heard of LSW was highest in IPAs (100%) and MASs (97%), followed by SCHs (91%), generalist long-term care homes (82%) and CDSs (72%).

Our sampling strategy allowed us to estimate the numbers of all services that are currently carrying out LSW in England. In doing this, we made the conservative assumption that no non-respondents did LSW.

We also assumed that respondents who had never heard of LSW were also not doing it. We then estimated the minimum extent of LSW across our chosen services (see *Appendix 1, Table 18*). This suggested that perhaps two-thirds of IPAs and just under half of SCHs offer LSW. Under one-third of MASs, just over one-fifth of generalist long-term care homes, and slightly more than one-tenth of CDSs may do LSW.

The remaining analysis is confined to the 189 services that currently did LSW, excluding those who referred people elsewhere for LSW.

## How is life story work done?

### *Starting life story work with service users*

Memory assessment services were least likely to start LSW immediately or within 1 month of people coming to the service (7%), compared with SCHs (56%) and generalist long-term care homes (52%). MASs were more likely to say that the timing of LSW depended on the individual and their readiness to start (33%) or on how long it took to confirm a diagnosis of dementia (19%).

### *Type of records used in life story work*

Care homes and IPAs were more likely to report using a written summary type of life story record than other services (see *Appendix 1, Table 19*). By contrast, MASs were more likely to mention using photo albums or books that included text alongside photographs. Two-thirds (66%) of respondents gave multiple responses, suggesting a level of flexibility in the practice of LSW.

When only one type of LSW record was reported, the most common was a written summary (57%) followed by a book with a mixture of photographs and text (31%). IPAs and generalist long-term care homes were the services most likely to be using only a written summary. By contrast, MASs and SCHs were most likely to be using more than one record, with photo albums with text or books with photographs and text the most common. Numbers are small here, but do seem to reflect a more general difference in practice that is evident as we progress through the rest of the analysis.

### *In a group or one to one?*

Almost all services (98%) said that LSW was done one to one, although 38% also referred to group-based approaches and 33% mentioned both. Generalist long-term care homes were most likely (43%) and CDSs were least likely (27%) to mention both approaches. Only three respondents reported doing LSW solely in a group and all of these were in MASs.

Some respondents referred to 'other' ways of doing LSW, most often that it was done *by* family members and carers (5%) or that it was done *with* family members or carers (17%). We assume by the former that staff took a minimal role in LSW, and by the latter that they worked in partnership with family members and carers.

### *Who is involved in life story work?*

Even when people with dementia are at a late stage in their journey it is possible to involve them in LSW (see *Chapters 2 and 3*). Overall, 95% of respondents mentioned the involvement of the person with dementia and 95% mentioned family members or other people close to the person with dementia ('carers' from here on). In terms of staff involvement in LSW, the most common response was a person employed to provide care in the service (61%). Few mentioned a volunteer (3%) or someone employed specifically to do LSW (12%). Twelve per cent mentioned OTs or OT assistants and 11% mentioned activity co-ordinators. It is possible that other respondents included these types of staff in the category of people employed to provide care.

Reported involvement of the person with dementia in LSW was almost universal across the services. By contrast, although all generalist long-term care homes and 98% of IPAs said that carers were involved in LSW, only 81% of MASs reported this.

The predominant model when only two categories of people were involved was the person with dementia and a carer (53/69 cases), followed by the person with dementia plus an OT or activities co-ordinator (24/69 cases).

The role of carers was clearly important, regardless of the involvement of staff, which raises the question of what happens when people do not have carers who are available and/or willing to help.

### How is the life story used?

We asked respondents both to select as many options as they wished about use of the life story in their care setting and which they felt was most important (see *Appendix 1, Table 20*).

Responses varied by type of service. MASs (79%) and inpatient settings (78%) were somewhat less likely than SCHs and generalist long-term care homes (both 90%) and CDSs (93%) to choose helping the person to remember important parts of their lives. By contrast, SCHs were most likely to choose helping to soothe or calm the person (85%), followed by IPAs (78%), generalist long-term care homes (77%), CDSs (73%) and MASs (61%). This difference seems likely to reflect the different stages of the dementia journey that predominate in these different settings.

Again, perhaps reflecting the nature of their work with people with dementia, IPAs (82%) and MASs (79%) were more likely than generalist long-term care homes (67%), SCHs (59%) or CDSs (47%) to say that they used the life story so that health and social care staff elsewhere could provide better care. This difference reached statistical significance ( $\chi^2 = 11.79$ ,  $df = 4$ ;  $p = 0.019$ ).

Although the option of using the life story to help staff to see the person behind the dementia was a common choice, MASs were less likely than other services to choose this option ( $\chi^2 = 9.613$ ,  $df = 4$ ;  $p = 0.047$ ).

When it came to choosing the most important use of the life story, similar differences between the services were also evident (see *Appendix 1, Table 20*). Again, these seem likely to be influenced by the type of people using the services and the nature of the service involvement.

### What information is included in the life story?

Respondents were asked whether they always, sometimes or never included particular types of information in the life story.

*Tables 21–24* (see *Appendix 1*) show the answers given across all respondents and whether or not we found significant differences between services.

#### Family information

Memory assessment services were less likely than other services 'always' to include the names and descriptions of carers, and the least likely ever to include information about reactions to or meanings of these people to the person with dementia (see *Appendix 1, Table 21*). IPAs included the names of carers but were less likely than other services to include their descriptions. These differences were all statistically significant.

#### Person's life

The second group of questions was about including the important events, dates, places and life stages of the person with dementia (see *Appendix 1, Table 22*).

Differences between care settings were less evident here. MASs were much less likely than other services 'always' to include lists and details about life events, but more likely 'sometimes' to include this information. However, overall differences between services did not reach statistical significance.



Recording feelings about life events and stages was less common overall. CDSs were slightly more likely to report that they always included this information, but these differences did not reach statistical significance.

### **Likes and dislikes**

The third group of questions was about the record made of people's likes and dislikes (see *Appendix 1, Table 23*). Although this type of information was included in most life stories, preferred clothing and topics for conversation were less commonly included than information about activities and food.

Services varied substantially here. MASs were significantly less likely to say that they always included information about people's food, clothing, activity and conversation topic preferences. CDSs were significantly more likely to record information about what people liked talking about.

### **Needs**

Finally in this section of the questionnaire, we asked whether or not the life story recorded medical or care needs and spiritual or cultural needs (see *Appendix 1, Table 24*).

It was relatively unusual for life stories to include information about medical or care needs, as one might expect, given that such information would more appropriately be included in care plans. By contrast, the majority of respondents said that spiritual or cultural needs were included 'always' or 'sometimes'.

There were substantial differences between services here. IPAs were most likely to report that they 'sometimes' included medical or care needs, while SCHs were most likely to report that they 'always' included this type of information. MASs and IPAs were least likely and SCHs and CDSs were most likely to report that they 'always' included spiritual or cultural needs.

Overall, then, there was very different patterning of the contents of life stories across different services. To some degree these may reflect both the main function of the service and the point in the dementia journey at which LSW takes place.

### **Leaving things out of the life story**

Overall, 61% of respondents said that things were sometimes left out of the life story, with little difference between services; 62% reported that this was because some things were too private to include and 84% reported that some things were too upsetting to include. Other reasons given were related to memory problems (11 of the 32 respondents who gave an additional reason) or to the general difficulty of getting relevant information about the person with dementia (10/32). Again, there was little difference between the services.

We then asked who made the decision to leave things out of the life story. Sixty-eight per cent of those who had said that things were sometimes left out said that the person with dementia made this decision; 90% mentioned carers and 22% mentioned staff.

Services reported significantly different levels of involvement of the person with dementia in the decision [MASs (93%), CDSs (89%), IPAs (71%), generalist long-term care homes (56%) and SCHs (55%);  $\chi^2 = 10.40$ ,  $df = 4$ ;  $p = 0.034$ ]. MASs were least likely to say that family members or others close to the person with dementia made the decision (73%), compared with IPAs (96%), SCHs (94%), generalist long-term care homes (89%) and CDSs (89%). However, this difference did not reach statistical significance, perhaps because numbers were small. Again, these differences may reflect the stage at which services see people with dementia and carry out LSW with them.

### **Is the life story static or dynamic?**

Life story work literature suggests that the life story should be a dynamic product, adding material as new information about the past comes to light and as new memorable events take place.



Overall, 28% of respondents said that items relating to both past and recent events were added to the life story, suggesting that they adopted a dynamic approach to LSW (see *Appendix 1, Table 25*). IPAs were most likely to say that the life story was a one-off product. Along with MASs, they were also less likely to add recent events, while SCHs were most likely to refer to adding items related to recent events. This difference reached statistical significance and, again, seems likely to reflect the different work different settings would be doing with people with dementia.

### Who can look at the life story and who gives permission for this?

Good practice suggests that the life story should be seen, first, as the property of the person with dementia.

*Table 26* (see *Appendix 1*) indicates that 'ownership' of the life story by the person with dementia is almost, but not completely, universal. Carers in CDSs and MASs were slightly more likely than carers in other settings to be able look at the life story. The pattern of staff access to the life story was low, with only 24% of all respondents saying that all staff in the service could look at the life story. Differences between the services were very striking and statistically significant, with over two-thirds of IPAs saying that any staff could look at the life story, while no respondent in a generalist long-term care home chose this option. SCH responses were surprisingly low here.

As might be expected, IPAs were more likely to say that staff in other settings could look at the life story; indeed, some respondents in these services added further detail, pointing out that the life story was often specifically intended to accompany the person with dementia to their next, often long-term, care setting. By contrast, MASs and care homes, of whatever sort, were unlikely to suggest that staff in other care settings could look at the life story.

If the life story belongs to the person with dementia, we might expect their permission to be sought before others look at the life story. Further, seeking permission might explain some of differences in the involvement of staff in looking at the life story. We asked respondents directly about whether or not the person with dementia was asked for their permission and in what circumstances this might not happen.

There was substantial and significant variation between settings here (see *Appendix 1, Table 27*), mostly explained by the extent to which IPAs said that they 'sometimes', rather than 'always', asked the permission of the person with dementia. This may reflect the acute nature of confusion encountered, by definition, in IPAs. CDSs were most likely to report that they 'always' asked permission of the person with dementia.

Who could look at the life story did, indeed, vary according to whether or not the person with dementia was asked for their permission for this. When the person was always asked for their permission, it was less likely that any staff working in the service would be able to look at the life story (15%). By contrast, if the person with dementia was 'sometimes' asked to give permission, it was much more likely that any staff would be able to look at the life story (41%). These differences reached statistical significance ( $\chi^2 = 13.45$ ,  $df = 2$ ;  $p = 0.001$ ).

We also asked if carers were asked to give their permission for other people to look at the life story; 54% said that carers were 'always' and 29% said that carers were 'sometimes' asked for their permission, when they were available to be asked. There were few differences between services in this aspect of LSW practice.

Although two-thirds of respondents said that the person with dementia was always asked for their permission for others to look at their life story, very few (15%) reported that this permission was formally recorded in the life story itself. CDSs (33%) were more likely than MASs (9%), SCHs (13%), IPAs (14%) and generalist care homes (19%) 'always' to include such a statement in the life story, but this difference did not reach statistical significance.

## Access to the life story

### *Where is the life story usually kept?*

Producing a life story is one thing; having it to hand to look at or for other people to look at so that they can understand the person with dementia in more depth is another. We asked where the life story was usually kept to give some idea of how 'active' the life story was (see *Appendix 1, Table 28*). The most common response here was that the life story was usually kept in the care record of the person with dementia (61%), followed by the person with dementia keeping the life story (44%) including those who said that it was kept in the person's room in a residential setting. Multiple responses were possible, as we know that in some settings there is more than one copy of the life story.

There were striking differences between services, some explicable by the nature of the service and others not. As one might expect, all MASs said that the person with dementia kept the life story, and they were also much less likely to keep the life story in the person's care record. By contrast, SCHs were significantly less likely to report that the person with dementia kept their life story and more likely to say that the life story was kept in an office or other secure place within the service. IPAs were very unlikely to keep the life story in an office or other secure place, while generalist long-term care homes were much more likely to keep it in the person's care record. SCHs and IPAs were slightly more likely to display the life story in some form, but this difference was not statistically significant. Only one respondent (a CDS) reported that a carer kept the life story.

When respondents reported that the life story was kept in more than one place, the person with dementia was more likely to have a copy than when only one place was mentioned (73% vs. 33%). Consequently, perhaps, mentioning more than one copy was also associated with the life story being kept in an office, in the care record or being on display.

## Policies and practices to support life story work

### *How life story work is done*

We asked a range of questions about the policies and practices that underpinned how LSW was done, ordering them to avoid possible response set effects by asking questions about similar sorts of issues in different places. We then grouped responses into three thematic areas: (1) responsiveness to individual needs and wishes of the person with dementia; (2) training and supervision of those carrying out LSW; and (3) knowledge of LSW and its use across the service. Policies and practices varied considerably, depending on the type of service (see *Appendix 1, Table 29*).

**Responsiveness to individual needs and wishes** Although many respondents (82%) said that their service offered LSW to everyone regardless of the stage of their dementia, this was significantly less likely to be the case in MASs (43%). Almost all respondents said that people with dementia who also had visual impairments were offered the opportunity to do LSW, and there was very little variation here between the services. CDSs were significantly less likely and IPAs were more likely than other services to use a template for LSW. IPAs were also much more likely to say that staff and volunteers mainly made decisions about the format and look of the life story, possibly reflecting this greater use of templates.

Most respondents reported that LSW was adapted to the strengths and needs of the person with dementia, with little variation between them. This is slightly puzzling in relation to IPAs, which were also much more likely to be using a template throughout in their LSW. We examined this further and saw that all those who said that they used a template throughout were also more likely than others (94% vs. 85%) to say that they adapted LSW to the strengths and needs of the person. This suggests that this question may have been eliciting socially desirable responses rather than responses that reflected reality.

**Training and supervision of those carrying out LSW** CDSs were significantly more likely to say that they expected staff to do their own life story before doing LSW with service users. Staff in IPAs were more likely to be trained to do LSW, rather than learning how to do it 'on the job', but the difference between services did not reach statistical significance. There was considerable variation in the extent to which respondents said that staff or volunteers doing LSW received supervision from more senior or more experienced staff. MASs and SCHs were less likely to say that this happened, while IPAs were more likely to say that they provided this sort of oversight.

We saw earlier that some services relied on carers to carry out LSW, but only one-quarter overall said that they trained carers before they embarked on LSW. CDSs were slightly more likely to say that they did so, but this difference did not reach statistical significance.

**Knowledge of LSW and how to use it** Seventy-two per cent said that all staff and volunteers in their service knew what LSW was, with some small but non-significant differences between services.

By contrast, when it came to knowledge about how to *use* the life story to improve care, only two-thirds responded positively, with significant differences between the services. MAS respondents were less likely than others to feel that everyone in the service knew how to use a life story in this way, while SCHs and CDSs were slightly more likely to feel this.

### ***Resources used to support life story work***

We also asked about institutional policies that might support LSW (see *Appendix 1, Table 29*).

Respondents were about equally divided between those that felt that LSW was done in spare moments and those that reported dedicated and protected time for LSW. IPAs were slightly more likely to report doing LSW in spare moments and significantly less likely to report that there was protected time for it. By contrast, SCHs were slightly less likely to report doing LSW in spare moments and significantly more likely to report having protected and dedicated time.

The majority of respondents (although not all) felt that senior staff supported LSW in their service, but this did vary, with SCHs significantly more likely and MASs significantly less likely to report senior staff support. We checked whether or not this reflected the involvement of senior staff in completing the questionnaire. Indeed, three-quarters of respondents from SCHs who completed this part of the questionnaire (42/56) were managers, owners or directors of the homes. By contrast, almost three-quarters of those in MASs (16/22) were ward or team leaders or occupational therapy staff. These results thus need to be interpreted with care.

Services also varied in whether or not they reported that any staff in their service would be freed up from other work if they wanted to carry out LSW. SCHs and generalist long-term care homes were most likely and IPAs and MASs were least likely to report that this was the case. As with SCHs, respondents in care homes were mostly managers (20/26) and so perhaps were more inclined to positive responses here. However, as we saw above, generalist long-term care home respondents were *not* more likely to say that senior staff supported LSW.

## **Survey of carers of people with dementia**

We also carried out a survey of carers of people with dementia to focus on the experiences of those who supported a person with dementia who had made a life story. We were interested in how the life story was used, in which settings or circumstances, and in how the life story was produced, by whom and whether or not this followed good practice identified in stage 1.

Our partnership with Dementia UK gave us access to a network of carers in contact with Uniting Carers that provided the sampling frame for the survey. Although we recognised that this was unlikely to provide a representative sample, there is no existing sampling frame from which to draw a representative sample of carers of people with dementia. For the purposes of this stage of the research, we felt that even non-representative data from the carers' perspective would provide a valuable addition to the data collected from service providers.

The main ethical issue was the potential impact on carers of participating in the survey. Carers experience pressures on their time and energy (both emotional and physical) and it would be unethical to add to these pressures unnecessarily or excessively. We therefore worked closely with Uniting Carers to ensure that the survey and its administration had the minimum necessary impact.

## Methods

### Sample

The Uniting Carers database contained the details of over 700 carers of people with dementia; this included both current and past carers. Uniting Carers regularly communicated with carers in the network via e-mail, and agreed to send an e-mail to members informing them about the survey and providing a link to the questionnaire. It was then up to the carers whether or not to click the link to the survey. A copy of the e-mail is in *Appendix 9*. Based on previous experience, Uniting Carers expected between 10% and 20% of carers in their network to complete the survey ( $n = 78\text{--}156$ ).

### Survey development

Learning from stage 1 and expert advice from coapplicants and our advisory groups informed the content and design of the survey. We also pre-piloted the draft survey face to face with members of our carers' network of advisers to ensure face validity and comprehensibility.

The questionnaire was designed to take around 15–20 minutes to complete. No explicitly emotive issues were included, and during the pre-piloting stage we asked participants to flag up any aspects of the questionnaire that could unwittingly cause distress. Some people might have been caring for more than one person with dementia or have done so in the past, so we designed the questionnaire to deal with this possibility and asked people to provide answers only about the person who they spent or had spent the most time supporting.

Once the questionnaire was finalised, we entered it into Qualtrics. A text version of the final questionnaire is given in *Appendix 9*.

### Survey administration

The questionnaire front sheet gave more information about the project and stated clearly both that participation was optional and that by completing the questionnaire carers were consenting to the information they provided being used for the research. The research team's contact details featured prominently so that anyone who wanted to discuss the research before deciding whether or not to take part could do so. The e-mail also made clear that we could provide paper copies of the questionnaire on request.

One reminder e-mail was circulated around the entire network 2 weeks after the first e-mail but no further correspondence was received by non-responders. Those who completed the questionnaire were asked whether or not they would like to receive a summary of the study findings in due course.

We included information about who to contact for further support at the end of the questionnaire, and repeated the research team's contact details in case respondents had any questions or concerns.

## Response rate

One hundred and three carers responded to the survey, and 96 completed enough of the survey to allow analysis of their responses. This response rate is in line with the 10–20% that Uniting Carers had predicted (see *Sample*). There is no way of knowing whether or not respondents were representative of all carers in the Uniting Carers network, nor would it be sensible to compare those who responded with all carers of people with dementia, even if such comparative data were available.

Of the 96 respondents, 52 were current carers and 44 had cared for someone with dementia in the past. We compared the current and ex-carers across the full range of questions and found very few differences between them. We therefore combined the results for the two groups.

## Analysis

All data were imported from Qualtrics into SPSS (version 22) for analysis, which was predominantly descriptive. Bivariate analysis initially compared those who had and had not had experience of LSW. Subsequent analysis explored the experiences of the small number ( $n = 39$ ) who had experience of LSW. Frequencies and chi-squared statistics are thus the main forms of analysis presented. We have also used the adjusted standardised residual to explore the main drivers of significant differences within cross-tabulations.

## Results

### Carer characteristics

Three-quarters of carers were female, and the majority (74%) were aged  $\geq 55$  years, with 40% aged  $\geq 65$  years. Most (98%) classified themselves as white; only two carers reported non-white ethnicity. One-third (33%) were caring for a spouse or partner and over half (57%) were caring for a parent or parent-in-law. Men were significantly more likely to be caring for a spouse or partner and women for a parent/in-law or other relation ( $\chi^2 = 4.41$ ,  $df = 1$ ;  $p = .036$ ), while those aged  $\geq 65$  years were much more likely to be caring for a spouse or partner ( $\chi^2 = 47.89$ ,  $df = 3$ ;  $p < 0.000$ ). As a result of this patterning, male carers among the respondents were significantly more likely than females to be aged  $\geq 75$  years ( $\chi^2 = 8.58$ ,  $df = 3$ ;  $p = 0.035$ ).

These patterns are all broadly what we might expect to see in a population of carers of people with dementia.

### Characteristics of the person with dementia

Sixty-three per cent of the people who were or had been supported by carers were female.

Current carers were most likely to be supporting someone aged  $\geq 75$  years (69%); 19% were supporting someone aged between 65 and 74 years. Forty-eight per cent reported that the person with dementia's memory loss had become apparent between 6 and 10 years previously, with 35% reporting that this had happened between 1 and 5 years previously.

We asked those who were no longer carers how long they had cared for the person with dementia; almost two-thirds had done so for  $\geq 6$  years, and 21% had done so for  $\geq 11$  years. We also asked ex-carers how old the person with dementia had been when their memory problems had first become apparent. The majority (63%) reported that this had happened when the person was aged  $\geq 75$  years.

Among current carers, the largest group (44%) were those supporting someone who lived at home with them, followed by those supporting a person with dementia living in a residential or care home (23%) or nursing home (15%).

## Knowledge of life story work

Three-quarters of respondents (75%) said that they had heard of LSW, but only 41% (39 carers) reported that the person they supported had ever done LSW. Carers under the age of 65 years were more likely to have heard of LSW ( $\chi^2 = 9.38$ ,  $df = 3$ ;  $p = 0.25$ ) but there were no other obvious relationships between carers' characteristics and their knowledge of LSW.

The most common source of information for carers about LSW was a voluntary organisation (46%), followed by a health or social care professional (37%). A small proportion had found out about LSW via the internet (13%) or from published material (13%). Some respondents mentioned more than one source of information.

There were no apparent relationships between whether or not LSW had been done and the characteristics of carers or those of the person with dementia.

The 36 carers who said that they had heard of LSW but that the person with dementia had not done it were asked about the reasons for this. The most important reason given (16 carers) was that LSW had never been offered to the person with dementia. Four said that it had been offered but that the person they supported was not interested in doing it and four said that they had not been sure of the benefits of doing LSW or were worried about it raising painful memories for the person they cared for. Four carers also mentioned that by the time they had heard about LSW it was 'too late', as the person they cared for had deteriorated too far or had died.

We explained the general principles of LSW in our questionnaire introduction. We therefore asked those who had not previously heard about LSW whether they felt that it might help or could have helped the person they supported; most (13/24) felt unsure about whether or not doing LSW might be of value.

## Doing life story work

The remainder of the analysis is based on the 39 carers with experience of LSW and should be read in the light of small numbers.

### *Type of records used in life story work*

Most carers (21/39) reported that LSW had involved only one type of record. Around one-third reported a photo album with no text and just under one-third reported the use of photos alongside written comments or stories. One-third also mentioned the use of a written summary. One-quarter mentioned that a book had been produced using a mixture of photos and stories and one-quarter mentioned the use of a memory box. Very few ( $n = 3$ ) mentioned the production of a collage or similar to display. Other forms of LSW were a DVD or film ( $n = 1$  carer) or a poem ( $n = 4$ ). Some carers mentioned other forms of memory prompts such as smells or favourite plants being used to represent the person's life.

Where only one type of record was reported, this was most likely to be a book with a mixture of photos and stories ( $n = 7$ ) followed by a photo album with no text ( $n = 5$ ). Four carers reported that the life story was a written summary only. A written summary combined with other type of records such as photo albums and memory boxes was the most common pattern of multiple records ( $n = 9$ ).

### *How, where and when is life story work done and who was involved?*

Most carers (34/39) said that the person with dementia had done LSW in a one-to-one situation; the remainder reported a group setting. Some carers provided additional detail here, usually reporting that they themselves had done the LSW with the person with dementia.

How the LSW was done was related to where it was done. First, most carers ( $n = 20$ ) said that the LSW had been done in the home of the person with dementia or in the care home where the person lived ( $n = 13$ ). One referred to LSW being done in a support group and four to a community service setting such as a memory café or day centre. When this was examined against how the LSW was done, the



predominant model that emerged was of one-to-one work in the person's own home ( $n = 26$ ) or in a care home ( $n = 11$ ). As these numbers suggest, some carers reported more than one setting in which the LSW had been done.

Carers themselves were the people most involved in doing the LSW ( $n = 34$ ), followed by the person with dementia ( $n = 24$ ). Care staff ( $n = 7$  carers) or people paid specifically to do LSW ( $n = 2$  carers) were also mentioned, and three mentioned volunteers. Overall, one-quarter of carers ( $n = 10$ ) said that there was only one person involved, one-quarter ( $n = 10$ ) said that two people were involved and the remainder reported that three or more people were involved. Nine carers reported that they were the only person involved in doing the LSW.

Carers were most likely to be involved when the LSW was done at the home of the person with dementia ( $n = 25$ ) or in the care home where the person lived ( $n = 12$ ). Care staff or volunteers were most likely to be mentioned ( $n = 8$ ) when the LSW was done in a care home, as might be expected. In both cases in which a person paid to do LSW was involved, the work had taken place in the person with dementia's own home.

Some carers ( $n = 12$ ) said that the life story had been created before or soon after the person showed signs of memory problems. The majority ( $n = 18$ ), however, reported that LSW had been done between 1 and 5 years after memory problems had become evident, and a small group ( $n = 8$ ) reported that it had been done  $> 5$  years after onset.

### How is the life story used?

Most carers reported more than one use of the life story; over two-thirds reported five or more uses (see *Appendix 1, Table 30*).

The final column in *Table 30* shows some interesting patterns. Helping the person to remember important parts of their lives was chosen most often ( $n = 31$  carers) but when it came to the most *important* use, helping health and social care workers to provide better care was chosen most often.

### What information is included in the life story?

Different methods of doing LSW and different uses to which the life story is put both influence and are influenced by the information that is included in the life story (see *Appendix 1, Table 31*). Most of the life stories carers had experienced were based more in 'facts' than in 'feelings'. Thus, most reported that the names of family members and others close to the person with dementia were included, but only one-third said that the reactions of the person to these individuals were in the life story. Similarly, while many life stories included lists and details of important events, dates and so on, a record of the person's feelings about these was much less common.

Analysis of the clustering of these different types of information showed two fairly distinct models of LSW, each accounting for around half of the responses. One concentrated on the names and descriptions of family members and the other on close people, lists and details of events, and people's preferences for food and activities. The first model was more likely to include spiritual and care needs, people's clothing and conversational preferences, and their feelings about family members and events. The second type tended to be more associated with a life story that was in written summary form, which was done in care homes and for which the most important use was helping health and social care workers provide better care.

### Leaving things out of the life story

Just under half ( $n = 18$ ) of the carers said that something had been left out of a life story, the most usual reason being that some things would have been too upsetting (nine carers) or too private (eight carers) to include. Five felt that the life story needed to be positive and, therefore, presumably, some less positive aspects of the person's life had been excluded.

Carers were more likely to report that they had made the decision to leave something out (14 carers) than that the person with dementia made the decision (six carers). In two cases, the decision had been a joint one. Other family members (three responses) and health or social care workers (one response) were also mentioned as having influenced the exclusion of something from the life story.

### **Is the life story static or dynamic?**

Just over one-third of carers (14) said that the life story was a 'one-off', with nothing added to it subsequently. Another one-third (13) said that photos, descriptions or other items about the past had been added to the life story along the way, and 10 said that items related to recent events had been added as they happened.

It was unusual for the life story to include the person's hopes and views about the future and LSW was dominated by recollection of the past (see *Appendix 1, Table 32*). Overall, 16 carers reported that the life story was exclusively about the past, containing no information about the person's current life or about their hopes and views for the future. Life stories that were classified as the second 'type' (see above) were more likely to include information about the person's current life (14/19) than were those classified as the first 'type' (8/20) and this difference reached statistical significance ( $\chi^2 = 4.50$ ,  $df = 1$ ;  $p = 0.034$ ). This perhaps reflects the use of this type of life story in care home settings.

### **Who can look at the life story and who gives permission for this?**

The majority of carers said that they and the person with dementia were able to look at the life story (34 in both cases). Family members were next most likely to have access (32 responses). Only 17 carers reported that selected health and social care staff could look at the life story, and 14 that any health or social care staff could look at it.

Eighteen carers reported that the person with dementia had given explicit permission for the life story to be seen by others (or not); eight reported that the person with dementia had not given explicit permission and 11 did not know or could not remember. Rather more carers (27/39) reported that *they* had given permission. However, the majority of carers said that there was no written statement of permission included in the life story record that allowed others to look at the life story or that they could not remember such a statement.

### **Access to the life story**

#### ***Where is the life story usually kept?***

We saw earlier that some carers reported more than one life story record. This is reflected in 12 people reporting that there was a life story record in more than one place (see *Appendix 1, Table 33*). The most common combination was when the carer had a copy of the life story and a copy was also kept at the care home where the person with dementia lived.

#### ***Looking at and using the life story***

Finally, we look at the active use of the life story, indicated by how often people actually looked at it (see *Appendix 1, Table 34*).

We saw earlier that the use of the life story to enable care staff to look after the person with dementia was, for many carers, the most important reason for having a life story. Despite this, carers reported that use of the life story by care staff was relatively low, and lack of knowledge about whether it was ever used was relatively high. Even for carers and people with dementia, however, use was not as high as might have been expected. Only one-third of carers said that they or the person with dementia looked or had looked at the life story at least every week, and of these very few reported daily use (two and three responses, respectively).





## Chapter 6 Exploring feasibility

This element of our work related to stage 2c in our proposal: scoping the potential effects and costs of using LSW in specialist inpatient and long-term care settings (objective 3) and exploring the feasibility of formal evaluation (objective 4).

Medical Research Council guidance<sup>18</sup> confirms that assessment of feasibility and piloting of methods is vital preparatory work in developing and evaluating complex interventions. In this stage of our work we were interested, first, to see whether or not we could observe any effects from and costs of using LSW and, second, to test the feasibility of large-scale formal evaluation of LSW. We piloted two different study designs in two different settings to address our objectives:

1. a stepped-wedge trial design in independently provided care homes
2. a pre-test post-test design, with controls, in NHS mental health assessment units that specialised in the care of people with dementia.

In this chapter, we present the findings of the assessment of feasibility in both settings. The measured outcomes and costs are reported in *Chapters 7 and 8*.

The aims of the feasibility elements of the work were to:

- establish the likely rates of recruitment and retention
- identify any problems service providers experienced in delivering the intervention
- assess the feasibility of measuring the outcomes of LSW in these settings
- assess the feasibility of collecting data on the costs of LSW in these settings.

### Methods

#### *Study 1: a stepped-wedge trial design in independently provided care homes*

##### Design

We chose a stepped-wedge design to allow us to test the feasibility of not only evaluation but also rolling out the LSW approach to these new care settings. In this design, each setting receives the intervention at some point during the period of the study (ensuring equity), but roll-out is staggered, rendering implementation across multiple sites more straightforward than attempting a simultaneous start.<sup>134</sup>

We worked with a single, not-for-profit care home provider that was keen to introduce LSW across its services. The provider selected a purposive sample of six care homes. None of the homes currently practised LSW but all had managers who were disposed to introduce it.

The project was designed so that one care home introduced LSW each month for 6 months, with baseline data collected immediately before implementation and follow-up data collected 1 month, 2 months and 6 months after LSW was due to begin. The first care home entered the study in January 2014 (with training taking place in the previous month) and the following care homes entered at monthly intervals; thus, care home 6 entered the study in June 2014.

## Intervention

A training package was designed, informed by the findings on good practice from the development stage of the project (see *Chapters 2 and 3*). This consisted of:

- a 2-hour training session for care home staff (delivered by the care provider's dementia care consultant)
- printed guidance and hand-outs on good practice in LSW
- a template, 'some important things', to help staff get started (it was emphasised in the training that the template need not be followed – the form LSW takes should be led by the needs and desires of the individual – but it could be used as a starting point).

## Sample

Ten residents with dementia or dementia-like symptoms (and their family carer, if they had one) in each of the six care homes were randomly selected and invited to join the study. All staff who undertook the LSW training were also invited to take part.

## *Study 2: a pre-test post-test design, with controls, in NHS mental health assessment units that specialised in the care of people with dementia*

## Design

The stepped-wedge approach was not appropriate in the acute settings, as we were working with three mental health assessment units in which LSW was reported to be a routine part of care for all patients with dementia already. We instead opted for a pre-test post-test design in the acute settings, with a comparison setting providing a control, and collecting data over a 6-month period from baseline. All three wards in the intervention site joined the study in February 2014 and the comparison site joined in April 2014.

## Intervention

In the intervention site, a group that included the NHS trust's clinical lead for psychological therapies for older people had initiated LSW some years previously. In October 2013, we attended the trust's Service Line Planning Group meeting for older people's services and agreed with service managers to focus on three short-stay assessment units for older people with mental health problems where LSW (usually in book form) was routinely practised.

In the comparison site, LSW was not practised but the ward manager was keen to introduce it. We agreed that, once the 6-month participant recruitment period was over, the project team would support the ward to access LSW training.

## Sample

Ten people with dementia (and their family carer, if they had one) were to be recruited sequentially from each of three inpatient assessment units that practised LSW as or soon after they were admitted and 10 were to be recruited sequentially from each of three comparison sites as or soon after they were admitted. In addition, data were to be collected from a cross-section of staff on the wards at three time points over the 6-month period.

## *Process (both studies)*

## Quantitative data collection

We planned to measure selected outcomes for all participants with dementia and family carers at baseline (for those in the LSW groups, before any LSW had commenced) and then follow them up at 1 month, 2 months and 6 months after baseline, wherever they were then living. We had originally considered training staff on site to use some of the outcome measures, but it soon became clear that this would not be workable without additional funds to backfill staff time. Two researchers in the project team (KG and JB),

supported by a research assistant employed on a casual basis (LC) for the care homes study, collected data at all time points.

Innovations in Dementia provided advice on consent and data collection processes with people with dementia, and observed the researchers in action at one care home to ensure that ethical practices were in operation.

We also planned to collect data from participants' care records about dementia diagnosis and severity at baseline, and on relevant drug use and adverse events for the 3 months prior to entering the study and the final 3 months of follow-up.

Levels of staff burnout, staff assessments of personhood and staff approaches to working with people with dementia were assessed using existing measures. In care homes, consenting staff provided baseline data and were followed up after 1 month, 2 months and 6 months. In the hospitals, cross-sectional data were collected at three time points over the 6-month study period.

### Qualitative data collection

We gathered in-depth, qualitative information about experiences of LSW and the processes involved in its evaluation from carers, staff and (where possible) participants with dementia. The aims here were to:

- develop a qualitative understanding of causal links between LSW and the outcomes measured in the quantitative element of the study
- explore the acceptability of the processes involved in evaluation
- understand any implementation issues, including barriers and facilitators to LSW, and any unanticipated consequences (including how these could be managed in future).

We conducted a mix of face-to-face and telephone interviews with family carers (guided by their stated preferences) and guided conversations with participants with dementia who were able to communicate verbally (and were happy to do so). We also conducted focus groups with staff, covering both their views on the use of LSW and their experiences of taking part in the study.

### Ethical approach

Research ethics approval for the feasibility study stage of the project (including the qualitative work discussed in *Chapter 9*) was obtained from the NIHR SCREC on 28 November 2013 for people with the capacity to consent to take part, and on 2 December 2013 for those without the capacity to consent.

## Findings of the feasibility studies

### Selection and recruitment of sites

#### Recruitment of care home study sites

As planned, we recruited six care homes to the study through the care home provider already partnered with the project. Selection of sites was purposive, to provide a range of research settings (some more and some less research ready) all within 2.5 hours' travel of York. Recruitment was initially straightforward: the coapplicant on the project made the initial approach to regional managers, who in turn approached individual care home managers. In April 2013, when the Social Policy Research Unit held a meeting for the care homes for them to learn more about the project and contribute to the design of the study, all six sites were enthusiastic about taking part. However, by the time fieldwork was due to commence, managers had changed in two of the six sites and a further two sites had withdrawn, citing staffing and capacity issues. Both of the sites that withdrew were replaced before fieldwork started (CH1 and CH6), using the same purposive sampling criteria.

The researchers visited each care home in advance to familiarise themselves with the setting, to ensure that managers were still committed to the research and to build rapport with staff. Nevertheless, the change in management at two sites did appear to have an adverse effect, as both seemed less engaged in the research for the remainder of the study period. Indeed, continuity continued to be an issue at both of these sites throughout the fieldwork, with the new care manager in one home leaving part way into the study and both the care manager and the business manager leaving the other before final follow-up was carried out.

*Table 35 in Appendix 1* summarises the characteristics of the six care homes that were finally included.

The ethical issues regarding the assessment of people for dementia in a research project, when no formal diagnosis exists, are considerable. This is particularly the case in relation to people who live in residential care homes where diagnosis may have considerable financial consequences for those who are self-payers. We also know that diagnosis rates are below 50% in England.<sup>135</sup> However, even when a formal diagnosis had been made for a care home resident, this was not always recorded in the resident's care records. We therefore decided to rely on the professional views of the care home managers in relation to the assessment of the presence of dementia and/or cognitive impairment.

### **Recruitment of specialist mental health assessment units**

As planned, we recruited the three intervention sites through the NHS trust already partnered with the project. The site had six eligible wards and the final decision about which three to include was taken by the older people's service-level managers after a meeting with the research team. As ward managers themselves did not actively opt into the study, this may have influenced ongoing engagement.

The research team visited each ward before fieldwork started, meeting ward managers and available staff. However, as ward staff work shifts and a high proportion of bank staff work on the wards, it was not possible to meet the entire staff team before the research started. Again, this may have affected engagement with the project.

There was one change of manager at one of the intervention wards immediately before the study commenced but this did not appear to influence engagement.

Recruitment of a comparison site was less straightforward. We had originally planned to recruit three comparable mental health assessment units through the survey of care providers. However, it took longer than anticipated to identify the survey sample, and, once the sample was identified, responses from the NHS in particular were slow to come in (see *Chapter 5*). It was not possible to recruit through the NHS Portfolio at this point, as we had not yet received research ethics approval for this stage of the project. We opted instead to utilise existing contacts and relevant networks to identify comparable sites. However, comparable sites were not in abundance. There seemed to be two main reasons for this. First, there has been a recent move towards greater community provision, meaning that fewer trusts now appear to provide inpatient mental health assessment. Second, several of the sites that expressed an interest already employed LSW in some form on their wards and so were ineligible as comparators.

The site eventually recruited was identified through a national database of clinical psychologists and related practitioners. The trust had only one mental health assessment unit but this was larger than the three intervention wards in total. Further, the ward manager and local principal investigator agreed to continue recruitment until we had reached the target of 30 comparison patients (as opposed to 10 patients per ward, in the intervention sites) or the 6-month recruitment period ended, whichever came first. *Table 36* (see *Appendix 1*) summarises the characteristics of the specialist mental health assessment units recruited for this part of the study.

## Selection and recruitment of staff

### *Care homes*

All staff taking the LSW training in the care homes were invited to join the study. Signing up to the project involved agreeing to complete three questionnaires (the ADQ,<sup>129</sup> the PDQ<sup>130</sup> and the CBI;<sup>133</sup> see *Chapter 4*) at baseline and three follow-up points over 6 months. There was also the option of taking part in a focus group at the end of the study, but it was stressed that staff could choose to opt in or out of this nearer the time.

Recruitment was undertaken directly by the research team who visited each care home before the training. Recruitment was most successful when the researchers were allocated a dedicated room to talk through the project with each member of staff, either individually or in small groups. It was also most successful when staff were granted time from their caring responsibilities to consider their decision and, if they consented, complete the baseline measures there and then. In CH2, this time and space was not available and recruitment here was poor. At CH3, the manager led by example in a communal dining area, making time to sit with the researchers and go through the information sheet. She then encouraged her staff to meet with the researchers (allocating a dedicated room) but emphasised that whether or not they decided to join the study was optional.

Obviously, staff recruitment was also affected by numbers of staff allocated (usually by a manager) to take the LSW training and who were also available when researchers were recruiting at the home. Both varied considerably. In total, 51 staff were recruited across the six homes (see *Appendix 1, Table 37*).

### *Specialist mental health assessment units*

The research team carried out recruitment of staff in these settings. As explained earlier, the aim of the study in relation to staff differed from that for staff in care homes. Rather than investigating change over time, we were interested in identifying overall differences in staff groups between the sites that did LSW and those that did not. We thus planned to collect cross-sectional data at three time points over an 8-month period (February–September 2014) and use this to calculate an overall average for the staff teams at each site. The measures were the same as those used in care homes and staff were also informed about the optional focus group to be held towards the end of the study.

All staff members working on the ward on the day of our visit, from managers to bank staff, were invited to take part. The numbers working each shift differed between sites. However, the numbers completing questionnaires depended less on the size of the staff team and more on the activities staff were engaged in; often they were allocated to work one to one with a patient or were required to accompany patients off-site, effectively excluding them from involvement. In such circumstances we left recruitment packs for individuals, including pre-paid envelopes for them to return completed questionnaires, but we did not receive any additional responses using this approach.

As with the care home sites, the most effective means of recruiting staff in the acute sites was through face-to-face discussion in a dedicated room. When there was no space allocated for these discussions, or for staff to use while completing questionnaires, recruitment was less successful. *Table 38* (see *Appendix 1*) shows the numbers of staff who completed questionnaires at each time point; in total, 47 staff over four wards were recruited.

Not all of those completing questionnaires at time points 2 and 3 were new recruits: all staff members working on the ward at each time point were invited to complete the questionnaires, regardless of whether or not they had already participated at an earlier time point.

In summary, the recruitment of staff was relatively successful in both care homes and hospital settings but was influenced by a number of factors:

- dedicated space for staff to read the information, ask questions and complete questionnaires
- availability of staff to meet the researchers on the day
- manager leading by example
- communication to staff that research was taking place on that day.

### *Selection and recruitment of people with dementia and family carers*

#### **People with dementia in care homes**

We planned to select 10 eligible residents from each care home, using random selection, and invite them to join the study, either directly (if they had capacity to give informed consent) or through a consultee. After we met with representatives from the included care homes in April 2013, it was agreed to keep the eligibility of care home residents as broad as possible. At this meeting, three basic criteria were set for inclusion/exclusion, as follows.

- Include:
  - residents with dementia or suspected dementia.
- Exclude:
  - residents considered by the care home manager to be reaching the end of their lives
  - residents who had been at the care home for < 3 months (in order to ensure that 3 months' baseline data were available from the person's care records).

In addition, recognising the importance of learning throughout the feasibility study, it was agreed that if managers identified further reasonable grounds for exclusion once selection began, these would be considered by the research team and, if agreed, applied throughout.

Ten eligible residents were to be randomly selected in each care home in the month prior to the intervention being introduced. However, obtaining a sampling frame of eligible residents from each care home was challenging, as pertinent information to establish eligibility (whether a person had dementia or suspected dementia) was not routinely recorded in care records. We decided therefore to ask each care home manager to make an assessment based on their knowledge of their residents and supply the research team with an anonymous list of all residents they considered to be eligible.

A researcher at the University of York who was independent of data collection and analysis then randomly selected residents, using the eligible participants' room numbers and a random number table. These allocations were communicated back to the researchers. In the case of CH3, the independent researcher was unavailable and so resident numbers were picked out of a hat by the two researchers in the presence of two members of staff.

The situation of people with dementia can change so suddenly that it is not always possible to exclude potentially ineligible residents before selection. For example, one resident, who was well when the random selection took place, became severely ill the following week and died soon after. Further, in two care homes, staff felt unable to approach some selected residents because a change in the residents' circumstances meant that the approach might now cause distress. We therefore added a further selection criterion, whereby residents were not entered for random selection if care staff had reason to believe that approaching the resident or (where necessary) their consultee would cause distress.

This openness to amending the criteria meant that we had to select some additional residents after the original selections, by generating a new random number table from the remaining eligible participant list. This approach does not meet the criteria for full randomisation but as this was feasibility work, and as participants were difficult to recruit, we felt it appropriate to randomly generate further participants where necessary. We also set a limit of selecting a maximum of two additional residents per care home, to preserve as much of the random approach to selection as possible.

*Table 39* (see *Appendix 1*) shows the numbers of residents selected and reselected at each care home and the final numbers invited to take part (either directly or via a consultee).

## Recruitment

The first 10 randomly selected residents were approached by a researcher and invited to take part in the study.

In consultation with care home staff, a researcher (supported where necessary by Innovations in Dementia) looked into what arrangements were necessary to support each potential participant to understand and retain information about the research, to weigh up this information and to communicate their decision (e.g. through the use of communication aids or the support of a trusted member of staff or family). If the person had capacity to consent, the researcher supported them to read through the participant information leaflet (see *Appendix 10*) and answered any questions they had. The information sheet was clear and easy to read, and project advisers with dementia had contributed to its design. If the person wanted to take part in the study, they were asked to complete a consent form or to give verbal consent witnessed by a family member or member of staff (see *Appendix 10*).

If the researcher had reason to believe that the resident did not have capacity to give informed consent, a consultee was identified and asked to advise on the potential participant's wishes. Again, this decision was made in consultation with care home staff and Innovations in Dementia, but responsibility for the final decision lay with the researcher. In most cases, consultees were family members or close friends (i.e. personal consultees). Nominated consultees (members of staff who knew the person well) were approached only if no close family or friends could be identified or if those approached felt that staff knew the person better than they did.

Contacting personal consultees was not always straightforward as, for data protection reasons, the researchers could not be given contact details without the consultee's agreement, and so care home staff had to make initial contact. We gave care homes consultee information sheets and asked them to make contact in whichever way they felt was most appropriate (passing information sheets on when the consultee came to visit, telephoning the consultee or sending an information sheet through the post). Success was patchy and we had to send several reminder calls and e-mails to prompt care homes to contact potential consultees and let us know the outcome.

At this stage, potential consultees were simply asked whether or not it was acceptable for a researcher to make contact to explain more about the study (i.e. consent to contact). However, this proved to be a critical gateway (or barrier) to recruitment, as the majority of the people with dementia selected for the study did not have capacity to give informed consent (43/59). Without agreement from the potential consultee that we could make contact, we could not progress (effectively excluding the person with dementia from the study). Moreover, the indirect nature of first contact means that we do not know the reasons for refusal or non-response from those who did not agree to initial contact.

Some consultees actively advised against including the person they cared for, for reasons that included the person with dementia's mental health status, lack of interest and current physical health.

*Table 40* (see *Appendix 1*) summarises the numbers of people with dementia selected in each care home who had capacity to consent and their decisions, as well as those without capacity and the responses of consultees. The majority (14/16) of people with capacity to make a decision consented to take part,



whereas fewer than two-thirds (25/43) of the people without capacity were included. Of these, seven were not included on consultee advice and a further 11 were effectively excluded because potential consultees did not agree to the researchers contacting them in the first place. In total, we recruited two-thirds (39/59) of potential participants (66%) sampled.

### Family carers of people with dementia in care homes

If a person with dementia was recruited to the study, we also invited a family carer or close friend to take part, as findings from our focus groups and literature review suggested that carers' QoL and relationships could be affected by LSW. Often, where a person with dementia did not have capacity to give informed consent, the family carer was the same person who had been contacted as a personal consultee. However, this was not always the case; in some families one person visited regularly but someone else took responsibility for managing the person's affairs, and we were guided by the family as to who should be involved in which capacity. For the 14 people with dementia who consented to join the study themselves, we needed to make contact with the family carers to invite them to take part in their own right, and this was again a lengthy process relying on care home staff having time to obtain consent to contact. Once this was obtained further information (see information sheets in *Appendix 10*) could be given via post or e-mail and consent discussed over the telephone or in person. Written consent was always obtained (see carer consent forms in *Appendix 10*).

*Table 41* (see *Appendix 1*) shows the number of family carers recruited against the numbers of people with dementia included and gives the reasons for the lower number of carers. In total, we recruited 31 family carers.

In summary, the factors contributing to success of recruitment of people with dementia and of family carers were:

- capacity of the person with dementia to consent directly
- time and enthusiasm of care home staff for making contact with potential consultees/carers participants and obtaining consent to contact
- consultees' concerns about health issues (mental and physical) and how these might be affected by the research.

### People with dementia in specialist mental health assessment units

Recruitment from the mental health assessment units (hereafter referred to as 'wards') was intended to be sequential and followed similar inclusion/exclusion criteria to those applied in care homes, as follows.

- Include:
  - new patients with dementia (i.e. new to the model of care, so patients transferred from one of the other study wards were excluded).
- Exclude:
  - patients considered by the ward manager to be reaching the end of their lives
  - if there was reason to believe that approaching the patient or (where necessary) their consultee would cause distress.

Wards agreed to notify the research team when a new patient with dementia was admitted and our links in the trusts' own research teams also agreed to track eligible admissions. A researcher contacted the wards each week for details of any new admissions who might be eligible for the study. After some discussion about the slow start to recruitment, an e-mail reminder was also sent at the start of each week reminding the ward manager (or a nominated member of staff) of the eligibility criteria and asking them to notify us of any new patients who might meet these. Where possible, we cross-checked these figures with

admissions figures from the on-site research team/trials unit at our sites but suspect strongly that we were not notified of all new admissions.

We were advised by service managers not to assume capacity to consent in the ward sites, as the majority of patients admitted did not have the capacity to make complex decisions. Instead, we asked ward staff to give an initial assessment (which would later be confirmed by a researcher in consultation with the individual and/or their consultee). Ward staff considered that none of the patients identified as potentially eligible had capacity to consent, so we sought a consultee in every case.

As in the care homes, data protection issues meant that consultees had to be contacted through the wards. However, this approach was even less successful in the wards than it had been in the care homes. The most frequent reason given for delays in staff obtaining consent for a researcher to contact a potential consultee was lack of time, as this extract from our field notes about one of the intervention wards illustrates:

*20th May 2014 – Recruitment has stalled somewhat at this site. Despite being notified of four new patients on the ward we have heard nothing about whether they would like to [be contacted about] the study. Moreover, it appears that LSW is not happening, at least while the ward is very busy . . .*

*2nd June 2014 – Had a long chat with [name], a nurse on the ward. She said that the staff have been so busy recently that they haven't had any time to approach any of the family members about the research (or do much LSW) . . . She said really they could do with someone on the ward whose job it is to do this (not clear if she is talking about LSW or recruitment for the research – possibly both). It turned out that several new people had been admitted to the ward in May that we hadn't been told about . . .*

*Field notes*

As a result of such delays we developed our exclusion criteria further.

- Exclude:
  - patients whose consultee has not been approached 2 months after admission
  - patients whose consultee has not been approached 1 month after recruitment period finished (or the month recruitment ended at the comparison site, to allow sufficient time for follow-up).

It also transpired that some ward staff were reluctant to approach some families because of concerns that this could cause distress, given the already-stressful situation the families were in. People with dementia tend to be admitted to a mental health assessment unit only when they and/or the people who care for them reach crisis. Their family carers are thus likely to be at a different point on the dementia journey from the families of people who have been living in long-term care. Indeed, we saw from the responses of consultees we did make contact with that ward admission was not always felt to be a good time to be engaging in research, either because the person they cared for was already distressed or because they themselves were overburdened with form filling and other caring responsibilities. Reasons given by consultees who decided not to proceed with the research included:

- Wife said she was tired and worried about her husband.
- Daughter did not want people ringing her when she was busy.
- Husband said that as long as his wife was getting good care he was not interested in taking part in research.
- Partner said he did not want the patient to be involved because he was already distressed by the things people were asking him on the ward.
- Son said it was not the sort of thing his dad would want (or would ever have wanted) to get involved with as he was quite wary of authority figures/people asking questions.

Reasons given by staff for not approaching potential consultees included:

- Staff member rang to say that the patient's wife was poorly at that moment so they decided not to approach her.
- Staff were reluctant to approach niece as the person had just had a fall and it would seem as if they had got their priorities wrong.
- Staff forgot to ask family member about the research last time she was in and now they did not want to approach her because she herself was poorly.

*Table 42* (see *Appendix 1*) sets out the numbers of potentially eligible participants and the stages they moved through before inclusion in the study. From an initial pool of 50 patients, we received consultee advice to include just 12 patients (24%). Sixteen potential participants were lost simply because the research team did not receive consent to contact (which could be arranged only by busy ward staff) in time and a further 15 were lost because consultees actively (or passively, by not responding) declined/advised against inclusion, or because the patients' circumstances changed after the consultee was approached.

There was a similar refusal rate among consultees for people with dementia on wards (48%) as there was among consultees for residents in care homes (42%), but, coupled with the high numbers of consultees who were never approached by staff and the fact that none of the patients had capacity to consent themselves, the recruitment rate on the wards was much lower than in the care homes.

Four potential participants were excluded because of doubt over their diagnoses. Although we had expected some uncertainty about diagnosis in the care homes, we had not anticipated this in the hospital sites. However, questions about diagnosis were largely related to newly admitted patients, so this is perhaps not surprising, given the focus on assessment in these settings.

However, even for patients for whom diagnosis was secure, there was little in their notes about severity. Discussion with the on-site research team suggested that this was because many patients on the wards were not able to undertake the Mini-Mental State Examination.<sup>136</sup> The information we did receive about severity of dementia was, therefore, more likely to be based on a consultant's clinical judgement (found, for example, by the on-site research team searching through correspondence).

This uncertainty and inconsistency in recording makes it difficult to envisage receiving accurate data on dementia severity for a full trial without conducting additional assessment with participants specifically for the research.

Not all consultees who agreed to participation were happy for the person with dementia to be approached to answer questions about their QoL and relationships. In most cases, consultees agreed to a researcher meeting the person and seeing if they were able to answer any questions, but in some cases consultees said that they would prefer the person not to be approached. In such cases the person could still be included in the study, but data were collected from proxies and/or their care records only, reducing further the amount of information available.

In summary, the recruitment of and gathering of data from people with dementia in specialist mental health settings was less successful than in care homes. The main reasons for this were that:

- None of the patients on the wards had capacity to consent and so, without consultee agreement, they could not be approached.
- Researchers could not make contact with over one-third of patients' potential consultees because they were never approached by staff for consent to contact.
- Even when consultees agreed to the person with dementia being approached, some placed restrictions on the type and nature of data to be collected.

The recruitment process through the mental health assessment units was also labour intensive, with multiple telephone calls and e-mails often leading to nothing, as the following extract from our field notes illustrates.

- ... email on 3rd March said two people had been admitted to [ward] in the previous fortnight – one of them ... is potentially eligible (the other has been transferred out).
- KG tried to ring on 5th March but was asked to ring back on Friday 7th.
- Rang on 7th March – manager not available – staff member said they would pass on a message for [manager] to ring me. Not heard by afternoon so rang at 4.40 pm but no-one answered.
- Spoke to manager on 11th March ... said [staff member 1] would ring me back that day but no-one did.
- I rang again the next day (12th March) and spoke to [staff member 2] who said that manager is now away until Monday, [staff member 1] is also off and [staff member 3, who might be able to answer my questions] is currently busy. I asked for [staff member 3] to ring me back and left my mobile number ... [no phone call received]
- Rang on 21st March but [manager] not there.
- Rang again on the 24th – left a message for [manager] to ring me back. Rang again in afternoon and spoke to [manager] who explained the patient had since had a fall and they were reluctant to approach him.

*Field notes*

- *Exclude* In this instance, it took 3 full weeks (and eight telephone calls) to speak to someone on the ward about obtaining consent to contact a family member. Eventually staff decided not to approach the family as, during the 3-week period since the research team had been notified of the patient's admission, the patient had fallen, and it was felt that approaching his family would now cause distress.

### Family carers of people with dementia in mental health assessment units

As in the study in care homes, we also invited the family carers of participants with dementia to join the study. In all cases this was the same person who was contacted as a personal consultee. However, carers were given a separate information sheet regarding their own participation (see *Appendix 10*) and it was stressed that their inclusion was voluntary and would not affect whether or not the person they cared for could take part. Information was given via whatever means carers felt would be most convenient for them (by e-mail, by post or face to face). No carers joined the study without at least one telephone conversation in which they had the opportunity to ask questions and researchers could explain the consent process. As with the care homes study, all included carers gave written consent to take part (see carer consent forms in *Appendix 10*).

*Table 43* (see *Appendix 1*) shows the number of family carers recruited against the numbers of people with dementia included and gives the reasons for the lower number of carers. In total, we recruited 10 family carers across the four wards.

### Delivery of the intervention

#### Implementation of life story work in care homes

The stepped-wedge design relies on an intervention being implemented at each site in turn over the period of a study. Our first observation in this feasibility study was that implementation varied considerably from care home to care home, despite the commitment of the care home provider (including training and resources) being the same at each site.

The training emphasised the role of all care home staff in making LSW a routine part of care rather than an additional 'task' to be completed. In keeping with this, homes were encouraged to enter as many staff as possible for the training, which ran twice at each care home at times agreed to be convenient with managers. It was also limited to 2 hours so that staff could attend without being kept too long from their core duties.

The numbers attending the training at each site ranged from 6 to 15. However, in care homes that went on to implement the intervention (carrying out at least some LSW with at least half of the study participants), one individual co-ordinated and in most cases also carried out the majority of the LSW single-handedly. In three care homes this person was the activities co-ordinator; in a fourth the activities co-ordinator left near the start of the project but another member of staff then took on LSW, fitting it around her other responsibilities. At these care homes other care staff were supportive of the process but found little time to engage in it themselves.

In the two remaining care homes the activities co-ordinators set up systems to support care staff to collect life story information during their day-to-day routines. Both created a folder for each resident: in one, care staff were then issued with notepads to note down life story information gleaned during everyday interactions and were encouraged to add this to the folders. In the other home, staff were allocated 20 minutes' protected time per day to work with named residents. However in both cases, according to the logs that assessed how long staff spent on LSW (see *Chapter 8*), it was still the activities co-ordinators who collected most information and they alone who spent time constructing the life story products.

Thus, although care staff did spend time talking to and learning about residents as part of their day-to-day routines, they found it difficult to find time to put this information into a format that could be used by others or enjoyed by the individual or their family. If we refer back to the potential challenges identified in the development phase of this study (see *Chapter 3*), this supports the argument that outcomes for care, as well as wider interpersonal benefits to people with dementia and their carers, may be lost if staff have time only to focus on the process of collecting life story information without then having time to do anything with it. Sites that appeared to have the most success in implementing LSW were those that combined a shared responsibility among staff to collect information with a designated worker who took responsibility, and had dedicated time, for pulling information together and presenting it in a way that others, including the people with dementia themselves, could use.

The approaches to LSW undertaken in each care home also varied and, crucially, tended to differ from the approaches often depicted in LSW literature and envisaged by those discussing the outcomes of LSW in our earlier focus groups. In *Chapter 3* we set out a range of approaches to LSW or 'mechanisms' through which LSW was intended to produce an outcome. These ranged from approaches focusing on the individual, such as LSW as a personal memory aid, a personal challenge or an approach to life review, through more interpersonal approaches, such as LSW as a shared memory aid, communication aid or platform to enhance connection between people with dementia and others, to LSW as a tool for care. The training given by the care home provider emphasised the full range of possible outcomes.

A template entitled 'some important things' was provided, which staff could use as a starting point. However, it was emphasised that completing this did not constitute LSW: it could be a useful tool to get the process started, but the approach and resultant products should be individually tailored and informed by the needs and preferences of the person with dementia. This tailored approach was taken in four care homes (in that personalised books, boxes or other items were created) but in all cases the design and construction of the life story products were led by staff, not by people with dementia or family carers. It appeared that in almost all cases residents were not considered to have the capacity to take a lead in the LSW themselves. This reduced the chances of seeing the outcomes anticipated by the people with dementia who took part in our focus groups, many of whom had a greater degree of capacity than those in the feasibility study, and who thought that LSW could provide a satisfying personal challenge or opportunity for reflection on achievements and identity. Moreover, family carers were only sporadically involved – perhaps to provide some photographs or view the 'finished' product – and so improvements to their QoL and relationships with the people with dementia also seemed unlikely. As evidenced in the focus groups with staff at study sites, the primary intention was that life story information could be used to improve care, which in turn might improve residents' QoL (see *Chapter 9*).

The organisational context at individual sites appears to have influenced the success or otherwise of the implementation of LSW. Although the care home provider as a whole was supportive of LSW (indeed, they provided the initial training and guidance), care home managers were essentially left to their own devices after this to bring about change in their own settings. In homes where managers proactively led this process and/or actively supported individual members of staff to dedicate time and energy to LSW, there was a degree of success.

A key factor appeared to be the consistency of management, with all four care homes that had retained the same managers from initial sign up to the 6-month follow-up seeing the most success. In the two sites where there had been a change in management there was less sense of ownership of the intervention, and while, ostensibly, managers had sanctioned staff to undertake LSW, there seemed to be confusion about whose responsibility this was, as this extract from field notes suggests:

*Popped up to see business manager who didn't recognise me (and didn't seem to be expecting me), and who also said she didn't know about any LSW, but the care manager [who was currently off site] would . . . She said the staff would know if they'd done any LSW.*

Field notes

At some of the sites that did undertake LSW, staff were also unsure at the start about how they should proceed, but were supported by managers, or enthusiastic/more experienced individuals who the managers encouraged to take a lead, as illustrated in this field note:

*Spoke to manager on [date] who said that staff are feeling a bit overwhelmed and as a result are struggling to get going with LSW (they have lots of good ideas but are struggling/or don't have the confidence to put these into action). Has decided to back fill the activities coordinator for two full days to support the other staff to get going with LSW. The activities coordinator is experienced in this sort of work.*

Field notes

In one of the sites, staff had only recently finished a previous project that had left them feeling disillusioned, and this 'project fatigue' was cited as a reason why there was little enthusiasm for LSW (see *Chapter 10*).

*Table 44* (see *Appendix 1*) summarises the approach to and organisational context of LSW implementation in the homes.

In summary, the factors that influenced the implementation of LSW in the care homes were:

- Care staff finding it difficult to find the time to put life story information into a format that could be used by others or enjoyed by the individual or their family.
- Sites that combined a shared responsibility among staff to collect information with a designated worker who had dedicated time to compile and present information appeared most successful in implementing LSW.
- The design and construction of life story products being led by staff, not people with dementia or family carers, might have reduced the chances of seeing certain types of outcomes such as improved relationships or carer QoL, thought to be associated with LSW.
- In sites where there had been a change in management, there was less sense of ownership of the intervention and some confusion about whose responsibility LSW was.



It should be noted that the above relates only to whether or not and in what ways care homes undertook the collection of information and creation of products necessary for LSW. It does not cover how life story information or products were used, something that the participants in our development stage focus groups (see *Chapter 3*) felt was key to achieving positive outcomes from LSW. Qualitative data about the use of life story information and products were collected through interviews and discussions with people with dementia and carers and focus groups with staff at study sites towards the end of the study (see *Chapter 9*).

### Life story work on mental health assessment units

In the three 'intervention' wards, LSW was considered a routine part of care and we were not, therefore, expecting to see any marked differences in the use of, or commitment to, LSW between the three wards. Instead, we wanted to assess how feasible it was to compare individual outcomes and costs on these three wards with those on a ward where LSW was not done. However, it soon transpired that the three intervention wards were not using LSW in similar ways or to a comparable extent: indeed, there appeared to be as great a difference between these wards as there was between them and the 'comparison' site. As such, rather than considering the wards as three intervention sites and one comparison site, it makes more sense to consider them as a continuum: from a ward that does LSW with most patients with fairly routine procedures for this to a ward that does no LSW at all (the comparison site); and two in between that did some LSW elements. *Table 45* (see *Appendix 1*) summarises the approaches at each site.

The resources available to do LSW at each of the wards differed considerably. In intervention ward (IW) 2, LSW was a core part of the work of three part-time occupational therapy technical instructors (OTTIs). They had dedicated time and access to a computer and scanner to produce the life story documents and were able to collect and use life story information during activities they ran with patients on the ward. IW1 and IW3 had had similar resources in the past but these had been lost some time before the research began and, thus, during the study period, IW1 nursing staff and assistants had no additional support to undertake LSW and IW3 had access to an OT only 1 day per week. *Chapter 9* provides a more thorough discussion of the reasons staff on IW1 and IW3 found it harder both to find time to undertake LSW and to participate in the research, but one factor was clearly the additional resource on IW2. By way of illustration, permission for the research team to contact the consultees of three out of the five patients recruited through IW2 was obtained not by ward staff but by the OTTIs. Without their support it is likely that recruitment on IW2 would have been no higher than it was on the other wards.

## Chapter 7 Measuring outcomes

In this chapter we continue the reporting of our feasibility work, examining the challenges of collecting outcome data and reporting what, if any, effects we detected from the use of LSW in our chosen care settings.

### Completion of outcome measures

#### *People with dementia in care homes*

Completion of outcome measures by people with dementia was challenging for a number of reasons, including:

- the capacity and frailty of the participants
- the context in which data collection took place (care homes getting on with their daily routines)
- the geographic location of the research settings, compared with that of the research team.

Some participants withdrew (or were withdrawn) from the study as it progressed and some died before the 6-month follow-up point. Of the 39 people with dementia recruited, 34 remained at 6-month follow-up (see *Appendix 1, Table 46*).

The measures chosen were all designed to be completed by people with dementia but completion rates leading to usable data were low and varied between the measures (see *Appendix 1, Table 47*).

The main reason for participants not completing a measure was that they were not able to understand and/or respond to the questions. Although both DEMQOL<sup>120</sup> and QoL-AD<sup>121</sup> have been shown to be valid and reliable QoL measures for people with mild to moderate dementia,<sup>122</sup> there is less evidence of their successful use with people with severe dementia.

In the care homes, we had most success with QoL-AD, which is a simple 13-question measure that we administered in interview form with a large-type visual aid (one question per page). Indeed, a higher proportion of participants with dementia were able to complete this at baseline (64%) than were able themselves to give informed consent (36%). DEMQOL, on the other hand, is a much longer tool (29 questions). Again, it was administered in interview form, but the only visual aid was a picking list of answer options. At baseline, only 31% of participants were able to complete this measure to produce usable data.

At baseline and the first two follow-up visits, we administered QoL-AD first, and on a small number of occasions, after completing QoL-AD, participants mentioned that they were tired, or did not want to answer any more questions. In order to test whether or not DEMQOL was indeed more difficult to complete, or whether or not participants were fatigued after completing QoL-AD first, we decided to administer DEMQOL first for some participants at the final follow-up to see if this affected completion rates. Two participants were able to complete both QoL-AD and DEMQOL at this follow-up when previously they had completed only QoL-AD, but the numbers involved were so small as to make this inconclusive.

Another reason for low completion rates of DEMQOL appeared to be the subject matter of some of the questions. This is rarely mentioned in the literature, but we found that, for example, asking people in quick succession whether they had lately felt sad (question 7), lonely (question 8) and then distressed (question 9) could trigger sadness. On one occasion (plus on two occasions in hospital wards) DEMQOL was abandoned specifically for this reason.



The closed-question format of the measures might also have affected completion rates. Often participants understood our questions but wanted to answer us fully (i.e. qualitatively), giving us examples of why they felt a certain way and caveats about how and when those feelings arose. It was difficult to bring some participants back to the picking list of answers (for QoL-AD the options are 'poor', 'fair', 'good' and 'excellent'; for DEMQOL they are 'a lot', 'quite a bit', 'a little' and 'not at all'). The guidance notes for DEMQOL instruct the interviewer in such circumstances to 'repeat the question and the response options verbatim and ask them to choose . . . reiterate that they need to choose [and]. . . if they still don't choose one of the response options . . . mark the questionnaire as missing. . .'.<sup>137</sup> In some cases, then, participants clearly understood the questions and were able to answer in their own words, but their responses were not recorded because they were unable to pick a response.

For QoL-AD this happened so often that we decided to record verbatim answers when these were given, and a third member of the research team (not involved in data collection) coded them for consistency. We adopted this approach in the interests of inclusivity, as the majority of participants did appear to be able to respond to QoL-AD (albeit sometimes in this semiquantitative way). Without this approach, precious data from people with dementia would have been lost.

Discrepancies between proxy and self-report are well documented, with proxies typically rating the QoL of the person with dementia lower than the person him- or herself would rate it.<sup>138</sup> We were, therefore, reluctant to rely solely on proxy estimates of QoL when these additional verbatim responses from people with dementia themselves were available.

Completion of the Scale for the Quality of the Current Relationship in Caregiving (QCPR): 14-item-version<sup>5</sup> by participants with dementia was the least successful of all the measures. The items in this measure are translated for use in English from a validated Dutch measurement tool. The language in the answer scale was particularly difficult for our first set of participants to understand, spanning from '1 = totally not agree' to '5 = totally agree'. Agree/disagree scales are cognitively complex for the general population, regardless of dementia, as they confound attitudinal position with strength of feeling.<sup>139</sup>

After our first attempt to use the measure, we amended the answer scale to the more conventional '1 = strongly disagree' to '5 = strongly agree'. However, participants still struggled to put their initial responses into this format. The subject matter of the measure served to compound difficulties, as the questions ask how well the person gets on with their family carer. Asking participants to clarify a response by saying to what degree they 'agreed' or 'disagreed' was inevitably confusing. We soon abandoned the answer scale altogether and opted instead simply to record verbatim answers and code post hoc, using the same approach as with QoL-AD.

Even accepting verbatim answers, the completion rate of the QCPR was lower than either DEMQOL or QoL-AD at each time point. One reason for this could be that completion of the QCPR relies on the participant being able to bring to mind their relationship with their family carer. This was facilitated for some participants at baseline when the carer was present (a number of carers combined a visit to the care home with a meeting with the researchers to go through the consent process in person). In contrast, although carers were always invited to follow-up sessions, they did not always attend these (choosing instead to complete proxy and carer-specific measures over the telephone or by post), and without the carer present, participants sometimes found it hard to bring to mind a close relationship. In addition, if people had experienced difficulty in answering QoL-AD or DEMQOL questions, or had become distressed when talking about relationships, we did not attempt the QCPR.

Participants' ability to understand and respond to the questions in the measures was not the only reason that some data are missing. Data collection had to fit around the routines and other priorities of care homes, and residents also had their own preferences and choices of daily activities. As the researchers often had to travel for  $\geq 2$  hours to attend research sites, it was not always possible to return on another occasion to complete data collection after interruptions.

Davies *et al.*,<sup>140</sup> focusing on the recruitment and retention of research sites, have argued that care homes can be particularly challenging environments in which to conduct research. We would add that the routines and competing priorities in these settings pose challenges to data collection itself. Despite agreeing all visits in advance, for example, it was not unusual for researchers to arrive to find alternative activities under way that meant residents were not free to speak to them. The general frailty and ill health of many residents also meant that illness, falls or unplanned hospital admissions could foil a planned data collection session.

Participants were not able to self-complete measures in their own time, and therefore we were reliant on obtaining face-to-face access to people who often required a considerable amount of time and support to participate, and might not, in the end, be available at all on the days planned.

Quality of life measures with people with dementia are intended to measure overall or health-related QoL at a specific time point (DEMQOL asks participants to consider 'the last week'; QoL-AD asks about 'your current situation'). The assumption is that QoL is something relatively stable over these short time periods. However, Trigg *et al.*,<sup>141</sup> when considering the discrepancies between self-report and proxy assessments of QoL, comment that the assessments people with dementia make are probably feeling-centred.

*Whilst observational or proxy ratings commonly provide QoL judgements based upon an appraisal of the patient's functional performance, the dementia patient may be appraising the situation on the basis of the mood states and feelings these activities produce . . .*

Feelings can change throughout the day, and during fieldwork we observed for ourselves several examples where people who were cheerful in the morning seemed very low in the afternoon, and vice versa. Time of day and night thus influence the answers given to QoL measures. Another example of the possible wide variability of QoL for people with dementia arose when we arrived at one care home while a singing activity was under way. The only time we could administer the measures was directly after this group: perhaps not surprisingly, participants were in a good mood, and they answered the QoL questions very positively. This may tell us something about the singing activity, but we are not sure that it tells us much about LSW.

There is a possibility that LSW (and other enjoyable or meaningful activities) may have an impact on the feelings of people with dementia 'in the moment'. If QoL measures are administered immediately after an enjoyable activity, it may be that the measures pick up the effect of this. However, people in care homes may engage in such activities most days; might the responses therefore tell us more about what the person has been doing that day than any longer-term effect of the intervention?

During the study, both staff and family carers suggested to us that the tools we were using missed the true benefits of LSW, which occurred 'in the moment' and thus could be fleeting. LSW was used either to lift a person's mood (albeit often temporarily) or to calm a person who was anxious or exhibiting behaviour that challenged. Both were seen as valuable outcomes, but were not expected necessarily to change a person's QoL in the longer term.

### **Completion of outcome measures by people with dementia in hospital wards**

In total, 12 people with dementia were recruited across three interventions and one control ward, 11 of whom remained at 6-month follow-up (see *Appendix 1, Table 48*).

Of the 12 recruited people with dementia, not all consultees gave permission to approach the person themselves. In four cases we were advised not to approach the person themselves, and given permission to collect information from care records only. This was extended to another participant after the first follow-up, as he had recently been sectioned and his wife felt it inappropriate for us to approach him again.

Table 49 (see Appendix 1) shows the low completion rates at baseline and follow-up for the three measures used in the hospitals study.

The main factor influencing completion of outcome measures in hospital wards was capacity. However, this barrier was compounded by the geographical spread of participants, as they were discharged to different settings. We then needed to obtain approval from both family carers and residential care or nursing homes before collecting data in the new settings.

Gaining access to these new sites was not always straightforward. Davies *et al.*<sup>140</sup> found that researchers wanting to conduct research involving care homes had to approach at least 40% more care homes than they needed in order to recruit the required number of sites. We needed access to the specific care homes into which participants had been discharged, but the care homes were not always receptive to this.

A researcher might have to make several telephone calls to arrange a visit, and then travel for a number of hours, in order to meet a person and support them to complete some or all of the questionnaires, if the person was able. In this way, a whole day could be spent completing one measure with one participant. We decided that this was not a good use of time and, after reviewing this as a team, reduced the follow-up time points from baseline for the hospital-recruited participants to two: one at between 1 and 2 months and one at 6 months.

We encountered similar issues to those in care homes in terms of the acceptability of the measures and their usefulness for our research.

### **Completion of outcome measures by family carers of people with dementia in care homes**

Completion of outcome measures by family carers was more straightforward, with no capacity issues and face-to-face administration not always necessary. Nevertheless, some issues regarding acceptability did arise which may have affected completion rates and warrant further exploration.

In total, 31 family carers of people in care homes were recruited and 25 remained in the study at 6-month follow-up (see Appendix 1, Table 50). One additional carer joined the study for the purpose of a final interview only, and did not complete the questionnaires.

Carers were asked to complete a measure of their carer-related QoL (the CES),<sup>127</sup> the QCPR from their own perspective (i.e. how they viewed their relationship with the person they cared for) and two proxy measures of QoL for the person with dementia: QoL-AD proxy and DEMQOL proxy.

Table 51 (see Appendix 1) shows the completion rates at baseline and follow-up for the two carer measures and two proxy measures by carer of people with dementia recruited through care homes.

We opted to give carers a choice of completion options for all of the measures, in recognition that flexibility is often paramount for busy carers juggling work, family and caring responsibilities. While the CES and QoL-AD proxy were designed for self-completion, DEMQOL proxy and the QCPR were designed for face-to-face administration. We suggested to carers that we should administer baseline measures face to face or over the telephone in order to familiarise them with the format and requirements. After this, we offered the opportunity for them to complete follow-up measures in their own time and post responses back (in the freepost envelope provided).

Although a high proportion of the carer measures and proxy measures were completed, carers often fed back that they did not enjoy completing the measures or did not see their relevance. We therefore included questions about this in the qualitative interviews at the end of the feasibility study (see Chapter 9).

### **Completion of outcome measures by family carers of people with dementia in hospital wards**

In total, 10 family carers of people with dementia were recruited and seven remained in the study at the 6-month follow-up (see *Appendix 1, Table 52*). An additional carer was recruited at IW1 for interview only.

Carers were asked to complete the same carer measures and proxy measures used in care homes, but were given an additional questionnaire to be completed when the person they cared for was discharged from the hospital (the Carer Satisfaction Questionnaire<sup>128</sup>).

*Table 53* (see *Appendix 1*) shows the completion rates at baseline and follow-up for these measures by carers of people with dementia recruited through hospital wards.

Carers in these settings appeared to find the outcome measures even less acceptable than those recruited through care homes, and one who consented to the study then refused to complete them at all. This extract from our field notes explains why:

*Started QoL-AD but [carer] wouldn't pick answers, and said very specifically she didn't like the questionnaires, that there wasn't much difference between poor and fair but there was a huge difference between poor and none (e.g. relationship with family or friends or marriage). Stopped before the end . . . Showed her Quality of Relationships scale but she started crying and said a year ago she had a relationship but not now . . . she thought questions were inappropriate and wrong and she couldn't answer them. Tried carer experience scale but again couldn't pick, and said question about fulfilment was offensive and abusive, and that she had no control over the care (she'd just brought in some cereal for husband but staff had said he hadn't used the old stuff yet because he didn't get up until lunchtime, she asked them to give it to him anyway). She just raised her hands in the air, exasperated at the final question.*

*Field notes*

Moreover, despite reading the participant information sheet and discussing the study with a researcher, it appeared that several carers found the use of follow-up questionnaires repetitive. At least one carer did not understand the 6-month span of the study, or the need for follow-up, and withdrew from the study after the first follow-up.

### **Completion of outcome measures by care home staff**

In total, we recruited 50 care staff over six care homes, with 45 retained until the 6-month follow-up (see *Appendix 1, Table 54*).

*Table 55* (see *Appendix 1*) shows the completion rates for the three measures care home staff were asked to complete at baseline and three follow-up points.

All three measures – the ADQ, the PDQ and the CBI – were self-completion questionnaires, but when possible a researcher sat with staff members as they filled them in, in order to answer any questions they had and to receive any feedback.

As with some of the family carers, a misconception among some staff was that completion of the measures was a one-off task (despite the researchers talking through information sheets that explained otherwise). Therefore, when it came to the first follow-up a number of staff members commented that they had already completed the measures – implying that there was no need to do this again. Others were concerned (again, despite assurances to the contrary in the information sheets) that the information they provided would reach their managers or higher in the care home provider organisation, and be used in performance management.

Hospital staff did not raise these sorts of concerns. This difference perhaps reflects the limited exposure that care home staff have to research, compared with that of hospital staff. Care home staff seemed generally more suspicious of the research process, and they were less likely to accept the associated reassurances involved. There was also a more limited understanding of research processes, such as in one notable example when a staff member completed one of the measures 'on behalf' of her colleague (who was busy), despite this being an attitudinal questionnaire and thus unique to the individual.

The shift patterns and busy work schedules of care home staff made follow-up particularly tricky and accounts for much of the loss to follow-up in this group. If staff who signed up to the project were not available when researchers visited to collect follow-up data, there was little option other than to leave packs for individuals to self-complete and return in the pre-paid envelope provided. However, this was an unsuccessful approach: very few packs were returned, even when researchers had handed them to staff in person.

In response to the poor rates of follow-up by month 2 in most sites, the team decided to write to each care home, enclosing packs for each of the members of staff who had not completed follow-up, asking participants if they would like remain in the study and, if they did, to complete and return the enclosed questionnaires. This was also unsuccessful: only three participants responded to the letter, and another one after the final follow-up, across all six care homes.

### **Completion of outcome measures by hospital staff**

Cross-sectional data were collected from staff working on the wards at three time points. There are no withdrawal rates for this group, as recruitment was done each time afresh; all staff on the wards on the day of the research visit were approached for consent and all staff who consented completed the measures. Some staff thus completed the measures more than once, if they happened also to be on duty on a subsequent visit of the researchers. When this happened, we calculated average values for their repeated measures.

As with the family carers in the care home study, staff did not always like the questionnaires and had much to say about their acceptability and relevance. The wording of the questions was described as 'extreme', 'horrible' and 'shocking'. One manager noted that the questionnaires were 'a bit simplistic for staff at this level on a specialist dementia ward':

*[He said the measures] seem to be aimed at agency staff, or staff on generic medical wards, or possibly unqualified staff. You would hope that anyone with those sorts of attitudes is rooted out before they get to a ward like this. Nurse filling in questionnaires at the same time agreed.*

*Field notes, IW3*

Members of staff also noted that many of the answers depended on the situation, and in some cases felt that they could not answer them at all:

*Decided to leave question number 16 on Personhood in Dementia questionnaire blank – said that sometimes if people can become quite vocal when they are agitated and may benefit from some one-to-one time with staff, which also gives other residents a bit of respite if the person is making a lot of noise, but this is different from isolating people.*

*Field notes, IW3*

Other staff expressed similar reservations about this particular question (and others):

*She also commented on the questionnaire about personhood that some of the questions are 'horrible'. Commented on Q16 – didn't like the wording so put strongly disagree, but said that she does think that sometimes it's in people's best interests to spend some time on their own (i.e. it was the wording that made her strongly disagree, not the content of the question).*

*Field notes, IW2*

Several people commented that the questionnaires lumped everyone together, whereas people with dementia can be very different, with some responding well to a strict routine, for example, and others not.

## Analysis

All of the data were recorded initially in Excel spreadsheets and then prepared for analysis and imported into SPSS version 22. Where instructions were provided for calculating overall scores and subscale scores, these were embedded in the Excel spreadsheet, with the exception of DEMQOL, which has separate SPSS instruction files for conversion and for imputation of missing values.

Once prepared and entered into SPSS, the data were tested for normality. When normal distributions were evident, we used paired *t*-tests to examine change over time in the care home participants and, when appropriate, in the hospital participants. We also used simple independent sample *t*-tests to examine differences in staff morale and attitudes between the comparison and intervention wards. When normality was not evident, appropriate non-parametric tests were used.

For most measures, we did not have data for baseline and all follow-up points. Where this was so, cases were omitted from the analysis on a case-wise rather than list-wise basis. This enabled us to make the most use of the valuable data that we had managed to collect.

## Quality of life for the person with dementia

### QoL-AD measure

The QoL – AD produced the largest amount of usable data on QoL for the person with dementia.

Because the person with dementia did not always answer all questions, and because some questions were not relevant to people living in care homes (e.g. ability to do chores around the home), we converted total QoL-AD scores into an average, using the number of completed questions as the denominator, and then scaled the score back up. Given that the QoL-AD produces a simple additive total score, we felt that this was acceptable and, again, this allowed us to use all of the data we had collected rather than discarding large numbers of questionnaires that had missing data.

Higher scores indicate better QoL (with total scores ranging from 13 to 52). Negative mean differences, therefore, indicate improvement.

### QoL-AD proxy in care homes

Paired data were available from 23 carers at baseline and first follow-up, 21 at baseline and second follow-up and 19 at baseline and third follow-up. These data were not normally distributed.

Median score at baseline was 26.5, at first follow-up 25.5, at second follow-up 24.5 and at third follow-up 25.0. The Wilcoxon signed-rank test for related samples showed no significant changes between baseline and any follow-up point.

### QoL-AD completed by person with dementia in care home

Paired data were available for 23 people with dementia at baseline and first follow-up, 23 at baseline and second follow-up and 18 at baseline and third follow-up.

The first thing to note is the higher average scores reported by people with dementia than by the proxies. The mean score was 37.22 at baseline, 35.94 at first follow-up, 35.82 at second follow-up and 35.79 at third follow-up. The data were also normally distributed, which allowed us to use *t*-tests.



Although the mean scores showed slight deterioration over time in QoL as reported by people with dementia, *t*-tests showed no significant changes. Between baseline and first follow-up, the mean difference was 1.27 ( $t = 1.12$ ,  $df = 22$ ;  $p = 0.274$ ); between baseline and second follow-up it was 1.91 ( $t = 1.01$ ,  $df = 22$ ;  $p = 0.324$ ); and between baseline and third follow-up it was 0.89 ( $t = 1.15$ ,  $df = 17$ ;  $p = 0.266$ ).

### ***QoL-AD in hospital wards***

There were proxy QoL-AD data for only one person in the control ward and only baseline data provided by two people with dementia themselves, so we could not make the planned direct comparison here. We therefore looked at change over time only for the respondents in the intervention wards when a family member had completed the proxy measure.

Numbers were small: seven proxy measures at baseline and first follow-up, six at baseline and final follow-up, and none with data at all time points. There were no follow-up data for the intervention wards from people with dementia themselves.

No differences were evident in the proxy data between baseline and any of the follow-up stages.

### **Dementia quality of life measure (DEMQOL)**

DEMQOL allows the imputation of missing values when at least half the questions are answered, and provides SPSS instructions for doing so. Despite this, we could calculate overall DEMQOL scores for only a few people with dementia. Data collection was somewhat more successful when carers completed the proxy DEMQOL.

Higher values of the total DEMQOL score indicate higher QoL. Negative mean differences thus indicate improvement.

### ***DEMQOL proxy in care homes***

We had paired data for 18 people at baseline and first follow-up, for 17 at baseline and second follow-up and for 13 at baseline and third follow-up. Minimal differences were evident between baseline and first follow-up (mean difference = 0.77;  $t = 0.25$ ,  $df = 18$ ;  $p = 0.804$ ) and between baseline and third follow-up (mean difference = -0.19;  $t = -0.06$ ,  $df = 13$ ;  $p = 0.952$ ). There was a larger difference between baseline and second follow-up but this was not statistically significant (mean difference = 5.83;  $t = 1.36$ ,  $df = 17$ ;  $p = 0.192$ ).

### ***DEMQOL completed by person with dementia in care homes***

We had enough data to calculate overall DEMQOL scores for 12 people at baseline and for each set of follow-up comparisons. Analysis suggested a small improvement in QoL over time, such that by the third follow-up the difference from baseline reached statistical significance. The mean difference between baseline and first follow-up was 0.99 ( $t = 0.330$ ,  $df = 11$ ;  $p = 0.747$ ), between baseline and second follow-up was -1.57 ( $t = -0.527$ ,  $df = 11$ ;  $p = 0.609$ ) and between baseline and third follow-up was -5.96 ( $t = -2.328$ ,  $df = 11$ ;  $p = 0.04$ ).

We reran the analysis solely for the 10 people with dementia who had DEMQOL scores at baseline and all three follow-up points. This showed a similar pattern, with an improvement between baseline and third follow-up but this did not reach statistical significance (mean difference = -5.44;  $t = -1.775$ ,  $df = 9$ ;  $p = 0.110$ ).

### ***DEMQOL proxy in hospital wards***

There were paired data for DEMQOL proxy in the control hospital for only one case.

In the intervention hospital, there were paired data for five people between baseline and first follow-up and for six people between baseline and final follow-up. There were only very small differences between baseline and any of the follow-up points and none was statistically significant.

### ***DEMQOL completed by person with dementia in hospital wards***

One person completed enough of DEMQOL at baseline to calculate an overall score, but did not complete any follow-up.

### ***Quality of relationships for the person with dementia and their family carers***

The QCPR measure generates two subscale scores: a positive subscale based on warmth and affection in the relationship and a negative subscale based on conflict and criticism. The latter is deducted from the former to give an overall measure of the quality of the relationship. A higher score on the positive scale indicates positive relationships and a higher score on the negative scale indicates negative relationships.

## **QCPR**

### ***Quality of relationships in care homes***

Only small numbers of people with dementia generated data on both subscales at baseline and any follow-up point; *t*-tests showed no differences from baseline to any point of follow-up, on either subscale or on the total.

We had paired data for 22 carers from baseline to first follow-up, 18 from baseline to second follow-up and 18 from baseline to third follow-up. *t*-Tests showed no differences from baseline to any point of follow-up, on either subscale or on the total.

### ***Quality of relationships in hospital wards***

There were insufficient data collected from control wards to analyse effect on quality of relationships.

Data from family members in the intervention wards (six at baseline and first follow-up, and five at baseline and final follow-up) were analysed. *t*-Tests showed no differences from baseline to any point of follow-up, on either subscale or on the total.

## ***Staff burnout***

### **CBI measure**

The CBI measure has three subscales: work-related burnout, personal burnout and client-related burnout. In all cases, higher scores indicate higher levels of burnout. Negative mean differences thus indicate a negative outcome (higher mean burnout at follow-up).

In care homes, the intention was to track change in burnout for individual members of staff before and after LSW was introduced to the care setting. In the hospital wards, with the different research design, the intention was to ask whichever members of staff were available at a given point to complete the measure in order to assess the overall morale of the workplace. The underlying hypothesis was that we might expect better overall morale in the intervention wards because they used LSW.

### ***Staff burnout in care homes***

We had paired data for 26 members of staff for baseline and first follow-up, for 17 for baseline and second follow-up and for 15 for baseline and third follow-up.

None of the paired *t*-tests showed any difference between baseline and any follow-up point on any of the subscales.



***Staff burnout in hospital wards***

Nineteen staff in the control hospital and 63 staff in the intervention hospital contributed data to this analysis. There were no obvious differences between the two settings on any of the subscale mean scores.

***Attitudes to dementia*****ADQ measure**

The ADQ produces an overall score and two subscale scores: one that is said to reflect 'hope' and one that is said to reflect 'person-centredness'. The authors of the questionnaire state that 'it is hope that especially predicts staff behaviour e.g. engagement in social interaction with residents, involvement in purposeful activity and stimulation, and the quality of physical care interactions'.<sup>129</sup>

In all cases, higher scores indicate positive attitudes. Negative mean or median differences, thus, indicate improvement.

***ADQ in care homes***

There were paired data for 27 staff members at both baseline and first follow-up, for 17 at baseline and second follow-up and for 18 at baseline and third follow-up. Only seven members of staff completed the measure at both baseline and all follow-up points.

Although the overall scores were normally distributed at baseline, first and second follow-up, they were not at third follow-up. Neither of the subscale scores was normally distributed at any point. We therefore carried out non-parametric analyses.

Analysis showed a statistically significant positive change in overall score between baseline and first follow-up (overall score median at baseline = 83, at first follow-up = 87; Wilcoxon signed-rank test  $z = -2.863$ ,  $p = 0.004$ ). Although overall median scores at second and third follow-up were also higher (improved) than at baseline (84 and 85, respectively), these values were not significantly different from baseline.

The difference between baseline and first follow-up appeared to be accounted for by an increase in the person-centred subscale, which also changed significantly between these points (person-centred subscale at baseline = 51, at first follow-up = 53; Wilcoxon signed-rank test  $z = -2.268$ ,  $p = 0.023$ ). There were no other significant changes in the person-centred subscale and none at all in the 'hope' subscale.

***ADQ in hospital wards***

We collected measures from 10 different staff members in the comparison wards and 47 staff members in the intervention wards. Analysis of median values in the two settings using the Mann-Whitney *U*-test showed no significant difference between them.

***Personhood in dementia*****PID measure**

The PDQ is a 20-item test of people's beliefs about personhood in dementia. Higher scores indicate more positive views; thus, negative mean or median differences indicate a positive outcome.

***PID in care homes***

Paired data were available for 21 staff members at baseline and first follow-up, and for 16 at both baseline and second follow-up and baseline and third follow-up. The data were not normally distributed, so we used non-parametric techniques to explore change between baseline and the three follow-up points.

The median score for all staff who completed a questionnaire was 130.5 at baseline, 134.0 at first follow-up, 135.5 at second follow-up and 136.5 at third follow-up, so showing a consistent improvement over time.

When paired data were analysed, these showed no significant change between baseline and first follow-up (Wilcoxon signed-rank test  $z = -0.435$ ,  $p = 0.664$ ) but significant change between baseline and second

follow-up (Wilcoxon signed-rank test  $z = -2.303$ ,  $p = 0.021$ ). Although third follow-up continued in the same positive direction, the difference from baseline did not reach statistical significance (Wilcoxon signed-rank test  $z = -1.527$ ,  $p = 0.127$ ).

### ***PID in hospital wards***

In total, we had completed measures for 13 different staff in the comparison wards and 40 staff in the intervention wards. Again, the data were not normally distributed.

There were no differences between the two settings in their median scores.

## ***Carers' experiences***

### **CES**

The CES assesses a range of issues for family carers or others who provide support to the person with dementia. It covers the extent to which carers feel that they can carry out activities outside caring, the support they receive from others in their network and from statutory organisations, the fulfilment they get from caring, the amount of control that they feel they have over caring and how well they get on with the person they are supporting.

Higher scores indicate better experiences; therefore, negative mean differences indicate positive change between baseline and follow-up.

### ***CES in care homes***

There were data for 23 carers at baseline and first follow-up, for 19 carers at baseline and second follow-up and for 14 carers at baseline and third follow-up.

The data were not normally distributed at baseline, but were at all three follow-up points. Visual inspection of the baseline normality plots suggested that the variation from normality was within tolerable limits, but we carried out both parametric and non-parametric tests to ensure robustness.

Both the  $t$ -tests and the Wilcoxon signed-rank test suggested that there was a significant deterioration in carers' experience between baseline and first follow-up [mean difference = 6.547, 95% confidence interval (CI) 1.08 to 12.015;  $t = 2.484$ ,  $df = 22$ ;  $p = 0.021$ ; Wilcoxon signed-rank test  $z = -2.128$ ,  $p = 0.033$ ].

The  $t$ -tests also showed a difference between baseline and second follow-up that approached conventional levels of significance (mean difference = 7.206, 95% CI -0.175 to 14.587;  $t = 2.051$ ,  $df = 18$ ;  $p = 0.055$ ), although this was not replicated in the non-parametric analysis (Wilcoxon signed-rank test  $z = -1.587$ ,  $p = 0.113$ ). Neither type of test showed any significant difference between baseline and third follow-up, although in both cases the deterioration in carers' experience scores continued.

### ***CES in hospital wards***

There were data for 7 of the 10 carers at baseline and first follow-up, and for five at baseline and final follow-up (at both follow-ups, only one carer was in the comparison ward group). Our analysis is thus confined here to carers of people who were in the intervention wards.

The mean difference in scores showed no change in carers' experiences between baseline and first follow-up. However, there was a large and significant improvement in their experience between baseline and final follow-up (mean difference = -14.58, 95% CI -26.24 to -2.92;  $t = -3.47$ ,  $df = 4$ ;  $p = 0.026$ ).

This was in contrast to the results for carers of people with dementia in care homes and may well reflect the acute nature of the person with dementia's condition when they were admitted to hospital.



# Chapter 8 The costs of life story work

## Introduction

The aim of this element of the project was to investigate the potential costs of using LSW in specialist inpatient and residential care settings by identifying and measuring relevant resource inputs, and valuing them by applying local or national unit costs.<sup>142–144</sup> We hoped to establish the size of organisations' investments in LSW, the potential for savings from reductions in the use of other health and social care resources, and the main drivers of costs.

We also aimed to test the feasibility of different methods of collecting resource-use data, using both routine records and specially designed data collection forms for completion by staff.

## Methods

Focus groups and meetings with staff from the sites identified the resources that staff felt were particularly important and specific to developing and using LSW (such as training in LSW, developing and using life stories, and physical resources for creating products), as well as potential areas for resource saving (service use, adverse incidents and prescribing).

The hospital intervention wards and care homes were issued with paper log-sheets to record the time that staff, family carers and volunteers spent working on LSW and using it with patients and residents. The log-sheets also included a section to record the materials and equipment used.

Data collection forms based on the Client Socio-Demographic and Service Receipt Inventory (CSDSRI)<sup>145</sup> were used to collect resource-use data. Care home staff completed these from care records. In the intervention wards, an on-site research team provided additional support for data collection; in the comparison ward, the local trials unit collected data.

The same teams collected ward-level data from routine records about staff sickness and turnover, prescribing and falls or other incidents. At the care homes, the business manager provided this information. The format of this data request was left deliberately open to assess which data were available and in what formats, and therefore what data would be feasible to collect in a formal evaluation.

## Challenges of data collection

This section describes the challenges of data collection and the feasibility of collecting similar data using these methods in a large evaluation.

## Training in life story work

One trainer (the dementia care consultant for the care home provider) was responsible for developing and delivering the LSW training in the six care homes. She provided information on the time spent developing, organising and delivering the training. Five of the six care homes provided information on the members of staff who attended the training and their approximate salary levels.

Hospital intervention wards routinely used LSW and so training was not necessary.

## *Development and use of life stories, and materials used*

### **Care homes**

All staff were asked to log the time they spent on LSW with each participant. This included time spent with the resident/patient creating and using the life story, as well as time spent creating the life story while the resident/patient was not present, for example sticking photographs into a booklet. Time spent by all staff members as well as by volunteers, students and residents' family members should have been included.

The LSW log-sheets for care homes were completed with few problems in three care homes. However, it was not usually possible to tell whether LSW required additional resources or the redirection of existing resources; sometimes, life story information was collected or discussed during a meal time or other routine activity. The information collected was useful in shedding light on how LSW was used as part of routine care, but not in identifying additional, LSW-specific resource use.

The person who co-ordinated, and in most cases carried out, the majority of the LSW completed the logs in these three care homes, even when recording another person's time spent working on the life stories. We originally anticipated that the logs would be kept in residents' care records and be completed by whichever staff members engaged in LSW. However, in each care home one member of staff took responsibility for the LSW, and kept the logs with the products as they were made. This staff member kept the products until they were 'finished' and given to the resident. Had residents been more involved in the LSW process, and the product kept in their room while it was in progress, keeping the log in their care records might have been more practical.

The majority of the activity recorded on the LSW logs related to the collection of life story information and the construction of life story products. However, life story 'work' also covers the use of the life story to improve care and QoL. This is much harder to capture and might arguably involve a wide range of people. Were the life story products used to trigger conversations with previously unresponsive residents, for example, or to understand why a person exhibited behaviour that challenged? There was little evidence of this type of use of the life story in the logs (or the reporting of adverse incidents and challenging behaviour) but staff did identify this use as important in the end of study focus groups (see *Chapter 9*). We cannot assume, therefore, that the life stories were not used in this way. To capture this routine use of LSW in everyday care, a different approach may be required, such as observation or ethnographic methods.

Life story work logs were not completed at all in the two care homes that did very little LSW and where no single individual took responsibility for it. In the final care home, the activities co-ordinator reported that extensive LSW logs were completed not just for study participants but for all care home residents, for the first 2 weeks of the study. After this, the logs were considered too time-consuming. None was provided to the research team.

### **Hospital wards (intervention wards only)**

Completed LSW logs were received from one of the three intervention wards. In this ward, three OTTIs took responsibility for LSW, although they were not based on the ward continuously. One OTTI completed the logs but covered the activities of all three. The OTTI explained that the logs did not capture any LSW activity undertaken by nursing or other ward staff. For example, ward staff routinely used life story information to put patients at ease while they were providing personal care, or for 'de-escalation' (i.e. calming or distracting a person when they became agitated, without recourse to medication).

Thus, LSW logs were missing from two intervention wards and those that were returned did not capture all use of the life story for all staff.

## Service use, adverse incidents and challenging behaviour

### Care homes

At baseline, a researcher and member of care staff together completed the data collection forms for service use, challenging behaviour and adverse incidents, with the staff member navigating participants' care records and the researcher entering information into the forms. However, this process was labour intensive (taking two people up to half an hour to collect data for each participant). The research team concluded that it would not be feasible to employ this approach in a full trial.

For the follow-up data collection, we issued the forms to care homes in advance and asked them to enter the information without the researcher's support. This resulted in some inconsistent and incomplete data collection. In some cases, the dates of incidents were outside the requested period, despite the dates of the follow-up period being pre-printed on the form. One possible reason for this is that care records were on paper in ring binders, which can be difficult to navigate.

Some adverse incidents and episodes of behaviour that challenges were recorded in separate sections of the care records, while others were recorded in the 'daily records', which were lengthy and not always filed in date order. Care staff would thus have found providing complete and accurate data very time-consuming. Without appropriate training and ring-fenced time, it is unlikely that care home staff could provide data for a full evaluation. If researchers were to collect these data without the support of care staff, ethical approval for unsupervised access to care records would be needed and explicitly agreed to by participants or their consultees.

### Hospital wards

For intervention wards, the trust's central research team offered to provide data on service use, adverse incidents and challenging behaviour. Data collection forms were converted to Excel spreadsheets in accordance with the team's preferences. Despite the small numbers of patients with dementia recruited to the study from each ward, it proved labour intensive to collect the required data. Indeed, the process highlighted issues with record keeping that this NHS trust is now looking to address.

As with the care homes, incidents and behaviour that challenges were usually entered only in the patients' daily care records (which in the intervention wards were paper records) rather than being reported separately. The trust's research team searched through large quantities of paper records. For one patient they found over 250 entries of behaviour that challenged; they entered every incident onto the spreadsheet, but this was time-consuming and clearly would not be feasible with a larger number of participants.

The trials unit covering the comparison ward found it easier to gather the information requested, as their records were electronic and could be accessed remotely. However, it was still time-consuming to collect the information, with at least three entries per participant per day.

The intervention wards used a 25-point challenging behaviour scale to identify incidents,<sup>146</sup> which might mean that they considered a wider range of incidents than the comparison ward. In a full trial it would be important to standardise the data collected.

We planned to collect data on service use, falls/other incidents and behaviour that challenges for 6 months after admission. When patients were discharged before 6 months, we tried to collect data from the care home or other discharge destination. This proved difficult, perhaps because the research team had no prior relationship with these organisations and they were not engaged with the project (see *Chapter 6*). Follow-up data were provided by only one of these organisations: the one the researcher visited in person.

## *Prescribed medication*

### **Care homes**

We developed a list of relevant antipsychotic, anxiety, hypnotic and antidepressant medications, in consultation with the care home provider, the project advisory group and a general practitioner (GP). The list was intended to represent medications that might be prescribed differently as a result of LSW. We designed a data collection form so that data could be collected from care home medical administration record sheets and then coded.

Care home managers anticipated that collecting these data would be time-consuming, as multiple paper records (which were stored separately from the care record files) would need to be retrieved for each participant. To minimise disruption, in one home the researcher agreed to collect data on baseline and follow-up medication use on a single day, at the 6-month follow-up visit. However, many medical administration record sheets had been archived and were not easily located.

In five care homes, on-site staff located the medical administration record sheets and extracted the data themselves. However, the results were variable, with forms not returned for all participants, those that were returned having gaps in the dates covered and/or entries made for medications not on the list of relevant medications. Again, it does not appear to be feasible to expect care staff to provide this type of data without training and ring-fenced time.

### **Hospital wards**

The hospital sites were asked to report all medication, both routine and as required (PRN), during the patient's stay on the ward. At the comparison trust this information was recorded electronically. Although it was easier to access data here than in the care homes, extraction and reporting took considerable time.

Medication for anxiety and depression (including antipsychotics) was also reported on the incident sheets. For the intervention wards, data on prescribed medication were provided as part of the incident reporting.

## *Care-home- and ward-level data*

All study care homes and wards were asked to provide data about staff sickness and turnover, prescribing rates and incidents at care home or ward level. The purpose was to explore the feasibility of collecting these data, as well as to understand any impacts of LSW on the care home or ward and vice versa.

### **Care homes**

We asked the six care homes to provide data for the whole care home for the 6 months from baseline. We did not suggest how this should be done; rather, we were interested in understanding how these records were kept and their accessibility. By the end of the fieldwork period (January 2015), one care home had provided all of the information requested, another had provided details of staff sickness and a third had given information on prescribing. Data were provided on staff sickness as number of hours per month, on prescribing as number of residents receiving named antipsychotic drugs and on incidents as total recorded incidents including falls.

### **Hospital wards**

The control ward provided details of staff sickness and turnover, and incidents, but not prescribing. Data on sickness were provided as number of days over the 6-month period, and incidents as number of falls and number of other incidents.

All three intervention wards provided data on staff sickness, prescribing and falls, and one ward provided data on staff turnover. Staff sickness was reported as percentage of staff off sick over the 6-month period, to comply with the NHS trust reporting requirements for monitoring target sickness levels, and could not easily be reported as number of days. Data were provided on falls but not on other incidents. This was

because not all behaviour that challenges was recorded as an incident, for example if such behaviour was 'usual' for that patient.

## Results

This section presents the costs associated with training in LSW; developing and using LSW products; numbers of adverse incidents and behaviour that challenges; use of the NHS and other services; and use of prescribed medication.

### *Development and delivery costs of life story work training (care homes only)*

The development of LSW training materials by the dementia care consultant took the equivalent of 1 working day, and a further day was spent developing the training sessions for care homes. There was no refresher training during the study period, although telephone support was available if required. The one-off costs for this activity ranged from £421 to £765, depending on the assumptions made about staff salary costs (see *Appendix 1, Table 56*).

All care homes received the training. Each training session lasted 2 hours and was repeated on consecutive days to ensure that as many staff as possible attended. Five care homes provided details of the staff members who attended the sessions and their approximate hourly wage rates. Sessions were attended by a variety of staff, including National Vocational Qualification-qualified and -unqualified care assistants; activity co-ordinators; team leaders; and non-care staff including a laundry worker, a chef and a housekeeper (see *Appendix 1, Table 57*).

The cost of receiving the training in a care home ranged from £950 to £1581, based on different assumptions about hourly rates (see *Appendix 1, Table 58*). The mean based on actual salary costs only was £1065; that based on unit costs per hour (including all overheads) of comparable staff<sup>142</sup> was £1449.

### *Costs of developing and using life story products*

This section describes the costs associated with staff developing and using the life story in care homes and hospital wards.

Logs were completed, at least in part, for 17 study participants (11 care home residents from three care homes and six hospital patients from one ward) and for an average of 80 days (approximately 11 weeks, range 13 days to 27 weeks). In care homes, they were completed for longer, on average, than in the hospital ward (16 weeks and 3 weeks, respectively). This may be because participants on the hospital ward were there temporarily, whereas participants in the care homes lived there, or because researchers visited care homes for multiple follow-ups and were therefore more visible to staff. As outlined above, the logs in the hospital setting were completed by an OTTI who was not based on the ward itself but who had dedicated time to do LSW.

The average number of hours spent on LSW per participant (including creating and using the life story) over the periods logged was 6.5 hours (6.7 hours in care homes and 6.1 hours in the hospital ward). In the care homes, the main member of staff involved in LSW, according to the logs, was the activity co-ordinator (or another staff member carrying out that role), who spent, on average, 4.1 hours on LSW per participant over the logged period. In the hospital ward the OTTI spent 6 hours per patient on average.

In one care home, care workers were involved in LSW with two residents, for half an hour and 1 hour, respectively. In the hospital ward, a nursing assistant was involved for 1 hour with one patient.



Occasionally in the care homes, a volunteer or student would be involved with LSW; for the five residents they were involved with, they spent on average 1.7 hours per resident. No volunteer or student involvement in LSW was recorded in the hospital ward.

Family members were also sometimes involved, more commonly in the hospital ward (5/6 patients compared with 6/11 residents), but with a similar average time of just over 1 hour per person across the logged periods.

Adjusting the averages to reflect the length of time over which LSW activity was logged revealed that the average time per week staff spent on LSW with residents of the care homes was 24 minutes, compared with 2 hours in the hospital ward. In addition, residents' families were involved for 6 minutes per week, on average, compared with 24 minutes per week for hospital patients.

Some logs clearly indicated how much time staff spent physically creating the life story product (such as a scrapbook or memory box), whereas others did not. From the limited information available, staff in the hospital ward spent considerably longer on creating the life story product (e.g. scanning photographs or searching for relevant pictures on the internet, and sticking photographs into a scrapbook) than care home staff. In the ward, staff spent on average a total of 3.3 hours creating the product, whereas care home staff spent 1.3 hours, possibly reflecting the dedicated time that staff doing LSW on the ward had for this activity, as a part of their usual role.

When converted into hours per week, ward staff spent just over 1 hour and care home staff, on average, spent just over 5 minutes per week creating the life story product. This difference arises in part because patients spent less time on the ward and so the time spent on creating the life story product is averaged over a shorter time period than for care home residents. Life story products created in hospital may be used after discharge (so the 'payback' from the initial time investment could be spread over a longer time period) but we did not collect these data in this study.

The average costs (Table 7) show that creating and using LSW was not an expensive activity in terms of overall monetary costs, but the intensive activity to create the product on the ward, presumably to complete it before the patient was discharged, might have substantial opportunity costs. However, on the ward LSW was done by staff based in another team, with dedicated time for LSW and a remit to do this as part of their usual routine.

### **Changes in the number of adverse incidents and challenging behaviour**

We received data on adverse incidents or behaviour that challenges for 32 residents from five care homes, and for three patients from the control ward and eight patients from three intervention wards.

**TABLE 7** Average staff costs of doing LSW in care homes and hospital ward

Type of cost <sup>a</sup>	Care homes (£)	Hospital ward (£)	All (£)
Cost of creating life story products			
Staff cost per participant	10.63	36.95	22.59
Staff hours per week per participant	Just over 1 hour	Just over 5 minutes	–
Cost of using LSW			
Staff cost per participant	37.42	68.21	48.29
Staff cost per participant per week	9.40	22.60	14.06
<sup>a</sup> All costs are salary only.			

## Care homes

Incidents and examples of logged behaviour in the care homes included falls; residents being agitated, distressed or unsettled; verbal abuse of other residents or staff; shouting; slapping, pushing or biting another resident or member of staff; unco-operativeness with care or refusing to take medication; and taking items from other residents/flats.

The highest number of incidents reported in any 3-month period for one resident was 18. The data are based on only 32 residents, but appear to suggest a decrease in the number of residents with one or more reported incidents over the 3-month data collection period (see *Appendix 1, Table 59*).

## Hospital wards

In the hospital control ward, the number of incidents per patient was recorded over approximately 6 months. In the three intervention wards, the number of incidents per patient was recorded over, on average, 12 weeks.

Data were reported for three patients from the control ward and for one, four and three patients from the three intervention wards (see *Appendix 1, Table 60*). The types of incidents were similar to those in the care homes except for falls; only one fall was recorded in the control ward and three were recorded in the intervention wards. The highest number of incidents reported for a single patient was 255 over 16 weeks.

## Changes in use of the NHS and other services

### Care homes

We received data for 38 residents from six care homes about the use of the NHS and social care services, residents' trips out with family and safeguarding referrals. These are reported as totals across all care homes to give an indication of the size of any changes.

*Table 61* (see *Appendix 1*) shows there were very few hospital admissions either before or after the implementation of LSW. *Table 62* (see *Appendix 1*) shows that there were fewer reported attendances at hospital outpatient services after than before implementation of LSW. *Table 63* (see *Appendix 1*) shows that there was little difference before and after implementation of LSW in the number of telephone calls to participants' GPs for advice or to the NHS 111 service.

*Table 64* (see *Appendix 1*) gives the number of appointments that primary care and community-based health and social care professionals attended at the care homes. GPs and district nurses undertook the most appointments. Except for the dietitians, the number of visits by all staff, particularly GPs, reduced during the follow-up period.

*Table 65* (see *Appendix 1*) shows the number of visits study participants made to the GP and other professionals outside the care home, and trips out with family or friends. There were no attendances at day centres (NHS, local council, for profit or not for profit). The number of trips out with family or friends appeared to increase after the implementation of LSW.

Data were collected on the number of safeguarding referrals made. One initial report was completed in the baseline period and one in the follow-up. There were no investigations and no visits from the local council safeguarding teams and the Care Quality Commission was not informed of any incidents.

### Hospital wards

*Tables 66 and 67* (see *Appendix 1*) show the number and types of services received on the wards and as outpatient/day cases, respectively, for the 11 patients in the study. Two patients moved temporarily from the control ward to another ward in the same hospital (one for 3 weeks and the other for 4 weeks). The most commonly used service was occupational therapy. Patients received art and music therapy on the control ward only.

No patient in either the control or intervention wards was reported to have used any community-based services during their hospital stay.

### *Prescribed medication use*

#### **Care homes**

The use of prescribed medications for anxiety and depression was reported for 27 residents from six care homes at baseline and for 23 residents from five care homes at follow-up (see *Appendix 1, Table 68*). Antipsychotic medication was reported to have been prescribed twice during the baseline and three times during the follow-up period. Hypnotics and antidepressants were prescribed 15 times at baseline and 13 times at follow-up. For the majority, the date on which the drug was first prescribed was provided, but the end date was not; this suggests that most were being taken on an ongoing basis rather than PRN. None was specifically stated as PRN.

Data were collected on the strength and dose of each drug prescribed, with the intention of applying a monetary value to drug use before and after LSW implementation.<sup>143</sup> However, given the overall low usage and minimal difference between the two data collection periods, drug use does not appear to have been a main driver of LSW-related costs in these care homes. Drug use for individual residents has, therefore, not been valued. These care homes may not, however, be typical of all homes.

#### **Hospital wards**

In the hospital wards, details about the use of medication were extracted from data on reported incidents. In the control wards, PRN medication for anxiety and depression was given 67 times over the total of 72 weeks the three patients stayed on the ward. In the intervention wards, PRN medication was prescribed 97 times over a total of 94 patient-weeks. PRN medication for anxiety and depression was therefore prescribed approximately once per patient week in both control and intervention wards. Antipsychotic medication was prescribed PRN more often in the control ward (see *Appendix 1, Table 69*). However, these data are based on very small numbers of patients and are not generalisable. Medication was also given on an ongoing basis (see *Appendix 1, Table 70*).

It is not clear from the data whether few patients were prescribed medication for anxiety and depression on a regular basis or whether these data were not reported consistently.

### *Care-home- and ward-level impact*

Partial care-home-wide and ward-level data on staff sickness and turnover, prescribing and incidents were received from three care homes, the control ward and the three intervention wards.

In two care homes, staff sick leave over the 6-month period following LSW training was the equivalent of 200 days in one care home and 103 days in the other (assuming 7.5 hours worked per day). In the control ward over an equivalent 6-month period, staff were off sick for 285 days. The data for the three intervention wards were provided as the percentages of staff off sick over a 6-month period; these were 5.6%, 5.3% and 6.8%. Given the different sizes and staff make-up of the wards, it is not possible to translate these percentages into days or hours.

One care home provided data on staff turnover in the 6 months following LSW training; eight staff left and nine were appointed. In the control ward, four staff left and four were appointed. Only one intervention ward provided data on staff turnover where, in a full year, four staff left and eight were appointed.

One home, the control ward and three intervention wards provided data on falls and incidents. There were 51 reported incidents (including falls) in the care home. In the control ward, 31 incidents (including falls) resulted in patient injuries; a further 21 were attacks on staff or other patients. In the three intervention wards, there were 43, 49 and 27 falls, with six resulting in significant or serious injury.

Two care homes provided data on the number of residents prescribed antipsychotic drugs across the whole home. Two residents were prescribed antipsychotic drugs in one home and 12 were prescribed them in the other (a SCH). In the latter, this included one resident prescribed PRN; the remainder were prescribed on a regular basis.

No data were available from the control ward.

In the intervention wards, six antipsychotic drugs were prescribed to be taken on a regular basis at a cost of £269.29, £417.07 and £1332.69, respectively. By far the most costly regular medication was aripiprazole, at £214.36, £264.12 and £926.35, respectively. The relatively high cost of regularly prescribed antipsychotic drugs on the third ward may be related to its geographical location, which covers a number of SCHs. Staff attitudes may also play a role, according to the person providing the data, with staff on this ward more comfortable about using antipsychotic medication. Five antipsychotic drugs were prescribed to be taken orally, PRN, at a cost per ward of £28.52, £58.97 and £22.60, respectively.

### **The costs of prescribed medication**

For the purposes of estimating the main drivers of costs in relation to medication, *Table 71* (see *Appendix 1*) gives the costs of packs of drugs for the dosages taken by participants in this study and the associated daily costs. The most expensive drugs when costed per day were amisulpride, quetiapine and venlafaxine; these drugs were taken on a continuous basis by one study participant each in the care homes (out of a total of 30 residents for whom we had data on medication). From the care-home-wide data, three people in two care homes had been taking quetiapine for > 3 months. At a cost of £7.54 per day, this equates to almost £700 each. A reduction in the use of these drugs as a result of LSW could, therefore, result in substantial savings.

For hospital ward participants, the most commonly prescribed drug was lorazepam, which has minimal cost. However, the ward-level data from the intervention wards show aripiprazole to be the most costly overall, at between £200 and £900 per ward over 6 months.



# Chapter 9 Doing life story work in care homes and hospitals: findings from qualitative interviews

## Introduction

This chapter reports the findings of in-depth, qualitative research carried out at the end of the feasibility study with people with dementia, carers and staff in both study settings. The aim was to assess how acceptable people with dementia, carers and staff found the LSW intervention, its implementation and the processes involved in evaluating its outcomes.

## Methods

### People with dementia

We collected qualitative information from 10 participants with dementia already consented into the study: nine in care homes and one in a hospital setting. Each had a life story product compiled as part of the project, in many cases made for them by someone else, usually a member of staff. We explored people's experiences of doing LSW and perceived outcomes and challenges, as well as their experiences of taking part in the research.

Sessions took place on the day of final follow-up. We held guided conversations, using the life story product as a starting point, supplemented by questions from a topic guide. We also took detailed field notes of the conversations and participants' reactions. Conversations were not audio recorded and took between 10 and 30 minutes.

### Carers

We interviewed 12 carers, eight whose family member was in a care home, and four whose family member was in intervention hospital wards. All had consented to take part in the study and their relatives had life story products compiled as part of the study. Carers were interviewed either in person (usually at the care home or hospital ward) or over the telephone, whichever they preferred. Interviews were audio recorded with the person's consent and took around 30–45 minutes.

### Staff

We conducted focus groups and interviews with staff in five of the six care homes, and all four hospital wards. *Table 72* (see *Appendix 1*) shows the number of sessions and participants for each site. A total of 30 staff were involved in this stage of the research.

We needed managers' permission to hold focus groups with staff, as they required the staff to be removed from their normal duties for the duration of the session. In some sites this was not possible, so we conducted individual interviews instead. In CH6, one key staff member was not available at the time of the focus group, so we conducted a separate interview with this participant.

## Analysis

Interviews and focus groups with carers and staff members were audio recorded and transcribed. Transcriptions, together with notes from conversations with people with dementia, were managed and coded using the framework approach<sup>111</sup> and analysed thematically.

## Findings

### People with dementia

Findings from people with dementia centre on their in-the-moment reactions to the life story product and its effectiveness as an aid to memory and interaction.

#### In-the-moment reactions to the life story product

Of the 10 people with dementia interviewed, only two recalled having any involvement in making the life story product, which may have contributed to a lack of a sense of ownership of the product. When asked to talk about his life story book, for example, one care home resident said 'I didn't do it, you'd better ask her [the member of staff who made it]' (RC3P01), and this was a sentiment expressed by others: 'it's just something they did, you know' (IH2P04). Some people gave a distinct sense of being underwhelmed – 'I read it once and then put it away' (RC3P01) – or said staff 'shouldn't have bothered' to make it (RC1P08).

Some of the people with dementia had not seen their life story book before looking through it with the researcher. Most had no recollection of making it, and some found this disconcerting (recognising photographs, for example, but not knowing how these had come to be there). Others were confused by the format of the book, or why certain things had been included. One book opened using an unusual mechanism which the person struggled to operate alone, while another person was unsure why there were heart shapes stuck onto her photographs, and one memory box contained birthday cards, which caused the participant to say, 'I didn't think it was my birthday' (RC3P06).

One person noted that the information in his book was wrong, and others felt that the book did not cover their whole lives, that there was more that they could have added: 'Well you've only seen the gist of my life in it, you know, it takes in my early days a bit. I have more photographs at home' (IH2P04).

However, several people with dementia did seem to enjoy looking at the life story product with us. For some, this was indicated non-verbally; for example, one woman who could not speak looked intently at each photograph for a long time while smiling broadly, and others expressed similar sentiments in different ways:

*Resident was happy and chatting generally, hard to make out words. Sometimes seemed to be talking about something relevant, for example when I said 'is this a picture of your dad?' she said 'he was the one . . . ' (but didn't finish the sentence) and said 'he was a lovely man' and laughed. Seemed happy, laughing and smiling, and talking to me.*

*Field notes, RC1P06*

Others were able to tell us how they felt: 'Had a long chat with [person with dementia] about his life story, prompted by his folder but continuing long after he had put it down. He said he had enjoyed talking to us about his life story' (field notes, RC4P03).

It is impossible to say to what extent this enjoyment was derived from the LSW itself, and how much from the opportunity for social interaction more generally. However, it was clear that the life story product did provide a hook for interaction.

## The life story product as an aid to memory and interaction

The presence of a life story product in some cases prompted memories of places, people and events:

RC1P08: *I remember them, yeah [referring to people in photographs].*

Researcher: *Would you have remembered without the book, do you think?*

RC1P08: *No, I don't think so.*

When people did not recognise people or places at first, captions and writing proved useful. In some cases, people with dementia could read the captions themselves, which then prompted them to talk further about the pictures. In other cases, we as researchers could read the captions or writing, and engage the person in a more detailed conversation than was possible without them. Even when photographs did not have captions, people were able to talk about them in some way, commenting on the clothes or appearance of the people in them, for example.

However, participants had mixed feelings about remembering the events and people depicted in their life stories. Some expressed sadness at recalling people who had died, or who they had lost contact with, but people also found it pleasurable to look back and see pictures of friends and family looking happy.

One woman appeared to enjoy looking at her book at the time, but staff reported that she later became upset, saying that the more recent information in the book was not true. Here, the life story book, although acting as an effective memory aid, appeared to highlight conflicts between the person's sense of reality and the memories recalled. Remembering, of itself, may not always be a positive outcome.

### Overall

Overall, people with dementia had little recollection of involvement in making their life story products, and this perhaps led to a lack of a sense of ownership. Looking at life story books could prompt some sad memories, but the in-the-moment interactions tended to be positive, and in many cases there was much smiling and laughing during the course of looking at the books. Although some might have felt underwhelmed by their life story book, a physical product has an important role to play in facilitating interactions, particularly with people who do not know the person with dementia well. However, there is the potential for confusion or distress if, for example, unfamiliar objects are included, or information is wrong or contradicts a person's understanding of their present reality.

### Carers

#### Doing and using life story work

Carers expressed mixed feelings about doing LSW. In many ways, it was seen as a positive experience for families: it was pleasant to remember happy times, and gathering stories and memories could build bonds between family members. Some carers found sharing life story information with others to be a positive experience; one described the process of writing her husband's life story after he was taken into hospital as 'cathartic', and how it gave her a sense of pride in his achievements:

*I think it was because I realised how much I knew of him and . . . I've always sort of been really proud of him, because he's achieved things, you know.*

IH1C01

However, some carers also expressed grief or sadness at the person no longer being 'the person we knew', or realising a sense of their relative's fragility.



Carers talked about the difficulty of involving their relatives in the process of doing LSW when the relatives could not talk, could not remember photographs or stories, or had no interest in looking back over their lives. Overall, however, carers seemed to be willing to be involved in the LSW process and pleased to be asked to be involved, as they considered it a worthwhile activity.

### Outcomes of life story work

Carers observed a range of outcomes of doing LSW. One of the most important benefits identified was that LSW could help staff understand the person with dementia, including elements of their past and more up-to-date information (e.g. about their current likes and dislikes). Part of this was preserving the identity of the person with dementia:

*You're never past it, are you, I guess, because there should always be an element of trying to keep some of that history for him even though he can't retain it himself; and still, I mean he's still the same person he just can't always tell us who he is.*

RC4C03

Another benefit observed by carers was the power of LSW (both the collection of information and a physical product) to facilitate conversations with both staff and visitors. This was felt to be particularly valuable in hospital wards, where temporary staff had no previous knowledge of the person. In such cases a memory board on a wall provided a valuable starting point for a conversation. For hospital patients who had been discharged and were now living in care homes, carers felt that having a life story product had played an important role in passing on information about the person and helping new staff to get to know them:

*I think that's very good because it's informative to them, you know, and it's good that they can talk to [person with dementia] then a bit; but it's not that she really understands, well none of us know how much she understands, you know, but at least they can talk to her about it and see if they get a response.*

IH2C11

In care homes, staff turnover was lower, and residents stayed for longer, so there was less need for quick access to life story information. Instead, carers felt that life story products were mostly used to facilitate conversations with them, as well as with grandchildren or less frequent visitors:

*There's another lady that comes to visit mum now and again and she, likes to get the box out and look at the pictures with her, so, you know, it's something else to do; 'cos mum can't speak any more, so I think people that don't know what to do are at a loss.*

RC4C06

One carer identified LSW as 'something to keep [mum] occupied' and several thought that their relative enjoyed looking through the life story product, and in some cases felt it even helped their relative to remember more: 'I didn't think mum got anything out of it, but as the days went on you would get names of people who she'd never mentioned before' (RC1C04).

Although carers identified these elements of LSW as of benefit to staff and carers themselves, they could also have distinct indirect benefits for the person with dementia, in terms of increased interaction and understanding and, possibly, more personalised care.

Some carers were not convinced that LSW had had any positive outcomes for their relative. Some reflected that relatives did not remember people in the photographs, or did not have any interest in looking at them, and therefore the benefits of doing LSW for the person with dementia was limited, although there may have been positive outcomes for other people.

## Challenges of using life story work

Some carers found it both time-consuming to find photographs and difficult to choose which pictures and stories to select. One said that receiving a list from a staff member including categories such as 'pictures from childhood' and 'pictures from work' had helped to narrow it down. Another carer, whose friend had dementia, found it particularly difficult to find information, as all of the person's relatives had died, and so 'there was nobody there to ask really' (IH2C11). Several carers found it frustrating when their relative could not remember events and people in photographs. Some also felt that doing LSW might be 'emotional' for the person with dementia, although this had not actually happened to any of the participants when doing LSW, and was based only on carers' past experiences of, for example, looking at family photographs.

Carers felt strongly that LSW should have been started much earlier. Depending on the person's circumstances, this might have been when they were admitted to the care home, or even when they were first diagnosed with dementia. This might have allowed the person with dementia to play a bigger role in putting the life story together, and given carers more time to collect information.

## Overall

Carers had mixed views about the benefits of LSW for people with dementia. Although some direct positive benefits were described, other carers felt that there was no benefit to people with dementia at all, as they could no longer recognise people in photographs.

However, positive benefits were identified for both family carers and staff working with people with dementia. Families enjoyed looking back at their photographs and memories, remembering positive things about their relatives' lives and reaffirming their relatives' identities. Carers felt that staff had benefited from knowing more about the lives of the people with dementia in their care, and could build relationships with them through doing and using LSW. Carers suggested the presence of a physical life story product both encouraged and facilitated interactions with both staff and visitors, particularly those not well known to the person with dementia, or who struggled to make conversation. This could lead to indirect benefits for the person with dementia themselves, through more interactions and perhaps more personalised care.

## Staff

### Doing life story work

The process of doing LSW differed between research settings, as discussed in *Chapter 6*. In both care homes and hospitals, some life story information was collected on the person's arrival (usually using a template), or soon after if they were unwell or the family was distressed. In some sites, more LSW was done later.

Staff usually attempted to collect information from the person with dementia themselves first, but explained that this could be difficult as people were often unable to recall details about their lives. Family involvement was, therefore, seen as important, although this was not always forthcoming.

In most sites, templates were used for the initial collecting of information. Some staff saw these as a useful starting point and a way of collecting the same information from everyone. Others felt them to be restrictive, lacking space for photographs or asking questions that were not always applicable, for example about a person's role during the war. In two care homes, activities co-ordinators set up a folder for each resident to enable all staff to collect life story information during their daily work. This was in addition to the use of templates.

Not all LSW in our care home and hospital sites resulted in the construction of a life story product. In some cases completed templates were considered to be a 'life story product'; however, in other sites further LSW was done and another, more personalised, product was made. On the ward with the OTIs, this usually took the form of both a book and a memory board. Books were A4 folders with typed information in plastic wallets, which could be added to if further information became available later. Memory boards were put on the walls in patients' rooms. In care homes, life story products included photo albums with captions, memory boxes, folders with written information and photographs, scrapbooks and, in one case, a memory blanket.

Completed templates were usually stored in a person's care records and, although theoretically people with dementia and their families could look at them, it was rare for anyone other than staff to do so. Where a more comprehensive life story product was developed, a staff member often kept this until it was 'finished', with families sometimes unaware that the product was being made. Once complete, it was then kept in the person's room and more usually used by both residents and families, and sometimes by staff who looked at it with the person.

### Outcomes of life story work

For people with dementia, staff described the emotional aspects of LSW, both good and bad. For some, LSW had provided an opportunity to 'open up' about aspects of their lives that they had previously been unable to talk about:

*I think she knew she was coming towards the end of her life and I think she just wanted to offload and tell people that, look, you know, I'm not really this person, this is really what I am . . . she broke her heart, but afterwards she said thank you.*

RC1FG1

Staff talked about people being proud of the achievements recorded in their life story books, and had observed people feeling valued because others were taking an interest in them.

Some staff also felt that doing LSW allowed them to tailor activities to residents' preferences, although they pointed out that it was important not to assume that people would still want to do the same activities they had done in the past. LSW had also uncovered opportunities for new activities, for example gardening.

Staff reported using life story products primarily for getting to know people better, but also for calming people down, understanding behaviour and problem solving. In the hospital ward that had made memory boards for patients' rooms, these were valued as communication aids for temporary staff in particular, giving them something to talk to the person about, which was seen as having value for the patient too:

*We take that information from the life story book and put it in a simple form on the wall . . . and it'll just have the patient's name on, the wife, the daughter, maybe where they've worked, where they're from, a little bit of information, so that when bank staff or someone who doesn't know the patient very well . . . they've got that communication aid, which just helps them providing the care that the patient needs.*

IH2FG2

Staff in intervention hospital wards also talked about the value of LSW for easing the transition to a new place after discharge from hospital.

Staff described how a physical life story product was beneficial for families as well as being an aid to concentration for people with dementia, as it provided something for them to look at together, to stimulate conversation or even just an activity for the carer if the person with dementia was not very responsive.

Staff noted that sometimes people with dementia could remember more when prompted with a visual life story product, and that families were sometimes surprised by what the person could remember. However, others felt that the main benefits had come from spending time with people, rather than creating a life story product as such:

*I think he just enjoys the company more than anything. So I don't know whether or not the life story, although it's something you can talk to him about, it's something he relates to, I think it's the company he's getting and the time you're spending with him more than the life story.*

RC1FG1

Some staff felt that knowing more about a person helped them to see that person as an individual. They had used LSW to help them to calm an agitated person, and found that knowing more about people made it easier to have conversations with them, and even provide better care or more appropriate activities. This helped staff to build relationships with the people with dementia in their care.

### Challenges of life story work

Not everything about LSW was seen positively by staff. Some found it difficult to do LSW with people with dementia, when people were reluctant to give information or unable to remember things about their lives. Some staff mentioned the difficulty of getting at 'the truth' about a person's history, and having to follow up information given by the person themselves by asking their family clarifying questions. Other staff members were happy to write down and use the information given by the person, but some noted that family members could be distressed if the information written in a life story product was wrong.

Doing LSW could be emotional for people with dementia, families and even staff, although this was not always considered to be a negative. Staff sometimes found it difficult to know who would respond well and who would not, and people with dementia responded differently at different times. Staff acknowledged that there was a degree of judgement in deciding who to do LSW with and when, and what to include in any written life story product.

Family involvement in LSW varied, and some staff found it challenging to involve families. Families were often asked to provide photographs, and also information about their relative's life if the person with dementia could not provide this him- or herself. Some care home staff had struggled to engage families, and in some cases there was a sense of disappointment about this:

*I think that it would be fair to say that I think the families could have a lot more responsibility in doing this . . . [S]ome have been fantastic, but I think the easy part for them is just bringing you some photographs, I do think they could spare some time during visiting to sit and help put these things together, they just don't, it's another task for the staff to do.*

RC1FG1

Families were sometimes reluctant to get involved in LSW, for example because their relative was very ill or had been admitted to hospital in difficult circumstances, or if they felt that it was 'too late' for LSW to have any benefit for the person themselves. If the person with dementia was in hospital, families could feel too overwhelmed to fill in a template, or might fear that upsetting information would come out. There might also be conflict within families, which could make it difficult for staff to do LSW with them. Staff also raised the question of how to do LSW when a person has no family or known friends:

*Sometimes we get people in we know nothing at all about, they've got no relatives alive, they've got no visitors visiting them, so the only thing you can do is find out what they're interested in, and maybe centred around the football team that they like . . . show them the pictures, see if they prompt any memories of anything.*

IH2FG2

A common observation from staff across all settings was that, although they did have time to collect information about residents' lives (and some felt that they knew their residents very well), they did not have time to sit and make a life story product. LSW, in that sense, was more successful when one member of staff (or team, in the case of the OTTI team on the hospital ward) took responsibility for leading LSW, collating information (even if this was collected by other staff members) and creating a life story product. However, in several sites this had been done solely for the purpose of the research, and only one care home site planned to continue doing LSW in this way. This site had been involved in a project with the local school to collect life story information, and three members of staff were trained as dementia champions, each taking responsibility for a particular aspect of LSW in the home (memory blankets, memory boxes near residents' doors and birthday celebrations). This concentration of effort and commitment from several staff members meant that there was confidence at this care home that LSW would continue after the research was over.

Creating a product not only was considered to be time-consuming, but in some cases also provoked anxiety. Reasons for this included finding it difficult to connect with the person they were working with (and so being unable to collect information about their life) and worrying specifically about making a product: it not being 'good enough', their handwriting being unreadable or their being unable to use a computer:

*You two [other staff in focus group] don't like computers but I've got awful handwriting and I think it'd just be easier for somebody to see it and read it, if it was like typed up, it'd probably last longer as well.*

IH1FG1

Both staff literacy and skill levels and the availability of technology such as computers and scanners were influential here. Care homes, in particular, had few available computers, and in some cases staff used their own computers at home (in their own time) to make the life story products.

## Overall

Staff were mostly enthusiastic about doing LSW and positive about the benefits it could bring, particularly for their own practice but also for carers and people with dementia. However, there was little time allocated to do LSW, and staff sometimes felt unable to do it in addition to their normal duties. In hospitals, where there were many temporary workers and a more regular turnover of patients, a physical product was considered valuable to facilitate staff interactions with people with dementia and help them to manage behaviour that might otherwise be challenging. In care homes, many staff members felt that they already knew the people they worked with well and some questioned the need for a physical product.

## Acceptability of the research

The people with dementia we interviewed told us that they enjoyed talking to us and 'didn't mind' answering our questions. However, as we interviewed only those who were happy to talk to us, this is not surprising. People with dementia sometimes conflated doing LSW with being involved in the research; for example, they might respond to questions about the process with answers about the photographs. This was perhaps understandable, as the LSW and research processes had been running concurrently, and the difference was not always clear.

Most carers explained that they were happy to take part in the research, that it did not take up much time and that, in many cases, they visited their relatives regularly anyway, and so meeting us did not cause an extra burden. Some carers felt that, although the research might not help their relative, it might provide useful information for others in the future and they were, therefore, happy to take part. There were also, however, comments that were more negative. For example, one carer noted the time and expense spent on the research, and predicted that little would be implemented as a result, and another noted how difficult it was to describe his family situation.

Carers described a range of ways in which they felt that the research had an impact on their relatives. Some noted that their relatives might not understand the premise of the research, but would be pleased that it was being done. In a small number of cases, however, carers felt that the person might have felt some anxiety, possibly as a result of feeling that they had said something wrong:

*I don't think it wasn't that he wasn't happy to talk to you but I think afterwards . . . he sort of gave me the impression that he felt, because he hadn't been expecting it, but I don't know that he would ever expect it even if you'd warned him, that he'd said things on the spur of the moment that perhaps if he'd had chance to think about it he wouldn't have said.*

RC4C03

*If I didn't do it [sit with the person while we went through the measures] she would be very worried if you were asking her all these questions, and she worries when you write things down because she thinks you're recording everything.*

RC2C07

As described in *Chapter 6*, some carers expressed difficulty or dissatisfaction with the QoL measures. They found it particularly hard to fill in the proxy measures which ask how the person with dementia is feeling. There were a variety of reasons given for this: their relative's condition was deteriorating, for example, or it stayed the same and so the answers to the questions also stayed the same each time. Carers found it difficult to know how their relative felt, and therefore felt that they were just guessing at answers. Others noted that their relative's mood was so changeable that it was impossible to say how they had been feeling in the past week.

The research appeared to have more of an impact on staff, and some described how they felt pressure to have achieved something in terms of LSW by the end of the study, or felt that they were doing us a 'disservice' by not doing LSW as planned. Several mentioned that they found it hard to take time out of their work to fill in the questionnaires or to take part in the focus groups, and there was a suggestion that staff should be given extra time or support to do this. This also applied to doing the LSW that was planned as part of the study:

*It's great they [care home provider] get involved in these kind of studies but I do think that they need to offer support to the staff. If we're going to be doing this study as we should, as we'd wanted to do it, and as we should, there should have been staffing arrangements made to free up time for people to do it properly.*

RC1FG1

Hospital staff, in particular, noted that it had been difficult to find the time to ask carers for consent for the research team to contact them (see *Chapter 6*) and suggested that a dedicated member of staff to do this would have been helpful.

Staff found questionnaires repetitive and vague, found the tick-box nature of the measures constraining and suggested that the answers had nothing to do with LSW.

As explained in *Chapter 7*, we did not persist with the QoL measures with people with dementia who found them distressing, and several carers and members of staff either pulled out of the study or simply did not fill in the measures at all time points.





# Chapter 10 Discussion and conclusions

## Discussion of findings

### Stage 1: literature review and qualitative work

1. Both elements of stage 1 showed that LSW is not simple conceptually, nor is it easy to pin down its potential benefits. Personal, temporal and organisational challenges may prevent positive outcomes being achieved, and an individually tailored approach is essential to ensuring maximum benefit for different people at different times.
2. The different models of LSW identified in the review and the theories of change that emerged echoed the different purposes of LSW identified in the qualitative work. Is LSW mainly about people preserving their own memories or is it to help staff learn about the person they are working with? Is its aim to improve QoL by reaffirming identity, or by personalising care and responding better to behaviour that challenges?
3. We saw these tensions played out in care settings in the survey and in the feasibility study, where the focus was on LSW as a tool for care and for managing behaviour. This does not necessarily make LSW in those settings any less valuable, but it may narrow the scope for benefit. It also raises the question of whether or not the potential personal benefits might be better achieved earlier in the dementia journey, when people with dementia themselves may have more control over the process and final product.
4. The experiences of people with dementia, family carers and professionals about good practice in LSW were consistent with messages from the literature review and, together, suggested a set of learning points for good practice (see *Conclusions*).

### Stage 2: surveys

The survey of services suggests that LSW has spread relatively widely, particularly in hospital assessment settings, albeit to a lesser extent in care homes.

We found wide variation between different services in the type of LSW they did, and in its overall objectives, including involvement of the person with dementia, whether it was past or forward looking and how it was used in the care setting. We saw throughout that these differences may reflect the different places on the dementia care pathway at which the services were located. Settings with an assessment and care planning focus tended to produce life story products that were less dynamic and sometimes designed specifically to capture information to pass on to other care settings. Care homes were more likely to be capturing information to inform everyday care and interactions with the person with dementia.

Across the board, however, the actual use of the life story product was not as common as might be hoped for. Doing LSW is one thing; using it to inform and improve care is clearly another.

The service survey emphasised the role of carers in doing LSW, and the survey of carers gave further detail. Although carers played an important part in services' LSW, they were unlikely to be trained to do it beforehand. Carers were likely to report heavy involvement and, in some cases, had led the LSW. Again, however, the *actual* use of the life story by care staff, and even by the person with dementia and carers, was lower than might be expected.

Different models of LSW in the carers' accounts echoed those found in the review, the qualitative work and the services survey, suggesting again two different types and uses of LSW.



**Stage 2: feasibility study process**

Our overall conclusion from this stage is that formal evaluation of LSW would be possible only with substantial staffing. Enabling people with dementia (and, to some extent, their family carers) to participate in a meaningful way meant that we used essentially qualitative methods to collect quantitative data. Working with people with dementia requires patience, and there will always be a high risk that data cannot be collected on a given day.

However, working in care homes and hospital wards is, of itself, labour intensive and runs the risk of 'wasted' researcher time. Contacting family members and other consultees relies on the goodwill of staff, and carers themselves often have busy/stressful lives and other priorities. Embedding researchers in the care settings is probably the best way to deal with these types of problems.

Staff turnover and the differing priorities of care settings also mean that the best-laid plans for data collection can fail. Continuity in management commitment to the intervention itself and to the research is clearly an issue, as others have also found.<sup>140</sup>

Overall, our work means that we now have a clear idea of the challenges and benefits of attempting to establish evaluation of this complex intervention in care settings that are themselves complex and often complicated.

**Stage 2: feasibility study outcomes**

Even after successful recruitment of people to the study, gathering data was challenging. Completion rates for outcome measures were mixed, being best overall for family carers in care homes and worst for people with dementia in hospital wards. Completion of measures by staff in care homes was particularly disappointing, given the commitment of the care home provider to the study.

However, we learned much of use for future research.

First, we observed fatigue effects, both immediate (for people with dementia) and over time (for staff and carers). To deal with the first issue, future research should randomise the order in which measures are presented to people with dementia. To deal with the second issue, two follow-up points after baseline, rather than three, might be better. We saw a considerable reduction in completion in all groups at 6 months after baseline. A shorter follow-up period would certainly have benefits in relation to the participation of people with dementia and carers. However, we think that follow-up for staff should be at *longer* intervals. This would allow for the 'bedding in' of the intervention into the culture of the care setting but also help to avoid any learning of the 'right' answers caused by repeating measurement at short intervals.

Completion was not always a function of capacity for people with dementia. Local or embedded research teams could be more flexible in response to the priorities of the care settings and needs of residents or patients, and allow data to be gathered at a time and pace to suit both.

We felt strongly that the QoL measures both missed and were influenced by 'in-the-moment' benefits for people with dementia. Different methods – whether qualitative (such as observation, photovoice or video ethnography) or quantitative (such as measurement of QoL 'in the moment' with subsequent aggregation) – are needed to catch these more fleeting benefits. Exploring and developing different methods is essential for *any* future research if it is properly to include the views of people with dementia themselves, rather than those of their proxies. Our observations also have implications for the way in which QoL measures are used with people with dementia in care settings, where many different activities may take place across each day and week.

The measures also missed how LSW was used, in particular the use of LSW for de-escalation of behaviour that challenges in hospital settings. Formal observational techniques at selected times of the day, in care homes and hospitals, would be useful for future research, but have substantial resource implications.

We did observe some change in our outcome measures from baseline to follow-up and these were significant for staff attitudes towards dementia in care homes, for self-reported QoL (using DEMQOL) for people with dementia in care homes between baseline and final follow-up, and for the experiences of carers.

The first change we think could be an effect of LSW, as we saw evidence of it in both measures of staff attitudes. Whether the change was due to the training associated with implementing LSW or to LSW itself is not clear. Neither is it clear whether the change can be maintained over time or whether it alters staff behaviour. However, we believe that this apparent effect is worth exploring in future research.

The second effect was measured only for the 12 people with dementia able to complete DEMQOL; they may thus have been less cognitively impaired than others in the study. However, the pattern was consistent over time (QoL improved further at each follow-up) and was also evident when we reran the analysis for only those who completed DEMQOL at all three follow-up points.

We saw deterioration in carers' experience scores in the care homes and an improvement in the hospital setting. We are not sure that either effect is related to LSW. People with dementia in the care homes were often approaching the end of the dementia journey, as we saw from the number of deaths in our sample. It is perhaps unsurprising that carers were less able to engage in their usual activities, and so on, as time passed. For carers of people in hospital, by contrast, it was often the case that the person with dementia had been admitted in a crisis, but, during his or her stay, was stabilised and assessed and had his or her future care planned (in some cases meaning admission to long-term-care). Again, we can understand why carers might feel that restrictions in their lives might have lightened somewhat. These findings, however, do suggest that the CES is a good candidate measure for any future research looking at the experiences of carers of people with dementia.

### **Stage 2: collecting resource-use data**

Staff collected resource-use data from care homes either alone or in conjunction with researchers. Data collection forms were filled out more consistently and completely if researchers were involved. Hospital staff collected data from hospital wards and this was equally time-consuming. In a full evaluation, either researchers would need to gain ethical approval and consent from study participants to extract data from their care/medical notes, or care home/ward staff would need to be appropriately trained in collecting the data and their time for doing so would have to be ring-fenced.

Reporting some data, for example on antipsychotic prescribing, was simple for the care homes, as their systems were already set up to run these queries. In the hospital intervention wards, the only way to provide an indication of the volume of prescribing was through the total cost per drug over a specified time period. In a full evaluation, this may be a useful reporting method for a ward-level intervention.

### **Stage 2: resource-use outcomes**

The cost of delivering the LSW training in care homes ranged from £950 to £1581; these costs would change if different staff members attended training sessions. The average cost (based on salary only) of creating and using LSW products for a resident in the care homes was £37.42 spread over a 16-week period. These costs included staff working in conjunction with residents as well as working alone, making it difficult to categorise which were additional costs and which were part of routine care. If we assume all costs are additional, resource implications would be relatively small at an individual resident level but could be substantial if extrapolated to all residents.

Life story work was a part of routine care in the hospital intervention wards, so there were no initial training costs. The average cost (salary only) of creating and using LSW products was £68.21 per patient over a 3-week period. The more intensive activity here may be due to staff attempting to complete life story products before patients are discharged, or to OTTI staff having dedicated time for this activity.

The intention had been to calculate the monetary value of, and the potential savings from, the NHS and other resources, including prescribing. However, given the small number of data, we did not calculate these costs, as they would not be robust and might be misleading.

However, the main drivers of costs are usually the services used most frequently or that have the highest costs per use.

The most frequently used services in care homes were visits to the care home by the GP and the district nurse. Care home staff accompanied residents to these consultations on at least 25% of occasions, which would add to overall costs if this took staff away from other valuable duties. Visits by the GP showed some reduction at follow-up compared with baseline, but visits by the district nurse did not.

The resources with the highest monetary values per use were an inpatient stay on a general medical ward, an accident and emergency (A&E) attendance by ambulance, an outpatient appointment and a GP visit to a care home. Because of their relatively high costs, these events are more likely to affect total costs than, for example, visits to the care home by professionals allied to medicine. As an example, four residents taken to A&E by ambulance in the 3 months prior to baseline would have cost £920, plus the value of the time for care home staff to accompany them on two of these occasions. During the follow-up period, two residents attended A&E by ambulance with no accompanying staff, at a cost of £460. Over a larger number of residents in a full evaluation, any differences in the costs of this type of activity might be substantial.

In a full evaluation, then, the priority should be on collecting data on high-cost or high-volume services such as hospital inpatient admissions, outpatient attendances, A&E attendances, and visits to care homes by GPs and district nurses. The number of times care home staff accompany residents to such appointments should also be recorded, as these may have opportunity costs.

The use of prescribed medication for anxiety and depression by participants in the care homes was small, with no recorded PRNs. Care-home-wide data on antipsychotic prescribing were provided by two homes. In one, prescribing of antipsychotic medication was low; in the other (the SCH) 12 residents were prescribed antipsychotics, all but one on a continuous basis. Overall, however, for study participants in these care homes, the use of antipsychotic or other drugs was not a big driver of costs.

Owing to the small numbers of participants in the hospital settings, it is not possible to judge from individual patient data how extensively antipsychotic drugs were used. However, ward-level data suggest antipsychotic prescribing costs up to £1350 per ward over 6 months.

Some drugs might drive overall costs but the majority, especially those available in generalist form, are not expensive, even on an ongoing basis, in comparison with other costs such as A&E attendances or GP consultations. In a full evaluation, the daily costs of the most expensive drugs or the ones most likely to be affected by LSW would need to be calculated for each participant. From this study, these are amisulpride, quetiapine, venlafaxine and aripiprazole.

Each result shows little on its own, as we would expect from small numbers, but taken as a whole there is the suggestion of a decrease in service use and adverse events. Although these data were never intended to be robust enough to demonstrate change, they do suggest a possible reduction in service use and an indication of the main drivers of costs that might be collected in a full evaluation.

## **Stage 2: participants' experiences of life story work as part of the research project**

Carers, in particular, were unsure of the benefits of LSW for their relatives with dementia, particularly when the dementia had progressed and the person could no longer even recognise people in photographs. This sometimes led to carers' reluctance to get involved in the LSW, feeling that it would have no effect. However, people with dementia in the study appeared to enjoy looking at their life story books, and staff were more certain that there was a positive effect, particularly in terms of facilitating interactions with both visiting family members and staff (particularly temporary staff), as well as encouraging staff to get to know the person. This suggests indirect benefits to LSW for the person with dementia, however far the dementia has progressed.

Staff were positive about collecting life story information, and many described how this was 'already' done, whether through use of a template on admission to the care setting or through the course of everyday interactions with the person. There was some scepticism about the need for a physical life story product, particularly as these were considered time-consuming to make. When products were made, staff usually led the process, often with some family involvement through, for example, providing photographs or stories. However, lack of time was a barrier, and some staff described how they spent time outside work making products. LSW was considered easier when one person or a small team took responsibility for it; where this had been implemented in sites, all staff members were encouraged to collect information, but did not have responsibility for making a product. This person or team could also take the lead in encouraging family members to be involved.

Although some aspects of LSW can be beneficial for people with dementia, it is unclear whether this is attributable to the presence of a physical life story product, or the act of spending time with someone, learning about their life. This may, of course, occur without LSW, but LSW can be a mechanism for this, and a physical life story product can have further benefits in facilitating interactions and therefore enhancing relationships with family members and staff.

## **Strengths and limitations**

There are two main strengths to our work.

The first strength was the use of a mixed-methods design, which allowed us to identify strong commonalities across the existing literature about LSW and carry out new qualitative exploration and preliminary outcome assessment. This enabled us to identify hypothesised routes to efficacy for LSW and then to explore these in a small outcome study. The qualitative work produced in-depth understanding; the literature review allowed us to develop models of LSW and theories of change; the survey generated insights into the practice of LSW nationally; the feasibility study was completed despite substantial challenges to process and progress; we observed some effects; and we were able to ascribe costs and possible savings to LSW. We thus generated new knowledge about LSW itself while improving understanding about how to approach the next stage of evaluation.

The second strength was the involvement of people with dementia, family carers, organisations that advocate for the rights of both, and care providers. Their involvement was not only as participants but also as influential advisors at all stages of the work. This strengthened our research practice and our understanding about the benefits and challenges of being involved in research for people with dementia and their carers. This understanding is invaluable for planning our own future research and also, we hope, that of others.

The two main limitations of the research are what we were not able to do.

We had planned to use the literature review to estimate the size of outcomes achieved in LSW, but there was insufficient evidence to allow this.

We had also hoped to do some Markov chain modelling to inform decisions about whether or not to carry out future evaluation. Five main factors militated against this:

1. There was a dearth of outcome data in the existing literature.
2. There were very low levels of data return for people with dementia in the hospital settings.
3. The only detected effect for people with dementia (and only in care homes) was for a very small proportion of respondents, and they were probably not typical residents.
4. There were question marks about implementation of LSW in both hospital and care home settings.
5. The largest effect observed related to attitudes to dementia for staff in care homes, not for people with dementia.

Given these issues, we did not feel that modelling would provide a secure basis for future research.

## Conclusions

Life story work has spread widely in health settings in England (although less so in social care settings), but our work has shown that what it is, how it is done and the outcomes it achieves vary substantially.

There are two predominant models of LSW.

First, there is LSW that is led by the person with dementia, usually at a relatively early stage of the dementia journey, and which serves to reinforce a sense of identity and support pride in the life led to date. This sort of LSW may be carried out over a long period and generate detailed and substantial life story products. This work is often narrative or at least biographical.

The second model, found more often in care settings (and thus at a later stage of the dementia journey), is less likely to involve the person with dementia (although there is no reason why it should not) and more likely to involve family carers. Although it is also about telling the story of a person's life, it is more often directed to aspects of and contents about a person's life that might aid communication with and increase staff understanding about the person. It may also be used to calm or soothe the person with dementia. This type of LSW is, thus, almost entirely care-focused, although there is no reason why a 'type 1' life story should not inform a 'type 2' life story.

The feasibility element of our project was more about the second type of LSW and found some evidence that it might improve care home staff attitudes about dementia, although it is not clear whether this change comes from the LSW training or from doing LSW itself. Care homes are important in the later stages of the dementia journey and the challenges of delivering person-centred care in these settings are widely acknowledged. We therefore feel that future LSW evaluative research could profitably focus on staff attitudes and whether or not changed attitudes lead to changed care practices. Overall, it does not seem to be expensive to implement this type of LSW, and there are some hints of areas of resource-use savings. Taken together, these suggest an agenda for future evaluation and one that can be carefully informed by the rich learning that came from our feasibility work.

## Implications for health care

Stage 1 of our work was based on in-depth qualitative research and a systematic review of the literature. Although this work could not point to definite outcomes from LSW, it did find consistent messages about good practice in doing LSW. The survey of health and social care services showed that not all services follow these practices. We have, therefore, drawn together good practice learning points which are summarised below, and we will disseminate these widely to health and social care audiences.

## Good practice learning points for life story work

1. Whether someone wants to take part in LSW is an individual thing. It should not be assumed that a person necessarily wants to make or share a life story and no one should be pushed into doing so.
2. A person's life story is never finished and LSW needs to reflect this. To avoid setting people 'in stone', ensure that life story documents can be added to and updated.
3. LSW can be emotional and may raise sensitive issues. Some people will value the opportunity to talk about these issues, but staff require training to handle this and should not be expected to do so without support.
4. A person with dementia may have very different views from others about what their life story is for. Respect the person's wishes about what goes into the life story and who will see it, now and in the future. If they do not have capacity to express their views, consult someone who knows them well.
5. Staff should consider making and sharing their own life stories. How does this feel? Who would they share them with?
6. Beginning the process early will enable people with dementia to take a more active role in producing their life story and communicate how they would like it to be used in the future. However, it is never too late to use LSW to improve care for a person and invoke a 'nice feeling'.
7. Outcomes for better care will only come about if care staff take (and, indeed, are granted) the time to absorb life story information and the flexibility to use this to inform and improve the care they provide.
8. Short summaries might be useful for busy staff, helping them to achieve better care, but they cannot replace a life story owned, shared and added to by a person with dementia him- or herself.
9. The *process* of collecting life story information enables staff to connect and build relationships with people with dementia and their families. However, in order to have wider benefits it is also important to *produce* something that can be used and enjoyed by others.

Stage 2 was intentionally exploratory. Although we did observe effects in this stage of the work, particularly in relation to staff attitudes in care homes, it is clearly not right at this stage to draw out implications for health and social care providers.

## Recommendations for research

The main point of stage 2 was to learn whether or not formal evaluation of LSW is possible and we have outlined above some of the detailed learning about how such evaluation might be designed and carried out. We will not repeat that detail here but confine ourselves to the larger research needs that have emerged. In order of priority, there is a need for:

1. Formal evaluation of LSW as a method of changing staff attitudes about dementia, and particularly in care homes. This should compare LSW, as such, against more general training input about dementia.
2. Qualitative research that explores the motivation and 'emotional intelligence' of care staff, recognising that delivering person-centred care for people with dementia requires particular qualities of both.
3. Methodological development in assessing QoL for people with dementia 'in the moment'. Existing measures of QoL do not capture the temporary pleasure that LSW (and other interventions) may give to people with dementia, even if the interventions do not have an effect that is measurable with existing instruments. The additive effect of episodes of temporary pleasure may well be worth having, but without ways of measuring it we will never be able to tell. Given the predominance of QoL measurement in health economics, and thereby its influencing on commissioning, we believe that this type of development is essential to the future of good-quality care for people with dementia. Such development would need to be multidisciplinary, involving cognitive psychologists and health economists as well as health service researchers.





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## Contributions of authors

**Kate Gridley** (Research Fellow, Social Policy Research Unit) was principal investigator until October 2014, designed the study, managed all aspects of the study, conducted fieldwork throughout, and drafted *Chapters 3, 4 and 6* and elements of *Chapter 7*.

**Dr Jenni Brooks** (Research Fellow, Social Policy Research Unit) conducted fieldwork for the feasibility studies, conducted and analysed the interviews and focus groups for this stage of the research, and drafted *Chapter 9*.

**Professor Yvonne Birks** (Professor of Health and Social Care, Social Policy Research Unit) contributed to the feasibility study design, contributed to the review and provided advice throughout.

**Dr Kate Baxter** (Research Fellow, Social Policy Research Unit) contributed to the design of the section of the study about the costs of LSW, analysed the resource-use and costs data, and drafted *Chapter 8*.



**Professor Gillian Parker** (Professor of Social Policy Research, Social Policy Research Unit) was principal investigator after Kate Gridley went on maternity leave in October 2014. She also designed the study, carried out the systematic review, conducted and analysed the surveys, analysed the outcome measures, drafted *Chapters 1, 2, 5, 7 and 10*, and was responsible for editing the final report.

## Publications

Gridley K. Understanding the Outcomes of Life Story Work. In Kaiser P, Eley R, editors. *Life Story Work with People with Dementia*. London: Jessica Kingsley Publishers; 2016. In press.

## Data sharing statement

Data extraction tables from the review and data from the feasibility study can be accessed via the corresponding author, Professor Gillian Parker.

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# Appendix 1 Tables

**TABLE 8** Databases and resources searched

Database	Interface
MEDLINE and MEDLINE In-Process & Other Non-Indexed Citations	OvidSP
EMBASE	OvidSP
PsycINFO	OvidSP
Cumulative Index to Nursing and Allied Health Literature	EBSCOhost
Cochrane Database of Systematic Reviews	The Cochrane Library/Wiley Online Library
Cochrane Central Register of Controlled Trials	The Cochrane Library/Wiley Online Library
Database of Abstracts of Reviews of Effects	The Cochrane Library/Wiley Online Library
Health Technology Assessment database	The Cochrane Library/Wiley Online Library
Science Citation Index	Web of Science
Social Sciences Citation Index	Web of Science
Conference Proceedings Citation Index – Science	Web of Science
Conference Proceedings Citation Index: Social Science & Humanities	Web of Science
Social Policy and Practice	Ovid
Social Services Abstracts	ProQuest
Social Care Online	<a href="http://www.scie-socialcareonline.org.uk/">www.scie-socialcareonline.org.uk/</a>
Research Register for Social Care	<a href="http://www.researchregister.org.uk/">www.researchregister.org.uk/</a>
Applied Social Sciences Index and Abstracts	ProQuest
ClinicalTrials.gov	<a href="http://www.clinicaltrials.gov">www.clinicaltrials.gov</a>
NHS Evidence	<a href="http://www.evidence.nhs.uk/">www.evidence.nhs.uk/</a>
OpenGrey	<a href="http://www.opengrey.eu/">www.opengrey.eu/</a>

**TABLE 9** Number of records identified from electronic searches by database

Resource	Number of records identified
MEDLINE and MEDLINE In-Process & Other Non-Indexed Citations	123
EMBASE	171
PsycINFO	177
Social Policy and Practice	165
Cochrane Database of Systematic Reviews	2
Cochrane Central Register of Controlled Trials	6
Database of Abstracts of Reviews of Effects	6
Health Technology Assessment database	1
Science Citation Index Expanded, Social Sciences Citation Index, Conference Proceedings Citation Index – Science, Conference Proceedings Citation Index: Social Science & Humanities	224
Cumulative Index to Nursing and Allied Health Literature	104
Applied Social Sciences Index and Abstracts	33
Social Services Abstracts	19
Social Care Online	113
Research Register for Social Care	0
ClinicalTrials.gov	2
NHS Evidence	53
OpenGrey	0
Additional studies identified from reference lists of studies included for review	19
Total	1218
Total after deduplication	657

**TABLE 10** Publication details and selection of screened publications for inclusion or exclusion from review after full reading (primary studies)

Primary study publication details	Further exclusion as not relevant	Excluded from both reviews	Good practice review	Theory of change review
Alzheimer's Society. <i>Remembering Together: Making a Life History Book</i> . London: Alzheimer's Society; 2001 <sup>41</sup>			Y	Y
Anon. Making a life story book. <i>Alzheimers Care Q</i> 2000; <b>1</b> :43 <sup>71</sup>		X	Y	
Archibald C. <i>Activities II</i> . Stirling: School of Human Sciences, University of Stirling; 1993 <sup>51</sup>		X	Y	
Archibald C. <i>Activities</i> . Stirling: School of Human Sciences, University of Stirling; 1990 <sup>53</sup>		X	Y	
Archibald C. Sharing activities. <i>J Dement Care</i> 1999; <b>7</b> :20–2 <sup>73</sup>		X		
Baker J. Life story books for the elderly mentally ill. <i>Int J Lang Commun Disord</i> 2001; <b>36</b> (Suppl.):185–7 <sup>74</sup>		X		
Batson P, Thorne K, Peak J. Life story work sees the person beyond the dementia. <i>J Dement Care</i> 2002; <b>10</b> :15–17 <sup>38</sup>			Y	Y

**TABLE 10** Publication details and selection of screened publications for inclusion or exclusion from review after full reading (primary studies) (*continued*)

Primary study publication details	Further exclusion as not relevant	Excluded from both reviews	Good practice review	Theory of change review
Berman C. Older adults with dementia: the value of Life-story Work. <i>Bold</i> 2009; <b>20</b> :19–22 <sup>27</sup>			Y	
Bruce E, Scheitz P. Working with Life History. In Downs M, Bowers B., editors. <i>Excellence in Dementia Care</i> . Maidenhead: Open University Press; 2008. pp. 168–85 <sup>82</sup>		X		
Bryan K, Maxim J. Enabling care staff to relate to older communication disabled people. <i>Int J Lang Commun Disord</i> 1998; <b>33</b> (Suppl.):121–5 <sup>75</sup>		X		
Burgess R. Life story project lives on. <i>J Dement Care</i> 2008; <b>16</b> :16–17 <sup>54</sup>			Y	
Buron B. Exploring life history collage exposure on personhood and person centered nursing home dementia care. <i>Alzheimers Dement</i> 2011; <b>1</b> :S637 <sup>77</sup>		X		
Buron B. Life history collages: effects on nursing home staff caring for residents with dementia. <i>J Gerontol Nurs</i> 2010; <b>36</b> :38–48 <sup>69</sup>				Y
Buron B. <i>Promoting Personhood among Nursing Home Residents Living with Dementia</i> . PhD thesis. Little Rock, AR: University of Arkansas; 2009 <sup>76</sup>		X		
Caratello A, Reed S. Collected short stories. <i>J Dement Care</i> 2011; <b>19</b> :16–17 <sup>40</sup>			Y	
Caron W, Hepburn K, Luptak M, Grant L, Ostwald S, Keenan J. Expanding the discourse of care: family constructed biographies of nursing home residents including commentary by Hargrave TD. <i>Families Systems Health</i> 1999; <b>17</b> :323–35 <sup>32</sup>			Y	Y
Centre for Policy on Ageing. <i>State of the Art in Dementia Care</i> . London: Centre for Policy on Ageing; 1997 <sup>72</sup>		X		
Chapman SB, Weiner MF, Rackley A, Hynan LS, Zientz J. Effects of cognitive-communication stimulation for Alzheimer's disease patients treated with donepezil. <i>J Speech Lang Hearing Res</i> 2004; <b>47</b> :1149–63 <sup>68</sup>				Y
Chaudhury H. Place-biosketch as a tool in caring for residents with dementia. <i>Alzheimers Care Q</i> 2002; <b>3</b> :42–5 <sup>70</sup>				Y
Clarke A, Hanson EJ, Ross H. Seeing the person behind the patients: enhancing the care of older people using a biographical approach. <i>J Clin Nurs</i> 2003; <b>12</b> :697–706 <sup>7</sup>			Y	Y
Clarke A, Hollands J, Smith J. <i>Windows to a Damaged World</i> . London: Counsel and Care; 1996 <sup>78</sup>		X		
Cohen GD. Two new intergenerational interventions for Alzheimer's disease patients and families. <i>Am J Alzheimers Dis</i> 2000; <b>15</b> :137–42 <sup>64</sup>			Y	
Cole A, Williams H. Life story work as an aid to well-being. <i>Signpost</i> 2004; <b>9</b> :14–17 <sup>55</sup>			Y	
Crete-Nishihata M, Baecker RM, Massimi M, Ptak D, Campigotto R, Kaufman LD, et al. Reconstructing the past: personal memory technologies are not just personal and not just for memory. <i>Hum-Computer Interact</i> 2012; <b>27</b> :92–123 <sup>24</sup>			Y	
Damianakis T, Crete-Nishihata M, Smith KL, Baecker RM, Marziali E. The psychosocial impacts of multimedia biographies on persons with cognitive impairments. <i>Gerontologist</i> 2010; <b>50</b> :23–35 <sup>67</sup>				Y

continued

**TABLE 10** Publication details and selection of screened publications for inclusion or exclusion from review after full reading (primary studies) (*continued*)

Primary study publication details	Further exclusion as not relevant	Excluded from both reviews	Good practice review	Theory of change review
Damianakis T, Crete-Nishitaka, Smith K, Baecker R, Marziali E. Remembering my life: the production and evaluation of individuals with Alzheimer's or mild cognitive impairment responses to digital life histories. <i>Gerontologist</i> 2008; <b>48</b> (Special Issue III):324 <sup>79</sup>		X		
Day MR, Wills T. Mind matters. <i>World Irish Nurs Midwifery</i> 2007; <b>15</b> :35–6 <sup>80</sup>		X		
Day MR, Wills Y. A biographical approach. <i>Nurs Older People</i> 2008; <b>20</b> :22–24 <sup>63</sup>			Y	
Dodd K. Psychological and other non-pharmacological interventions in services for people with learning disabilities and dementia. <i>Adv Ment Health Learning Disabilities</i> 2010; <b>4</b> :28–35 <sup>81</sup>		X		
Egan MY, Munroe S, Hubert C, Rossiter T, Gauthier A, Eisner M, et al. Caring for residents with dementia and aggressive behaviour: impact of life history knowledge. <i>J Gerontol Nurs</i> 2007; <b>33</b> :24–30 <sup>56</sup>			Y	Y
Flynn Z, Chapman B. Making animated films with people with dementia. <i>J Dement Care</i> 2011; <b>19</b> :23–5 <sup>65</sup>			Y	
Gibson F, Carson Y. Life story work in practice: aiming for enduring change. <i>J Dement Care</i> 2010; <b>18</b> :20–2 <sup>39</sup>			Y	
Gibson F, Haight B, Michel Y. Evaluating Long-Stay Care Settings: A Study of a Life Review and Life Story Book Project. In Innes A, McCabe L, editors. <i>Evaluation in Dementia Care</i> . London: Jessica Kingsley; 2006. pp. 124–43 <sup>60</sup>			Y	Y
Gibson F. Fit for Life: The Contribution of Life Story Work. In Marshall M, editor. <i>Perspectives on Rehabilitation and Dementia</i> . London: Jessica Kingsley Publishers; 2005. pp. 175–9 <sup>37</sup>			Y	
Gibson F. Reminiscence with People with Dementia and their Carers. In Gibson F, editor. <i>Reminiscence and Life Story Work: A Practice Guide</i> . London: Jessica Kingsley; 2011. pp. 187–217 <sup>84</sup>		X		
Gibson F. <i>The Lost Ones; Recovering the Past to Help their Present: Practice Example 3</i> . Stirling: University of Stirling, Dementia Services Development Centre; 1991 <sup>61</sup>		X		
Gibson, F. Tangible Representations of Reminiscence. In Gibson F. <i>The Past in the Present: Using Reminiscence in Health and Social Care</i> . 2004, Baltimore, MD: Health Professions Press; 2004 <sup>83</sup>		X		
Gilfoy K, Knocker S. Magic across the generations. <i>J Dement Care</i> 2009; <b>17</b> :22–5 <sup>85</sup>		X		
Hagens C, Beaman A. Reminiscing, poetry writing, and remembering boxes. <i>Activities Adaptation Ageing</i> 2003; <b>27</b> :3–4, 97–112 <sup>31</sup>			Y	Y
Haight BK, Bachman DL, Hendrix S, Wagner MY, Meeks A, Johnson J. Life review: treating the dyadic family unit with dementia. <i>Clin Psychol Psychother</i> 2003; <b>10</b> :165–74 <sup>57</sup>			Y	Y
Haight BK, Gibson F, Michel Y. The Northern Ireland life review/life storybook project for people with dementia. <i>Alzheimers Dement</i> 2006; <b>2</b> :56–58 <sup>66</sup>			Y	
Heathcote J. Life story work in practice: magic moments. <i>J Dement Care</i> 2010; <b>18</b> :22–24 <sup>58</sup>			Y	
Heathcote J. <i>Memories are Made of This: Reminiscence Activities for Person-Centred Care</i> . London: Alzheimer's Society; 2007 <sup>86</sup>	X			

**TABLE 10** Publication details and selection of screened publications for inclusion or exclusion from review after full reading (primary studies) (*continued*)

Primary study publication details	Further exclusion as not relevant	Excluded from both reviews	Good practice review	Theory of change review
Hepburn K, Caron WA. The Family Stories Workshop. In Gaugier J, editor. <i>Promoting Family Involvement in Long-Term Care Settings: A Guide to Programs That Work</i> . Baltimore, MD: Health Professions Press; 2005. pp. 143–61 <sup>33</sup>			Y	
Hepburn KW, Caron W, Luptak M, Ostwald S, Grant L, Keenan JM. The family stories workshop: stories for those who cannot remember. <i>Gerontologist</i> 1997; <b>37</b> :827–32 <sup>34</sup>			Y	Y
Hopkins G. <i>This is Your Life</i> . Community Care; 2002. URL: <a href="http://www.communitycare.co.uk/articles/07/03/2002/35387/this-is-your-life.htm">www.communitycare.co.uk/articles/07/03/2002/35387/this-is-your-life.htm</a> <sup>50</sup>			Y	
Ingersoll-Dayton B, Spencer B. A couples' life story approach to dementia care. <i>Gerontologist</i> 2010; <b>50</b> (Suppl. 1):368 <sup>88</sup>		X		
Ingersoll-Dayton, B. The couples' life story project: a dyadic approach to dementia care. <i>Gerontologist</i> 2011; <b>51</b> (Suppl. 2):14 <sup>87</sup>		X		
Institute for Research and Innovation in Social Services. <i>Insights No. 4. Supporting those with Dementia: Reminiscence Therapy and Life Story Work</i> . Glasgow: Institute for Research and Innovation in Social Services; 2010 <sup>62</sup>			Y	
Jones GMM. A Nursing Model for the Care of the Elderly. In Jones G, Miesen B. <i>Care-Giving in Dementia: Research and Applications</i> (Vol. 1). New York, NY: Tavistock/Routledge; 1992. pp. 100–18 <sup>89</sup>		X		
Kellett U, Moyle W, McAllister M, King C, Gallagher F. Life stories and biography: a means of connecting family and staff to people with dementia. <i>J Clin Nurs</i> 2010; <b>19</b> :1707–15 <sup>10</sup>			Y	Y
Kelson E, Chaudhury H. Sustaining personhood in dementia care: exploring staff perception of residents' visual life stories. <i>Gerontologist</i> 2008; <b>48</b> (Special Issue III):237 <sup>44</sup>			Y	
Kikhia B, Bengtsson JE, Synnes K, Sani Z ul H, Hallberg J. Creating Digital Life Stories through Activity Recognition with Image Filtering, in Ageing Friendly Technology for Health and Independence. In Lee Y, et al., editors. <i>ICOST 2010</i> . Berlin: Springer-Verlag; 2010. pp. 203–10 <sup>90</sup>		X		
Killick J. When your heart wants to remember. <i>Elderly Care</i> 1997; <b>9</b> :38–9 <sup>91</sup>	X			
Kunz JA. Mental Health Applications of Reminiscence and Life Review. In <i>Transformational Reminiscence: Life Story Work</i> . New York, NY: Springer Publishing Co; 2007. pp. 155–80 <sup>92</sup>	X			
Lai CKY, Chi I, Kayser-Jones J. A randomised controlled trial of a specific reminiscence approach to promote the well-being of nursing home residents with dementia. <i>Int Psychogeriatr</i> 2004; <b>16</b> :33–49 <sup>93</sup>		X		
Lai KY. <i>Improving the Quality of Life for Nursing Home Residents with Dementia: A Life Story Approach</i> . PhD thesis. Hong Kong: University of Hong Kong; 2004 <sup>94</sup>		X		
Let's Respect. <i>Do You See Me? Recognising, Understanding and Caring for People with Dementia, Depression and Delirium</i> . London: Let's Respect; 2011 <sup>29</sup>			Y	
Luyendyk K. Using life histories to enhance dementia caregiving. <i>Can Nurs Home</i> 2007; <b>18</b> :4–6 <sup>95</sup>		X		
Mackenzie J. Working with lesbian and gay people with dementia. <i>J Dement Care</i> 2009; <b>17</b> :17–19 <sup>45</sup>			Y	

continued

**TABLE 10** Publication details and selection of screened publications for inclusion or exclusion from review after full reading (primary studies) (*continued*)

Primary study publication details	Further exclusion as not relevant	Excluded from both reviews	Good practice review	Theory of change review
Magniant RCP. Lifebooks with Older Adults: Making Memories Last. In Magniant RCP, editor. <i>Art Therapy with Older Adults: A Source book</i> . Springfield, IL: Charles C Thomas Publisher; 2004. pp. 53–68 <sup>96</sup>	X			
May H, Edwards P, Brooker D. Life Story. In May H, Edwards P, Brooker D. <i>Enriched Care Planning for People with Dementia: A Good Practice Guide for Delivering Person-Centred Care</i> . London: Jessica Kingsley Publishers; 2009. pp. 23–32 <sup>97</sup>		X		
McCarthy B. <i>Hearing the Person with Dementia: Person-Centred Approaches to Communication for Families and Caregivers</i> . London: Jessica Kingsley; 2011 <sup>28</sup>			Y	
McKeown J, Clarke A, Ingleton C, Ryan T, Repper J. The use of life story work with people with dementia to enhance person-centred care. <i>Int J Older People Nurs</i> 2010; <b>5</b> :148–58 <sup>14</sup>			Y	Y
Mitchell R. Shooting into the past. <i>Nurs Older People</i> 2006; <b>18</b> :12–14 <sup>98</sup>	X			
Murphy C. <i>'It Started with a Sea-Shell': Life Story Work and People with Dementia</i> . Stirling: University of Stirling, Dementia Services Development Centre; 1994 <sup>9</sup>			Y	
Murphy C. <i>Crackin' Lives: An Evaluation of a Life Story Book Project to Assist Patients from a Long-Stay Psychiatric Hospital in their Move to Community Care Situations</i> . Stirling: University of Stirling, Dementia Services Development Centre; 2000 <sup>59</sup>			Y	Y
Petrukowicz MA, Johnson MMS. Using life histories to individualise nursing home staff attitudes towards residents. <i>Gerontologist</i> 1991; <b>31</b> :102–6 <sup>102</sup>		X		
Price L. Creating an interactive toolbox for the person, family and staff. <i>J Dement Care</i> 2010; <b>18</b> :17 <sup>48</sup>			Y	
Rainbow A. <i>The Reminiscence Skills Training Handbook</i> . Bicester: Speechmark; 2003 <sup>47</sup>			Y	
Rose S. Video portraits: creating lasting records. <i>J Dement Care</i> 2006; <b>14</b> :23–4 <sup>30</sup>			Y	
Ryan EB, Martin LS, Beaman A. Communication strategies to promote spiritual well-being among people with dementia. <i>J Pastoral Care Counseling</i> 2005; <b>59</b> :43–55 <sup>99</sup>		X		
Savitch N, Stokes V. <i>We Can Do IT Too</i> . Milton Keynes: Speechmark; 2011 <sup>26</sup>			Y	
Shi L, Setchi R. User-oriented ontology-based clustering of stored memories. <i>Expert Syst Appl</i> 2012; <b>39</b> :9730–42 <sup>100</sup>	X			
Smith KL, Crete-Nishihata, Damaniakis T, Baecker RM, Marziali E. Multimedia biographies: a reminiscence and social stimulus tool for persons with cognitive impairment. <i>J Technol Hum Serv</i> 2009; <b>27</b> :287–306 <sup>35</sup>			Y	
Thompson R. Realising the potential: developing life story work in practice. <i>Foundation Nurs Stud</i> 2010; <b>5</b> :1–4 <sup>52</sup>			Y	
Thompson R. <i>Realising the Potential: Developing Life Story Work in Practice. Final Report</i> . 2009			Y	
Thompson R. Using life story work to enhance care. <i>Nurs Older People</i> 2011; <b>23</b> :16–21 <sup>36</sup>			Y	

**TABLE 10** Publication details and selection of screened publications for inclusion or exclusion from review after full reading (primary studies) (*continued*)

Primary study publication details	Further exclusion as not relevant	Excluded from both reviews	Good practice review	Theory of change review
Thwaites S, Sara A. Tailor-made cognitive stimulation. <i>J Dement Care</i> 2010; <b>18</b> :19–20 <sup>46</sup>			Y	
University of Stirling Dementia Services Development Centre. <i>Dementia Skills Starters: A Set of Six Workbooks Covering Key Areas of Dementia Care</i> . Stirling: University of Stirling Dementia Services Development Centre; 2010 <sup>49</sup>			Y	
van den Brandt-van-Heek M-E. Asking the Right Questions: Enabling People with Dementia to Speak for Themselves. In Kenyon G, Bohlmeijer E, Randall WL, editors. <i>Storying Later Life</i> . Oxford: Oxford University Press; 2011. pp. 338–53 <sup>25</sup>			Y	
Williams BR, Woodby LL, Goode PS, Blizard T, Burgio KL. Forever: feasibility of life review in early dementia: Veterans' experiences remembered. <i>Gerontologist</i> 2011; <b>51</b> (Suppl. 2):569 <sup>43</sup>			Y	Y
Williams BR. <i>Feasibility of Life Review in Early Dementia: Veterans' Experiences Remembered</i> . URL: <a href="http://www.hsrd.research.va.gov/research/abstracts.cfm?ProjectID=2141700380#.UWV5qJPvsmM">www.hsrd.research.va.gov/research/abstracts.cfm?ProjectID=2141700380#.UWV5qJPvsmM</a>				
Woods RT, Portnoy S, Head D, Jones G. Reminiscence and Life Review with Persons with Dementia: Which Way Forward? In Jones GM, Meisen B. editors. <i>Care-Giving in Dementia: Research and Applications</i> . New York, NY: Tavistock/Routledge; 1992. pp. 137–61 <sup>101</sup>		X		
Yasuda K, Kuwabara K, Kuwahara N, Abe S, Tetsutani N. Effectiveness of personalised reminiscence photo videos for individuals with dementia. <i>Neuropsychol Rehabil</i> 2009; <b>19</b> :603–19 <sup>42</sup>			Y	Y
<i>n</i> = 83	6	27	47	18

**TABLE 11** Systematic reviews and meta-analyses selected for review

Systematic reviews and meta-analyses	Good practice review	Theory of change review
McKeown J, Clarke A, Repper J. Life story work in health and social care: systematic literature review. <i>J Adv Nurs</i> 2006; <b>55</b> :237–47 <sup>11</sup>	Y	N
Moos I, Bjorn A. Use of the life story in the institutional care of people with dementia: a review of intervention studies. <i>Ageing Soc</i> 2006; <b>26</b> :431–54	N	N
Pinquart M, Forstmeier S. Effects of reminiscence interventions on psychosocial outcomes: a meta-analysis. <i>Ageing Ment Health</i> 2012; <b>16</b> :541–58 <sup>103</sup>	N	N
Subramaniam P, Woods B. The impact of individual reminiscence therapy for people with dementia: systematic review. <i>Expert Rev Neurother</i> 2012; <b>12</b> :545–55 <sup>70</sup>	Y	N
Vasse E, Vernooij-Dassen, Spijker A, Rikkert MO, Koopmans R. A systematic review of communication strategies for people with dementia in residential and nursing homes. <i>Int Psychogeriatr</i> 2010; <b>22</b> :189–200 <sup>104</sup>	N	N
Woods B, Spector AE, Jones CA, Orrell M, Davies SP. Reminiscence therapy for dementia. <i>Cochrane Database Syst Rev</i> 2005; <b>18</b> :CD001120 <sup>17</sup>	N	N
<i>n</i> = 6	2	0



**TABLE 12** Study details (primary studies)

First author and date	Country	Type of publication or study	Setting	n involved	Methods used, if research	Who delivered LSW?
Alzheimer's Society 2001 <sup>41</sup>	UK	Guide to practice	–	–	–	–
Archibald 1990 <sup>51</sup>	UK	Guide to practice	–	–	–	–
Archibald 1993 <sup>53</sup>	UK	Guide to practice	–	–	–	–
Batson 2002 <sup>38</sup>	UK	Evaluation of LSW	Home/care home	9	Semistructured interviews	Health-care professionals
Berman 2009 <sup>27</sup>	Malta	Theoretical	–	–	–	–
Burgess 2008 <sup>54</sup>	UK	Description of LSW project	Day club	20	–	Facilitator and care staff
Buron 2010 <sup>69</sup>	USA	Evaluation of LSW	Nursing home	Five people with dementia, 36 staff	Pre-test, post-test staff individualised care measure	Nursing care staff
Caron 1999 <sup>32</sup>	USA	Description of LSW project	Nursing home	At least 12 'biography groups' of family carers	–	Not entirely clear but probably care staff and a facilitator
Catarella 2011 <sup>40</sup>	UK	Description of LSW project	Care home	Staff and 20 family members	–	Social enterprise specialising in life story products
Chapman 2004 <sup>68</sup>	USA	Evaluation of LSW when in combination with Donepezil	Own home	54 with mild to moderate Alzheimer's Disease	RCT (creation of life story book plus drug vs. drug + placebo condition)	Speech and language therapists/students
Chaudhury 2002 <sup>70</sup>	USA	Evaluation of LSW	Nursing home	12 people with dementia and their family carers, plus 12 professional and care staff	'Short survey' n.o.s.	Not clear but probably the author
Clarke 2003 <sup>7</sup>	UK	Evaluation of LSW project	Transitional care unit in NHS trust and nursing home		Qualitative before and after design, with focus groups with staff in both settings and semistructured interviews with people with dementia and family members	Support workers in care settings

First author and date	Country	Type of publication or study	Setting	n involved	Methods used, if research	Who delivered LSW?
Cohen 2000 <sup>64</sup>	USA	Description and underpinning rationale for LSW, early evaluation also	Not clear but evaluation appears to be in a long-term care setting	40 people with dementia in evaluation	Not clear but appears to be pre-test, post-test	Not entirely clear but seems to involve college students as volunteers and family members of people with dementia
Cole 2004 <sup>55</sup>	UK	Description of LSW project and how to do it advice	Mobile community day service	Not stated	–	Not clear – care staff?
Crete-Nishihata 2012 <sup>24</sup>	Canada	Evaluation of LSW	Not clear but perhaps own home and long-term care settings	12 people with dementia and their family members	Semistructured interviews with family members	Family members with support from research assistants
Damianakis 2010 <sup>67</sup>	Canada	Evaluation of LSW (related to R23)	10 in own home, two in long-term care setting	12 family members of people with dementia (six with diagnosed AD and six with diagnosed MCI)	Observation and in-depth interviews	Family members supported by 'multi-media biographers and social workers'
Day 2008 <sup>63</sup>	UK	Guide to practice	–	–	–	–
Egan 2007 <sup>56</sup>	Canada	Evaluation of LSW	Long-term care settings	Four people with dementia and all staff who worked with them	Single subject, repeated measures design logging aggressive behaviours, plus interviews with staff	Research assistants
Flynn 2011 <sup>65</sup>	UK	Description of LSW	Varied care and housing settings	Not reported	–	Authors
Gibson 1991 <sup>61</sup>	UK	Guide to practice	–	–	–	–
Gibson 2005 <sup>37</sup>	n/a	Description of LSW	–	–	–	–
Gibson 2006 <sup>60</sup>	UK	Evaluation of LSW	Residential care setting	30 people with dementia, 14 care staff	Pilot study using pre-test, post-test design and control group. Range of standardised measures	Not entirely clear. One part of chapter mentions family members (p. 128), but rest of chapter is about care staff
Gibson 2010 <sup>39</sup>	UK	Description of LSW project	NHS trust settings	30 staff from 15 'facilities'	–	NHS staff n.o.s.
Hagens 2003 <sup>31</sup>	Canada	Evaluation of LSW project	Nursing home	Five people with confirmed cognitive impairment	Participant observation and interviews with two residents	Authors

continued

**TABLE 12** Study details (primary studies) (*continued*)

First author and date	Country	Type of publication or study	Setting	<i>n</i> involved	Methods used, if research	Who delivered LSW?
Haight 2003 <sup>57</sup>	USA	Evaluation of LSW when done with and without family carer	Not clear but appears to be in own home	22 pairs of people with dementia and family carers	Pre-test, post-test comparing LSW with and without involvement of family carer, and a control condition	Not entirely clear but seems that authors worked with people with dementia and carers
Haight 2006 <sup>66</sup>	UK	Evaluation of LSW	Long-term care settings	30 people with dementia and 15 care staff	Pilot study of 15 intervention and 15 controls	Care staff and people with dementia, with family input
Heathcote 2010 <sup>58</sup>	UK	Guide to practice	–	–	–	–
Hepburn 1997 <sup>34</sup>	USA	Description and ‘field testing’ of LSW	Nursing homes	–	–	Professional facilitator and family members
Hepburn 2005 <sup>33</sup>	USA	As above	As above	–	–	As above
Hopkins 2002 <sup>50</sup>	UK	Description of LSW project	Residential care setting	Two staff in each of two ‘care communities’	–	Care staff
IRISS 2010 <sup>62</sup>	UK	Description of LSW	–	–	–	–
Kellett 2010 <sup>10</sup>	Australia	Evaluation of LSW	Residential care	Seven family members, seven care staff	Qualitative pilot study using focus groups with participants	Family members and care staff facilitated by researcher
Kelson 2008 <sup>44</sup>	Canada	Evaluation of LSW	Long-term care settings	Not reported	Qualitative study using focus groups with care staff	Not reported, possibly one of the authors
Let’s Respect 2011 <sup>29</sup>	UK	Guide to practice	–	–	–	–
Mackenzie 2009 <sup>45</sup>	UK	Guide to practice	–	–	–	–
McCarthy 2011 <sup>28</sup>	UK	Guide to practice	–	–	–	–
McKeown 2010 <sup>14</sup>	UK	Evaluation of LSW	NHS inpatient and day care settings	Four people with dementia, their family carers and care staff	Multiple case study design. Semistructured interviews, observation and conversation	Author facilitated
Murphy 1994 <sup>9</sup>	UK	Evaluation of LSW project	Nursing homes	34 care and nursing staff in two homes, seven family friends/carers, four people with dementia	Individual interviews – not clear if structured or unstructured	Not clear – perhaps advocacy service that funded project

First author and date	Country	Type of publication or study	Setting	n involved	Methods used, if research	Who delivered LSW?
Murphy 2000 <sup>59</sup>	UK	Description of LSW and guide to practice	–	–	–	–
Price 2010 <sup>48</sup>	UK	Description of LSW project	Specialist ward in NHS trust	–	–	Care staff
Rainbow 2003 <sup>47</sup>	UK	Guide to practice	–	–	–	–
Rose 2006 <sup>30</sup>	UK	Description of LSW	Range of settings	–	–	Author who is a film-maker works with people with dementia and family members
Savitch 2011 <sup>26</sup>	UK	Guide to practice	–	–	–	–
Smith 2009 <sup>35</sup>	Canada	Description of LSW project (related to studies 25 and 72)	See 25 and 72	See 25 and 72	See 25 and 72	See 25 and 72
Thompson 2010 <sup>52</sup>	UK	Evaluation of LSW project	Seven older adult mental health service wards in two NHS trusts	Various	Mixed methods design, including before and after test of staff attitudes and staff questionnaire, reflection, and feedback from family members	Admiral Nurses worked with staff to facilitate use of LSW
Thompson 2011 <sup>36</sup>	UK	Guide to practice	–	–	–	–
Thwaites 2010 <sup>46</sup>	UK	Description of LSW project	Inpatient setting in NHS trust	–	–	Care staff
USDSDC 2011 <sup>49</sup>	UK	Guide to practice	–	–	–	–
van den Brandt-van-Heek 2011 <sup>25</sup>	The Netherlands	Guide to practice	–	–	–	–
Williams 2011 <sup>43</sup>	USA	Evaluation of feasibility and acceptability of LSW	Veterans' health service settings or own home	12 veterans with diagnosed early-stage dementia	Observational checklist and short interview survey of people with dementia	Not clear, possibly author
Yasuda 2009 <sup>42</sup>	Japan	Evaluation of LSW	Memory clinic	15 memory clinic outpatients with probable diagnosis of AD	Experimental ABCA design, with TV programmes as control conditions	Authors
N/A, not applicable; n.o.s., not otherwise specified; USDSDC, University of Stirling Dementia Services Development Centre.						

**BOX 1** Initial theories of change from mind mapping

1: increases understanding of person in family and intergenerational context.

1.1: which provides knowledge of personal identity and meaning.

**1.1.1: which enables personalised nursing care.**

2: increases (staff) knowledge of person with dementia.

2.1: which increases staff respect for people with dementia.

**2.1.1: which improves ability to provide personalised care.**

**2.2: which increases tolerance, understanding and empathy of care staff.**

2.3: which changes view of person's adaptability, goal setting and interaction skills.

2.3.1: which prompts more meaningful interaction.

2.3.1.1: which provides more positive staff attitudes and job satisfaction.

**2.3.1.1.1: which improves QoL for people with dementia.**

3: facilitates meaningful conversation with person.

3.1: which increases staff knowledge of and comfort with the person with dementia.

3.1.1: which enables staff to modify their behaviour to meet specific needs of people with dementia.

**3.1.1.1: which leads care staff to respect and promote people with dementia's remaining 'competencies'.**

4: can assist communication.

**4.1: which aids development of positive relationship between people with dementia and others.**

5: provides mechanism for **increasing connection between staff and person with dementia.**

6: promotes more individualised approaches to interaction with person.

**6.1: which leads to more mutually satisfying communication between people with dementia and staff.**

7: makes personhood of person with dementia more 'accessible' to others.

7.1: which restores the person's history.

**7.1.1: which helps to improve communication between people with dementia and staff in care environment.**

**BOX 1** Initial theories of change from mind mapping (*continued*)

8: provides foundation for interactions between staff and family.

8.1: which reinforces unique expertise and legitimacy of family's knowledge and its importance in care context.

8.1.1: which balances out technical expertise of staff.

8.1.1.1: which alters power relationships in nursing home environment.

**8.1.1.1.1: which promotes more equal and collaborative relationship between staff and family.**

8.2: which gives staff information that captures unique narratives of the person with dementia.

8.2.1: which supplements 'medical discourse' usually predominant in nursing home care.

**8.2.1.1: which provides basis for new modes of discourse and ways of thinking about people with dementia.**

9: signifies that family/friend are trying to make work of staff more satisfying.

9.1: which shows that the family/close person values the work of staff.

**9.1.1: which endorses a shared family/staff goal of person-centred care.**

10: provides organisationally sanctioned role for family and friends in gathering and relaying the life story.

**10.1: which assists care staff to personalise care for residents.**

11: activity symbolises family members' continuing loyalty to the person with dementia.

**11.1: which reshapes carer/family member's experiences of the illness of the person with dementia.**

11.2: which allows families to experience themselves as a group.

11.2.1: which provides them with vital support.

11.2.1.1: which helps to 'normalise' experience of placing people with dementia in long-term care.

**11.2.1.1.1: which helps remove stigma and shame.**

12: signifies continued involvement of family/friends.

**12.1: which endorses a shared family/staff goal of person-centred care.**

13: allows family/friends to gain distance from immediate situation of person.

13.1: which thereby affirms the whole life of the people with dementia.

**13.1.1: which helps families 'heal from trauma and guild of nursing home placement'.**

**BOX 1** Initial theories of change from mind mapping (*continued*)

14: provides a new technique to assist family member.

14.1: which empowers family member by increasing sense that they can make a difference to how person with dementia is seen (in care environment).

**14.1.1: which can help to alleviate family members' sense of helplessness.**

15: provides a legacy of memories and family history/captures things that would otherwise be lost.

15.1: which provides an 'exit gift'.

15.1.1: which is a legacy.

**15.1.1.1: but also can help family members work through cognitive and eventual actual loss of person with dementia.**

15.2: which becomes an external memory aid and communication resource.

**15.2.1: which prompts interesting conversations with person with dementia.**

16: allows family members to reacquaint themselves with person's past and individuality.

16.1: which reactivates family pride in the person with dementia.

**16.1.1: which helps elicit more meaningful, pleasurable interactions between family and person with dementia.**

17: provides pleasurable or engaging moments/conversations for person and family member/carer.

**17.1: which increases communication between them.**

**17.2: which supports identity, communication and well-being.**

18: structures time in a satisfying and pleasant way.

18.1: which competes with time that might otherwise be filled with agitation.

**18.1.1: which reduces discomfort of people with dementia.**

**18.1.2: which reduces burden on caregivers.**

19: triggers predominantly positive emotions (and occasional moments of sadness).

**19.1: which supports identity, communication and well-being.**

**BOX 1** Initial theories of change from mind mapping (*continued*)

20: provides a gateway to activities that memory makes possible.

**20.1: which allows reviewing the past.**

**20.2: which allows connecting to family members.**

21: emphasises what can be remembered rather than what cannot.

**21.1: which can raise self-esteem and improve well-being of people with dementia.**

22: stimulates/supports reminiscence of past events.

**22.1: which supports identity, communication and well-being.**

23: helps person to remember distant past.

**23.1: which counters threats to personhood.**

24: conveys texture and detail of the person's life.

24.1: which may improve understanding of the person with dementia.

**24.1.1: which may help to improve care.**

25: reinforces personal identity.

**25.1: which leads to preservation of personhood.**

26: values past lives.

26.1: which helps people with dementia to value themselves.

**26.1.1: which improves QoL for people with dementia.**

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Final outcomes are shown in bold.



**BOX 2** Concluding theories of change from mind mapping

1: family members involvement in LSW leads to greater involvement in life of care home.

**1.1: leads to greater knowledge of the families of the person with dementia.**

2: creates stronger bonds between (family) carers than conventional family involvement mechanisms.

2.1: which may lead to carers becoming a more autonomous interest group.

2.1.1: which means that their voice may be more strongly heard in the system.

**2.1.1.1: which may affect the social climate of the care home.**

3: leads to interactions with family members.

**3.1: strengthened understanding of and relationship with family members.**

4: leads to staff and family carers using knowledge of people with dementia in their 'intergenerational context'.

4.1: leads to social stimulation for the resident.

**4.1.1: leads to 'benefits' for residents.**

4.2: empowered staff.

**4.2.1: to provide individualised and 'less pathologically oriented care'.**

5: increases staff awareness of experience and meaning of caring for family member with dementia.

5.1: leads to engagement in more participatory approach.

5.1.1: which promotes insight into and appreciation of how to work with family carers.

**5.1.1.1: which leads to more 'inclusive delivery and planning of dementia care.**

**5.1.1.2: which improves care outcomes for residents.**

6: is an enjoyable and a shared process.

6.1: which reduces concerns about behaviour of people with dementia.

**6.1.1: which leads to reported improved mood and reduced problem behaviours for people with dementia.**

7: means family carers are less bothered by problem behaviours.

**7.1: which leads to reported improved mood and reduced problem behaviours for people with dementia.**

**BOX 2** Concluding theories of change from mind mapping (*continued*)

8: provides family carers with a 'sounding board'.

8.1: which helps them see people with dementia as 'creating fewer problems.

8.1.1: leads to carers feeling more focused and able to plan for the future.

**8.1.1.1: leads to lowered measured burden scores.**

9: helps to recognise the (family) carers' legitimate and unique contribution to care.

**9.1: which leads to increased involvement in and connection to the place of care.**

10: helps family carers feel more in charge.

10.1: which enables them to organise their caregiving 'in a more efficient manner'.

**10.1.1: which 'strengthened them in their caregiving processes'.**

11: empowers family members to contribute family knowledge.

11.1: knowledge is shared with, recognised and valued by staff.

**11.1.1: which leads to increased sense of satisfaction for family carers.**

12: facilitates intergenerational interaction by preserving family legacy.

**12.1: which supports in the person with dementia the 'generativity or desire to give of oneself to future generations'.**

13: creates legacies for family members.

**13.1: which preserves long-term memories before they are lost to advancing illness.**

14: leads to sharing of life story with family members.

**14.1: helps maintain 'accurate memories of the self'.**

15: enables family members to discover more about their family history.

15.1: which generates shared interest for family carers.

**15.1.1: which helps family members to see more of the person 'beyond the dementia'.**

16: allows family/close people to break free of 'disease saturated narrative'.

16.1: associated with fuller sense of meaning and accomplishments of life of people with dementia.

**16.1.1: which helps family/close people deal with impact of dementia.**

**BOX 2** Concluding theories of change from mind mapping (*continued*)

17: helps family members recall the person they knew prior to the onset of disease.

17.1: leads to family members re-engaging with people with dementia.

**17.1.1: leads to enhanced personal coping for family members/carers.**

17.2: leads to family members shifting perception of people with dementia.

**17.2.1: leads to enhanced personal coping for family members/carers.**

18: revives memories of the 'whole person'.

18.1: enables family carers to step out of their everyday experience.

**18.1.1: leads to them seeing beyond 'disease saturated context'.**

19: brings carers back in touch with pre-dementia memories.

19.1: which they then share with the other carers.

19.1.1: which enables them to see what has been lost but also what they have 'refound' which was previously obscured by 'disease saturated narratives'.

**19.1.1.1: which allows carers to connect with grieving processes.**

20: allows family member to 'show' the person their relative was.

20.1: which helps to maintain 'continuity' of the person.

20.1.1: which leads to upholding personhood of people with dementia.

**20.1.1.1: which enhances possibility of staff providing person-centred care.**

21: enhances resident and care staff communication.

21.1: helps with staff job satisfaction.

**21.1.1: which might have longer lasting effect on care environment.**

22: enables staff to take an interest in the story of the person with dementia.

22.1: which engenders a sense of being valued and being interesting.

**22.1.1: which can lead to people with dementia taking pride in themselves.**

**22.1.2: which values their lives.**

**BOX 2** Concluding theories of change from mind mapping (*continued*)

23: increased recognition of people with dementia's history, personhood and life experiences.

**23.1: leads to self-affirmation for people with dementia.**

**23.2: leads to enhanced communication and social interaction between family members.**

24: enables staff to gain fuller and more dynamic picture of people with dementia.

24.1: which increases their knowledge of the person.

**24.1.1: which enables them to find out more about person's needs and behaviour.**

**24.1.2: helps staff see person in context of whole life rather than in terms of their medical condition/physical needs.**

24.1.3: which provides a talking point between staff and people with dementia.

**24.1.3.1: which helps develop common bond between people with dementia and staff.**

25: increases knowledge of former interests and tastes of people with dementia.

25.1: which is input into care planning.

**25.1.1: which allows for provision of more meaningful activities for people with dementia.**

26: increases knowledge of the 'normal life' of the person with dementia.

26.1: helps care staff to relate to individual as someone who is 'knowable'.

26.1.1: which facilitates empathetic identification.

**26.1.1.1: which helps to transcend the 'job' aspect of caregiving.**

**26.1.1.2: which helps staff to 'approach the daily routine of work on a more humane level'.**

27: increases knowledge of resident's personal past.

**27.1: leads to increased understanding of current actions or behaviour of people with dementia.**

28: increases knowledge of care staff about people with dementia.

28.1: which may help staff to form more genuine and empathetic relationships with residents.

28.1.1: which may assist care staff to individualise their approach to the resident.

**28.1.1.1: which may help to minimise residents' aggression.**

**BOX 2** Concluding theories of change from mind mapping (*continued*)

29: increases understanding of care staff about people with dementia.

29.1: leads to staff seeing person beyond being a patient.

**29.1.1: leads to person-centred care.**

30: increases staff knowledge about the person with dementia.

30.1: which helps to make the person 'more real'.

30.1.1: which enables staff to see the person with dementia as an individual.

**30.1.1.1: which helps them to deliver better care.**

31: increases staff knowledge about people with dementia.

**31.1: which enables a less 'one dimensional' perception of the person.**

**31.2: which enables more individualised conversation.**

32: helps staff have greater knowledge of the person with dementia.

32.1: which enables them to see beyond the dementia.

**32.1.1: which might enhance job satisfaction while working with challenging group.**

33: improves attitudes of staff towards people in their care.

33.1: which increases staff awareness of positives of working with older people.

**33.1.1: which enables family members to feel more satisfied with care that the residents received.**

34: using outputs, reminds people with dementia, staff and family members of enduring capabilities of people with dementia.

34.1: which leads to enhanced interactions with and for people with dementia.

34.1.1: which leads to better solutions to behavioural issues being adopted.

**34.1.1.1: which enables more satisfying interactions**

**34.1.1.2: which reduces anxiety, agitation or boredom.**

**34.2: which leads to improved communication.**

35: creates something new which represents the uniqueness of the person with dementia.

**35.1: which signals family loyalty.**

**35.2: which is a concrete representation of family expertise.**

**BOX 2** Concluding theories of change from mind mapping (*continued*)

36: leads to focus on preserved abilities rather than areas of weakness.

36.1: people with dementia may continue to stay involved in their environment.

**36.1.1: which may lead to longer-term maintenance of abilities and slowed rate of decline in discourse, functional ability, emotional well-being and global functioning.**

37: offsets negative feelings associated with dementia for the person with dementia.

**37.1: which may enhance well-being of people with dementia.**

38: offers people with dementia opportunity to share significant or important facts with staff.

38.1: which gives opportunity of reciprocity – ‘giving something back’.

**38.1.1: which redresses imbalance of power between people with dementia and staff.**

39: provides information which can provide common ground for conversation between staff and residents.

39.1: leads to increased understanding and appreciation of the resident.

**39.1.1: which helps staff see person with dementia as an individual.**

40: leads to engagement in meaningful conversations.

40.1: person with dementia continues to stay involved in their environment.

**40.1.1: leads to longer-term maintenance of abilities and slowed rate of decline in discourse, functional ability, emotional well-being and global functioning.**

41: allows voice of person with dementia to be heard.

**41.1: which enhances possibility of staff providing person-centred care.**

42: increased sense of being listened to for people with dementia.

**42.1: which increases the sense of control for the person with dementia in relation to interactions with others.**

43: via a ‘therapeutic listener’ elicits troubling memories.

43.1: which allows people with dementia to work through these memories or integrate them into their lives.

**43.1.1: which leads to resolution of long-standing emotional issues.**

44: provides a ‘listening tool’.

44.1: which enables staff to identify and understand individual needs of people with dementia.

**44.1.1: which leads to more person-centred care.**

**BOX 2** Concluding theories of change from mind mapping (*continued*)

44.2: which provides way of passing information about people with dementia between care settings.

**44.2.1: which leads to more person-centred care.**

45: mode of display (video) catches attention of people with dementia.

45.1: which allows them to focus their attention for substantial periods of time.

**45.1.1: which leads to improved psychological stability.**

**45.1.2: which leads to reduced (family) carer burden.**

46: [concrete nature of LSW product] enables knowledge about the person with dementia to circulate round the care home.

**46.1: which has an impact on the entire social environment of the home.**

47: [nature of LSW product] provides easy access to information about lives of people with dementia.

47.1: which increases staff knowledge about residents.

**47.1.1: which might, but does not always, lead to change in staff behaviour.**

47.1.2: which might, but does not always, lead to changes in care outcomes for residents.

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Final outcomes are shown in bold.

**TABLE 13** Details of the focus groups and people with dementia who took part

Group	Date focus group held	Type of group	Location	Experience of LSW	Participants (female/male split)
DF1	January 2013	Voluntary sector day service	South of England	Minimal (we introduced the idea using props)	10 (six female, four male)
DF2	January 2013	Voluntary sector reminiscence group	South of England	Some (participants were all members of a reminiscence group so were familiar with the concept)	Five (four female, one male)
DF3	February 2013	User-led support and campaigning group	North-west of England	Considerable (five participants had been supported to do LSW through the NHS)	Seven (three female, four male)
DF4	February 2013	Support group held in a church	North-east of England	Minimal (we introduced the idea using props)	Three (two female, one male)
Total	25 participants with dementia (15 female, 10 male)				

**TABLE 14** Details of the focus groups and carers who took part

Group	Date focus group held	Location	Participants (female/male split)	Current/former carers	Relationships to people with dementia
CF 1	January 2013	London	Six (three female, three male)	Five current/one former	Three daughters, one son, one son-in-law and one husband
CF2	February 2013	London	Seven (six female, one male)	Seven current	Two daughters, one son, one granddaughter, three wives
CF3	February 2013	York	Eight (seven female, one male)	Five current/three former	Three daughters, one daughter-in-law, one niece, two wives, one husband
Total	21 carer participants (16 female, 5 male)				

**TABLE 15** Details of focus groups and professionals who took part

Group	Date focus group held	Location	Participants (female/male split)	Roles	Settings (where LSW had been used)
PF 1	February 2013	London	Nine (eight female, one male)	OTs, nurse, day centre managers, housing association officer, library worker, self-employed	Acute mental health wards, early diagnosis unit, day services, community (with families), supported housing, hospital library, care homes
PF2	February 2013	York	Eight (eight female, none male)	Arts and health practitioner, assistant psychologists, OT, care worker, support worker, volunteer co-ordinator, voluntary sector manager	Care homes, inpatient assessment unit, MAS, older adults' mental health service, retirement villages and nursing homes, community, day services
PF3	February 2013	York	10 (10 female, none male)	Speech and language therapists, OTs, OT technical instructor, research nurse, care home managers, social work manager	Community mental health teams, assessment and treatment community service, general hospital, specialist dementia residential care, day services, reablement
Total	27 professional participants (26 female, 1 male)				



**TABLE 16** Details of sampling frames, sampling fraction and sample sizes for survey of services

Category of service	Source of information	Number of potential organisations identified	Issues with source	Filtering/sampling of numbers	Number of services/settings after filtering/sampling	Sampling proportion (%)	Final sample size
Memory clinics/services	Royal College of Psychiatrists website	146	Most have physical address but no e-mail or contact name	Contacted all and asked for e-mail contact. Some services no longer in existence and some were found that were not on original list	114	100	114
SCHs	CQC database – care homes (with or without nursing) which specify dementia as their sole specialism	134	Most have name of registered manager and telephone number	Contact with these to check nature of service provision and identify e-mail contact to generate final sample	134	100	122
IPAs	Mental health NHS trusts in CQC database of registered health and social care providers. Then checked against the NHS Choices website	66 trusts clearly identified as providing mental health services	Trusts listed as providers of one or more dementia specialist services, but not clear what these services are	Contacted trusts and also a clinical psychologists' network. Identified wards in trusts identified as providing inpatient assessment services	89	100	89
CDSs	CQC database – registered social care or health-care organisations (not care homes) registered for care of people with dementia and providing relevant service type <sup>a</sup>	4907 social care 204 NHS 42 independent health care	Physical address provided but not always e-mail contact name	Random 3% sample of 5153 identified organisations. Contact with all of these to check nature of service provision and identify e-mail contact to generate final sample	150	3, with further direct contact	101
Generalist long-term care homes	CQC database – care homes (with or without nursing) that do not specify dementia as their sole specialism but that are registered for care of people over the age of 65 years and for dementia care	3051	Most have name of registered manager and telephone number	Random 5% sample of 3051 care homes. Contact with these to check nature of service provision and identify e-mail contact to generate final sample	150	5, with further direct contact	139
Total		8550			637		565

CQC, Care Quality Commission.

<sup>a</sup> Relevant services types: community-based services for people with mental health needs; community health-care service (nursing agencies); community health-care service; domiciliary care service; extra care housing service; long-term conditions service; Shared Lives; supported living service.

**TABLE 17** Percentage response rate by type of service

Service category	Number of survey links distributed	Number of services found to be 'out of scope' <sup>a</sup>	Number of services 'in scope'	Number of returned questionnaires	% response rate of in scope
Memory clinics/services	114	1	113	72	64
SCHs	122	0	122	75	61
IPAs	89	2	87	61	70
CDSs	101	1	100	52	52
Generalist long-term care homes	139	0	139	44	32
Not classifiable	—	—	—	3	< 0.1
Total	565	4	561	307	58

a No longer providing service.

**TABLE 18** Estimate of the numbers and proportion of services/settings that carry out LSW currently or refer people elsewhere for LSW

Service category	% of services or settings that responded (a)	% of responding services that carried it out or referred to other services for LSW (b)	Sampling proportion (%)	Population size (c)	Estimated % of all services carrying out LSW currently or refer to another service for LSW ( $d = b/100 \times a$ )	Estimate of number of services/settings where LSW is currently carried out ( $d/100 \times c$ )
Memory clinics/services	64	44.4	100	146	28.4	41
Dementia specialist care homes	61	78.7	100	134	48.0	64
IPAs	70	88.5	100	89	62.0	55
CDSs	52	26.9	3	5153	14.0	721
Generalist care homes	32	70.5	5	3051	22.6	689

Three missing cases.

**TABLE 19** Type of record used for LSW by type of service

Type of record included in life story	% of service using specified type of record					
	Memory assessment	SCH	Inpatient assessment	CDS provider	Generalist care home	All
Photo album	36	33	37	43	35	36
Photo album with text/stories	76	32	53	21	41	45
Book with mix of photos and text	72	47	45	36	45	49
Written summary	44	72	78	57	83	70
Box or other container with important objects/memories	56	40	37	36	31	40
Collage or display for wall/door	24	22	24	14	24	22
DVD or film	16	0	4	0	10	5
Poem	4	2	6	7	7	6
<i>n</i> (100%) <sup>a</sup>	25	60	51	14	29	179
a Sums to > 100 because of multiple responses. Ten missing cases.						

**TABLE 20** Main uses of a life story, most important use of a life story and most important use of a life story by type of service

Uses of life story	% of respondents selecting	% of respondents choosing this option who then said it was the most important	Type of service that most often chose this option as the most important (% choosing)	Type of service that least often chose this option as the most important (% choosing)
Help person remember important parts of their lives	89	14	SCHs (20) and community care providers (20)	Inpatient assessment (4)
To give pleasure to person when they look at it	82	10	MAS (25)	Generalist care home (0)
To help soothe or calm person	81	3	Inpatient assessment (7)	Generalist care home (0) and community care provider (0)
To help staff see person behind the dementia	98	55	Generalist home care (75)	MAS (38)
As something for person and staff to enjoy looking at together	81	10	SCH (13)	MAS (0)
As something for person and family member/close person to enjoy looking at together	84	7	MAS (21)	SCH (2)
So that health/social care workers elsewhere can provider better care	72	10	Inpatient assessment (17)	Community care provider (0)
<i>n</i> (100%)	181 <sup>a</sup>	179 <sup>b</sup>	179 <sup>b</sup>	
a Eight missing cases. b Ten missing cases.				

**TABLE 21** Inclusion of information about family members and other people close to the person with dementia and whether or not this varied by services and settings

Type of information	Always included (%)	Sometimes included (%)	Never included/not answered (%)	n (100%)	Comparison of services/settings
Names	78	16	5	189	$\chi^2 = 31.25$ , df = 8; $p < 0.0001$
Details/descriptions	46	42	12	189	$\chi^2 = 33.65$ , df = 8; $p < 0.0001$
Reactions to and meanings of this person	20	44	36	189	$\chi^2 = 19.18$ , df = 8; $p = 0.014$
Percentages may not sum to 100% because of rounding.					

**TABLE 22** Inclusion of information about life events and whether or not this varied by services and settings

Type of information	Always included (%)	Sometimes included (%)	Never included/not answered (%)	n (100%)	Comparison of services/settings
List of important events, dates, places, stage of life	62	24	13	189	$\chi^2 = 11.73$ , df = 8; $p = 0.163$
Details about the above	67	22	11	189	$\chi^2 = 15.26$ , df = 8; $p = 0.054$
Feelings about the above	42	40	19	189	$\chi^2 = 10.11$ , df = 8; $p = 0.257$
Percentages may not sum to 100% because of rounding.					

**TABLE 23** Inclusion of information about likes and dislikes and whether or not this varied by services and settings

Type of information	Always included (%)	Sometimes included (%)	Never included/not answered (%)	n (100%)	Comparison of services/settings
What they like to eat	73	12	15	189	$\chi^2 = 25.59$ , df = 8; $p = 0.003$
What they like to wear	66	19	15	189	$\chi^2 = 25.17$ , df = 8; $p = 0.001$
What they like doing	82	8	11	189	$\chi^2 = 25.91$ , df = 8; $p = 0.001$
What they like to talk about	68	18	14	189	$\chi^2 = 19.66$ , df = 8; $p = 0.012$
What they prefer not to talk about	53	28	19	189	$\chi^2 = 17.49$ , df = 8; $p = 0.025$
Percentages may not sum to 100% because of rounding.					

**TABLE 24** Information about personal needs and whether or not this varied by services and settings

Type of information	Always included (%)	Sometimes included (%)	Never included/not answered (%)	n (100%)	Comparison of services/settings
Medical or care needs	30	27	44	189	$\chi^2 = 23.83$ , df = 8; $p = 0.002$
Spiritual or cultural needs	59	28	13	189	$\chi^2 = 24.99$ , df = 8; $p = 0.002$
Percentages may not sum to 100% because of rounding.					

**TABLE 25** Dynamic nature of LSW and whether or not this varied by services and settings

Type of life story	% of services or settings						Comparison of services/settings
	Memory service	SCH	Inpatient assessment	Community care provider	Generalist care home	All	
One-off, nothing added	11	13	26	20	3	15	$\chi^2 = 8.61$ , df = 4; $p = 0.072$
Things about the past added along the way	57	64	62	60	70	63	$\chi^2 = 1.156$ , df = 4; $p = 0.885$
Things about recent events added as they happen	21	53	26	47	53	40	$\chi^2 = 15.35$ , df = 4; $p = 0.004$
n (100%)	28	61	55	15	30	189	

**TABLE 26** Who can look at the life story and whether or not this varied by services and settings

Who can look at the life story?	% of services or settings						Comparison of services/settings
	Memory service	SCH	Inpatient assessment	Community care provider	Generalist care home	All	
The person with dementia	96	91	96	93	96	94	$\chi^2 = 1.575$ , df = 4; $p = 0.813$
Family members and close people	100	93	98	100	89	95	$\chi^2 = 6.13$ , df = 4; $p = 0.189$
Selected staff who work here	50	23	28	47	39	32	$\chi^2 = 7.68$ , df = 4; $p = 0.104$
Any staff who work here	5	5	69	7	0	24	$\chi^2 = 82.70$ , df = 4; $p < 0.0001$
Staff elsewhere	5	5	18	13	0	15	$\chi^2 = 9.17$ , df = 4; $p = 0.06$
n (100%)	28	61	55	15	30	189	
Nineteen missing cases.							

**TABLE 27** If the person with dementia gives permission for others to look at their life story and whether or not this varies by services and settings

Does the person with dementia give permission?	% of services and settings					
	Memory services	SCH	Inpatient assessment	Community care provider	Generalist care home	All
Always	82	63	35	87	73	61
Sometimes	5	23	57	7	27	30
Never or not known	14	14	8	7	0	9
<i>n</i> (100%)	22	56	51	15	26	170
$\chi^2 = 34.62$ , <i>df</i> = 8; <i>p</i> < 0.0001. Nineteen missing cases.						

**TABLE 28** Where the life story is kept and whether or not this varies by services and settings

Where life story is usually kept	% of services and settings <sup>a</sup>						Comparison of services/settings
	Memory services	SCH	Inpatient assessment	Community care provider	Generalist care home	All	
Person with dementia keeps it	100	29	43	47	31	44	$\chi^2 = 35.30$ , <i>df</i> = 4; <i>p</i> < 0.0001
Family member keeps it	0	0	0	7	0	< 1	$\chi^2 = 10.39$ , <i>df</i> = 4; <i>p</i> = 0.34
In office or other secure place	0	27	4	33	23	17	$\chi^2 = 18.43$ , <i>df</i> = 4; <i>p</i> = 0.001
In person's care record	14	66	65	60	85	61	$\chi^2 = 27.79$ , <i>df</i> = 4; <i>p</i> < 0.0001
On display	5	14	16	0	4	11	$\chi^2 = 6.08$ , <i>df</i> = 4; <i>p</i> = 0.193
<i>n</i> (100%)	22	56	51	15	26	170	
<sup>a</sup> Sums to more than 100% because of multiple responses. Nineteen missing cases.							

**TABLE 29** Policies and practices to support LSW and whether or not these varied by services and settings

Policy or practice	% of services having this policy or practice						N (100%)	Comparison of services/setting
	Memory services	SCH	Inpatient assessment	Community care provider	Generalist care home	All		
Responsiveness to individual need								
Offer LSW to everyone regardless of stage of dementia	43	86	90	92	86	82	156	$\chi^2 = 25.73$ , df = 4; $p < 0.0001$
People with dementia with a visual impairment are offered opportunity to do LSW	91	98	96	100	95	96	153	$\chi^2 = 2.84$ , df = 4; $p = 0.586$
How LSW is done is adjusted, depending on the needs and strengths of the person with dementia	96	89	92	100	87	91	159	$\chi^2 = 2.78$ , df = 4; $p = 0.596$
Use a template to guide LSW throughout	81	77	88	46	52	75	158	$\chi^2 = 16.76$ , df = 4; $p = 0.002$
Decisions about format and look of life story made mainly by staff/volunteers who do LSW	33	44	69	23	33	47	152	$\chi^2 = 16.18$ , df = 4; $p = 0.003$
Training and supervision of those carrying out LSW								
Staff/volunteers do own LSW before working with service users	14	10	6	43	5	11	156	$\chi^2 = 16.13$ , df = 4; $p = 0.003$
Staff learn how to do LSW 'on the job' rather than through training	62	73	52	62	76	64	154	$\chi^2 = 6.02$ , df = 4; $p = 0.198$
Staff doing LSW get regular supervision from senior or more experienced staff	62	73	94	100	86	82	153	$\chi^2 = 16.49$ , df = 4; $p = 0.002$
We train family members/close people before they do LSW	33	22	19	46	25	25	152	$\chi^2 = 5.12$ , df = 4; $p = 0.275$

Policy or practice	% of services having this policy or practice						N (100%)	Comparison of services/settings
	Memory services	SCH	Inpatient assessment	Community care provider	Generalist care home	All		
Knowledge of LSW and use across service/setting								
Everyone who works/volunteers here knows what LSW is	52	80	69	85	74	72	152	$\chi^2 = 7.14$ , df = 4; $p = 0.129$
Everyone who works/volunteers here knows how to use a life story to improve care of person with dementia	33	80	61	85	67	66	153	$\chi^2 = 15.53$ , df = 4; $p = 0.002$
Institutional policies to support LSW and whether or not these varied by services and settings								
LSW is done in spare moments in care routine	32	38	55	43	52	45	158	$\chi^2 = 5.06$ , df = 4; $p = 0.281$
LSW done in dedicated and protected time	48	67	37	62	52	52	157	$\chi^2 = 9.61$ , df = 4; $p = 0.048$
Senior staff are fully committed to LSW being done	67	96	83	100	91	88	156	$\chi^2 = 15.01$ , df = 4; $p = 0.005$
Any staff wanting to do LSW will have time freed up from other duties	38	87	51	77	83	68	158	$\chi^2 = 25.94$ , df = 4; $p < 0.0001$



**TABLE 30** Use of the life story reported by carers

Uses of life story	Number of carers reporting this use	Number of carers reporting this as the most important use
Help person remember important parts of their lives	31	14
To give pleasure to person when they look at it	26	12
To help soothe or calm person	12	9
To help carer remember the person	18	7
As something for carer and person to enjoy looking at together	25	8
Something to share with family members/close people	24	7
So that health/social care workers can provide better care	25	17
Total (n)	38	38
One missing case.		

**TABLE 31** Information included in the life story reported by carers

Type of information	Number of carers reporting this is included in the life story
Names of family and close people	31
Details/descriptions of family and close people	21
Reactions to family and close people	13
List of important events, dates, places, stage of life	24
Details about the above	29
Feelings about the above	12
What likes to eat	19
What likes to wear	12
What likes doing	26
What likes to talk about	20
What prefers not to talk about	5
Medical or care needs	12
Spiritual or cultural needs	14
Total (n)	38
One missing case.	

**TABLE 32** Temporal orientation of the life story reported by carers

Temporal orientation of the life story	Number of carers reporting that the life story included this
Memories and information about the past	37
Current information	22
Hopes and views about the future	5
Total (n)	38
One missing case.	

**TABLE 33** Where the life story is kept

Location of the life story	Number of carers reporting this
In the home of the person with dementia	19
In the carer's home	5
At a day centre	1
At the care home where the person with dementia lives	20
Total (n)	38
One missing case.	

**TABLE 34** How often the life story is or was looked at and by whom

Who looks?	How often this person looks or looked at the life story					Total (N)
	Every week	Every month	Less than every month	Never	Do not know	
Carer	13	10	9	2	3	37
Person with dementia	13	7	8	4	5	37
Care professionals/staff	7	3	6	7	10	33

**TABLE 35** Characteristics of care homes

Care home ID	Number of rooms	Proportion with dementia or dementia like symptoms (%)	Percentage self-funders (%)	Manager	Original site?
CH1	39	67	38	Remained	Replacement
CH2	41	37	34	Changed	Original
CH3	35	50	63	Remained	Original
CH4	40	35	90	Remained	Original
CH5	40	74	31	Changed	Original
CH6	38	100 (SCH)	66	Remained	Replacement
CH, care home; ID, identification.					

**TABLE 36** Characteristics of specialist mental health assessment units

Ward ID	Beds	Intake	Ward manager	LSW
IW1	12	Mixed ward (some functional, some organic)	Remained	Established
IW2	10	Organic	Changed	Established
IW3	11	Organic	Remained	Established
CW	18	Mixed ward (some functional, some dementia)	Remained	None
CW, comparison ward; ID, identification.				

**TABLE 37** Recruitment of staff in care homes

Care home ID	Staff trained	Staff recruited	Conditions for recruitment
CH1	12	11 (92%)	Dedicated room, staff met the researchers individually or in small groups
CH2	Missing <sup>a</sup>	4 (% not known) plus 1 for focus group	No dedicated space or time. Staff usually engaged in another task when they met researchers. Most asked to take the information away with them. Activities co-ordinator did not do training but was involved in delivery of LSW so was invited to the focus group at final follow-up
CH3	11	10 (91%)	Dedicated room, staff met the researchers individually or in small groups. Manager led by example
CH4	14	7 (50%)	Communal lounge, staff met the researchers individually or in small groups
CH5	6	3 (50%)	Dedicated room, but only three members of staff available to meet researchers
CH6	15	15 (100%)	Dedicated room, staff met with the researchers as a single (large) group
Total recruited		51	

CH, care home; ID, identification.  
<sup>a</sup> The manager of CH2, who had this information, left unexpectedly after a period of sickness.

**TABLE 38** Recruitment of staff in specialist mental health assessment units

Ward ID	Staff team	<i>n</i> (%) staff completed measures TP1	<i>n</i> (%) staff completed measures TP2	<i>n</i> (%) staff completed measures TP3	Total <i>N</i> completed measures	Conditions for recruitment
IW1	Morning: 4 Afternoon: 4 1 manager (Total 9)	8 (89)	8 (89)	8 (89)	24	Dedicated room; all staff aware of researcher's presence
IW2	Morning: 5 Afternoon: 5 1 manager 3 part-time OT technicians (WTE 1.4) (Total 14)	7 (58)	8 (65)	5 (40)	20	Dedicated room, but staff 'extremely busy' at TP3
IW3	Morning: 4 Afternoon: 4 1 manager (Total 9)	7 (78)	8 (89)	6 (67)	21	Dedicated room, but staff seemed unaware of researcher's presence for some of TP3
CW	Morning: 6 Afternoon: 6 1 manager 1 OT (Total 14)	7 (50)	6 (43)	6 (43)	19	No dedicated room at TP2; researchers approached staff while they were working on the ward
Overall	47	30 (64)	30 (64)	25 (53)	—	

CW, comparison ward; ID, identification; TP, time point; WTE, whole-time equivalent.

**TABLE 39** Selection of people with dementia in care homes

Care home ID	Originally selected	Excluded after selection	Reselected	Total approached (directly or via consultee)
CH1	10	1	2 <sup>a</sup>	11
CH2	10	0	0	10
CH3	10	0	0	10
CH4	10	0	0	10
CH5	10	4	2 <sup>b</sup>	8
CH6	10	0	0	10
Total	60	5	4	59

CH, care home; ID, identification.

a One extra person selected here in error.

b Maximum of two additional selections reached.

**TABLE 40** Recruitment of people with dementia in care homes

Care home ID	PWD with capacity (n = 16)		PWD without capacity (n = 43)			Total	Total recruited
	Consented (self)	Refused (self)	Advised to include (consultee)	Advised not to include (consultee)	Refused consent to contact/did not respond (potential consultee)		
CH1	3	0	5	1	2	11	8
CH2	5	1	2	2	0	10	7
CH3	3	0	5	1	1	10	8
CH4	0	1	6	0	3	10	6
CH5	2	0	3	1	2	8	5
CH6	1	0	4	2	3	10	5
Total	14	2	25	7	11	59	39

CH, care home; ID, identification; PWD person with dementia.

**TABLE 41** Recruitment of family carers of people with dementia in care homes

Care home ID	People with dementia recruited	Family carers recruited	Reasons for difference in numbers
CH1	8	6	No family carers identified for two participants
CH2	7	5	Unable to make contact with one carer and another took the information but did not respond
CH3	8	6	One person with dementia had no family carer. One family member refused
CH4	6	6	N/A
CH5	5	5	N/A
CH6	5	3	One family member refused and another did not respond
Total	39	31	Three people with dementia had no family carer  Four carers refused/did not respond  One carer was unable to be contacted

CH, care home; ID, identification; N/A, not applicable.

**TABLE 42** Recruitment of people with dementia in specialist mental health assessment units

Recruitment process	IW1	IW2	IW3	CW	Total
New admissions flagged to research team as potentially eligible	9	13	20	8	50
Of these					
Excluded because staff concerned about causing distress to family	0	0	3	0	3
Excluded owing to doubt over dementia diagnosis	1	1	0	2	4
Eligible patients identified	8	12	17	6	43
Of these					
Patients transferred, discharged or died before staff approached potential consultees	5	1	4	0	10
Potential consultees not approached two months after admission: excluded	0	0	2	0	2
Potential consultee not approached one month after recruitment period finished: excluded	0	1	3	0	4
Potential consultees approached by staff	3	10	8	6	27
Of these					
Consultee refused consent to contact/did not respond to staff	1	4	1	1	7
Consultee advised not to include/did not respond to researcher	0	1	3	2	6
Patient excluded after consultee approached (e.g. fell ill)	0	0	2	0	2
Consultee advised to include the person with dementia	2	5	2	3	12

CW, comparison ward.

**TABLE 43** Recruitment of family carers of people with dementia in specialist mental health settings

Ward ID	People with dementia recruited	Family carers recruited	Reasons for difference in numbers
IW1	2	1	One carer did not want to be included as spends all day filling in forms already
IW2	5	5	N/A
IW3	2	1	One carer did not want to be included as husband is deteriorating and did not want to answer questions about his QoL
CW	3	3	N/A
Totals	12	10	

CW, comparison ward; ID, identification.

**TABLE 44** Approach to LSW implementation and organisational context

Care home ID	PWD	Numbers of study participants who actually 'did' LSW	Staff undertaking LSW	Approach to LSW	Organisational context
CH1	8	8 (100%)	Activities co-ordinator (some info collected by care staff)	Tailored to the individual	Consistent management, activities co-ordinator allocated dedicated time
CH2	7	2 (29%)	Staff who undertook training were allocated to work with named residents	'Some important things' template	Two changes in management, activities co-ordinator did not receive training
CH3	8	4 (50%)	Single member of staff undertook all LSW	Tailored to the individual	Consistent management, but activities co-ordinator left early on
CH4	6	3 (50%)	Activities co-ordinator	Tailored to the individual	Consistent management
CH5	5	1 (20%)	Staff who undertook training were allocated to work with named residents	Tailored to individual, done by volunteer	Two changes in management, activities co-ordinator did not receive training, staff suffering project fatigue
CH6	5	5 (100%)	Activities co-ordinator (some information collected by care staff)	Tailored to the individual, group activities	Consistent management, activities co-ordinator and care staff allocated dedicated time. SCH

CH, care home; ID, identification.

**TABLE 45** Approaches to collecting LSW information at each hospital site

Ward ID	Approach to collecting LSW	Use of LSW information
IW1	Ward staff give a template to carers to collect life story information	Information is compiled into hand-written booklets kept in the main office
IW2	Ward staff give a template to carers to collect life story information. Three OTTIs collect information from patients one to one and during activities	The OTTIs compile electronic life story books. Multiple copies can be printed so that both staff and patients have a copy. Life story information is posted on bedroom walls and used by staff in de-escalation
IW3	Ward staff give a template to carers to collect life story information	Any information returned is kept in care records
CW	LSW not yet implemented	LSW not yet implemented

CW, comparison ward; ID, identification.

**TABLE 46** Recruitment and retention of people with dementia in care homes

Care home ID	<i>n</i> recruited	<i>n</i> withdrawn (self)	<i>n</i> withdrawn (consultee)	<i>n</i> died	<i>n</i> remaining at 6-month follow-up
CH1	8	0	1	2	5
CH2	7	0	0	0	7
CH3	8	1	1	0	6
CH4	6	0	0	0	6
CH5	5	0	0	0	5
CH6	5	0	0	0	5
Total	39	1	2	2	34 (87%)

CH, care home; ID, identification.

**TABLE 47** Completion of measures by people with dementia in care homes and usable for analysis

Measure	<i>n</i> recruited	<i>n</i> (%) completed measures at			
		Baseline	Baseline and 1 month	Baseline and 2 month	Baseline and 6 months
QoL-AD	39	25 (64)	23 (59)	23 (59)	18 (46)
DEMQOL	39	12 (31)	12 (31)	12 (31)	12 (31)
QCPR	39	13 (33)	7 (18)	5 (13)	4 (10)

The 'I am' fluency task was administered separately to only a small number of the study participants, and is discussed in *Appendix 7*.

**TABLE 48** Recruitment and retention of people with dementia in hospital settings

Ward ID	<i>n</i> recruited	<i>n</i> withdrawn (self)	<i>n</i> withdrawn (consultee)	<i>n</i> died	<i>n</i> remaining at 6-month follow-up
IW1	2	0	0	0	2
IW2	5	0	0	0	5
IW3	2	0	0	0	2
CW1	3	0	1	0	2
Total	12	0	1	0	11 (92%)

CW, comparison ward; ID, identification.

**TABLE 49** Completion of measures by people with dementia recruited through hospital wards and usable for analysis

Measure	<i>n</i> recruited	<i>n</i> completed measures at		
		Baseline	Baseline and first follow-up (1–2 months)	Baseline and 6 month follow-up
QoL-AD	12	2	0	0
DEMQOL	12	1	0	0
QCPR	12	1	1	0

**TABLE 50** Recruitment and retention of carers of people with dementia in care homes

Care home	<i>n</i> recruited	<i>n</i> withdrawn	<i>n</i> remaining at 6-month follow-up
CH1	6	2	4
CH2	5	0	5
CH3	6	2	4
CH4	6	1	5
CH5	5	0	5
CH6	3	1	2
Total	31	6	25 (80%)

CH, care home.

**TABLE 51** Completion of measures by family carers of people with dementia in care homes and usable for analysis

Measure	<i>n</i> recruited	<i>n</i> (%) completed measures at			
		Baseline	Baseline and 1 month	Baseline and 2 months	Baseline and 6 months
CES	31	27 (87)	23 (74)	19 (61)	14 (45)
QCPR	31	30 (97)	22 (71)	18 (58)	18 (58)
QoL-AD – proxy	31	30 (97)	23 (74)	21 (68)	19 (61)
DEMQOL proxy	31	23 (74)	18 (58)	17 (55)	13 (42)



**TABLE 52** Recruitment and retention of carers of people with dementia in hospitals during the study

Ward ID	<i>n</i> recruited	<i>n</i> withdrawn	<i>n</i> remaining at 6-month follow-up
IW1	1	0	1
IW2	5	1	4
IW3	1	0	1
CW1	3	2	1
Total	10	3	7

CW, comparison ward; ID, identification.

**TABLE 53** Completion of measures by family carers of people with dementia in hospital wards and usable for analysis

Measure	<i>n</i> recruited	<i>n</i> completed measures at		
		Baseline	Baseline and second follow-up (1–2 months)	Baseline and 6 months
CES	10	10	8	7
QCPR <sup>a</sup>	10	6	6	5
CSQ	10	N/A	N/A	6 at discharge of person with dementia only
QoL-AD – proxy <sup>b</sup>	10	7	7	6
DEMQOL proxy <sup>b</sup>	10	8	5	6

CSQ, Carer Satisfaction Questionnaire; N/A, not applicable.  
<sup>a</sup> None collected at baseline for control ward.  
<sup>b</sup> None collected beyond baseline for control ward.

**TABLE 54** Recruitment and retention of care home staff

Care home ID	<i>n</i> recruited	<i>n</i> withdrawn	<i>n</i> remaining at 6-month follow-up
CH1	11	0	11
CH2	4	1	3
CH3	10	3	7
CH4	7	0	7
CH5	3	0	3
CH6	15	1	14
Total	50	5	45 (90%)

CH, care home; ID, identification.

**TABLE 55** Completion of measures by care home staff and usable for analysis

Measure	n recruited	n (%) completed measures			
		Baseline	Baseline and 1-month follow-up	Baseline and 2-month follow-up	Baseline and 6-month follow-up
ADQ	50	46 (92)	27 (54)	17 (34)	18 (36)
PDQ	50	46 (92)	21 (42)	16 (32)	16 (32)
CBI	50	48 (96)	26 (52)	17 (34)	15 (30)

**TABLE 56** Costs of developing and arranging delivery of the training package

Task	Time (hours)	Trainer costs			
		Assuming consultant annual salary (£53,000 p.a.) <sup>a</sup>	Assuming dementia training team hourly salary (£26 per hour) <sup>a</sup>	Assuming dementia training team annual salary (£38,000 p.a.) <sup>a</sup>	Assuming senior social worker hourly cost (£51 per hour) <sup>b</sup>
Course development	7.5	£294	£218	£211	£383
Course arrangements	7.5	£294	£218	£211	£383
Total	15	£588	£437	£421	£765

p.a., per annum.

<sup>a</sup> Salary-only costs were increased by 12% to allow for on-costs, excluding employer pension scheme.<sup>b</sup> Curtis.<sup>142</sup>**TABLE 57** Types and numbers of staff attending the LSW training

Type of staff member	Care home				
	1	3	4	5	6
Care assistant (no NVQ/qualification data missing)	4	4	7	3	4
Care assistant (NVQ)	5	1	4	2	5
Team leader		3	1	1	1
Activities co-ordinator	1	1	1		1
Bank/contract care assistant	2				
Laundry assistant		1			1
Night-time care assistant		1			
Care manager			1		
Night-time care leader					1
Chef manager					1
Housekeeper					1

NVQ, National Vocational Qualification.

**TABLE 58** Mean and range of costs of staff attending LSW training

	Actual salaries (assuming consultant annual salary £53,000 p.a.)	Actual salaries (assuming dementia training team annual salary £38,000 p.a.)	All hourly costs estimated (from Curtis <sup>142</sup> )
Average	£1065	£895	£1449
Range	£950 to £1145	£784 to £979	£1235 to £1581

p.a., per annum.

**Notes**

Uses actual staff costs, including £53,000 p.a. for the trainer.

Assumes that the training was provided by members of the dementia training team.

Uses hourly unit costs for the trainer and all attendees, as provided by Curtis.<sup>142</sup>

**TABLE 59** Number of participants for whom incidents were reported at baseline and follow-up

Number of incidents reported	3 months prior to baseline	3 months prior to follow-up
Number of participants with three or more incidents	9	7
Number of participants with two incidents	8	2
Number of participants with one incident	7	4
Number of participants with no incidents	14	24
Missing	0	1

**TABLE 60** Number of incidents reported and length of stay in hospital wards

	Control ward	Intervention wards
Number of patients for whom data were reported	3	8
Mean (range) length of stay (weeks)	24 (22–26)	12 (3–23)
Mean number of total incidents reported	84	75
Mean number of incidents reported per week	3.5	6.3
Maximum number of incidents reported per patient	98 over 26 weeks	255 over 16 weeks

**TABLE 61** Use of hospital inpatient services

Service	3 months to baseline		3 months to follow-up	
	Number of admissions	Total number of inpatient-days	Number of admissions	Total number of inpatient-days
Acute psychiatric unit	0	0	0	0
General medical ward	3	5	0	0

**TABLE 62** Use of hospital outpatient and emergency services

Service	3 months to baseline		3 months to follow-up	
	Number of attendances	Number of times staff accompanied resident	Number of attendances	Number of times staff accompanied resident
Psychiatric outpatient visit	1	0	0	0
Other hospital outpatient visit	4	0	1	1
Day hospital (e.g. for minor procedure)	0	0	0	0
Other (fracture clinic, radiography department)	3	1	0	0
A&E attendance (taken by ambulance)	4	2	2	0
A&E attendance (taken by family/friend)	0	0	0	0

**TABLE 63** Number of telephone calls for specialist advice

Telephone calls for specialist advice	3 months to baseline		3 months to follow-up	
	Number of calls	Attended by staff	Number of calls	Attended by staff
Call to GP for advice	8	0	9	1
Call to NHS 111 service	1	0	0	0

**TABLE 64** Primary or community services received at the care home

Professional visiting the care home	3 months to baseline		3 months to follow-up	
	Number of appointments	Number of times staff accompanied resident	Number of appointments	Number of times staff accompanied resident
GP	74	28	42	11
District nurse	67	15	65	13
Podiatrist	10	8	5	3
Community psychiatric nurse	7	5	2	0
Continence nurse	7	4	1	0
Physiotherapist	4	1	2	1
OT	4	3	1	0
Dietitian	2	2	3	2
Specialist nurse (e.g. diabetes mellitus)	2	1	2	0
Speech and language therapist	2	1	1	1
Social worker	1	0	0	0
Psychiatrist	0	0	0	0
Psychologist	0	0	0	0
Befriender	0	0	0	0
Other (chiropodist, optician, mental health team, phlebotomist, dentist)	35	18	4	4

**TABLE 65** Community-based services and other trips out of the care home

Type of service	3 months to baseline		3 months to follow-up	
	Number of appointments	Number of times staff accompanied resident	Number of appointments	Number of times staff accompanied resident
Visits to GP at the surgery	6	4	3	0
Trips out with family or friends	84	1	134	1
Other (nurse, podiatrist, dentist, church, singing, coffee morning)	20	1	6	0

**TABLE 66** Types of services and number of times received on the wards

Type of service	Number of contacts	
	Control ward, <i>N</i> = 3 patients (total inpatient-weeks = 72)	Intervention ward, <i>N</i> = 8 patients (total inpatient-weeks = 94)
Occupational therapy	53	168
Physiotherapy	37	2
Duty doctor	25	
Consultant/SHO (ward rounds)		69
Doctor review on ward (physical examination)		21
Medical assessment	1	
Art therapy	17	
Music therapy	12	
Nursing one to one		5
Social worker		5
Speech and language therapy	2	1
Podiatrist	1	1
Pharmacist		1
Dietitian		1

SHO, senior house officer.

**TABLE 67** Use of hospital outpatient or day services during stay on ward

Type of service	Number of contacts	
	Control ward, <i>N</i> = 3 patients (total inpatient-weeks = 72)	Intervention ward, <i>N</i> = 8 patients (total inpatient-weeks = 94)
A&E	1	3
CT scan	1	
Radiography		1
Colorectal appointment	3	
Urology		1
Endoscopy	1	
Hospital appointment	1	
Mammogram	1	
Opticians	1	
Chiropodist	1	

**TABLE 68** Use of prescribed medications for anxiety and depression in care homes

Name of medication	3 months to baseline	3 months to follow-up
Antipsychotics		
Amisulpride	0	1
Olanzapine	1	1
Risperidone	1	1
Hypnotics and antidepressants		
Citalopram	2	3
Diazepam	1	1
Fluoxetine	1	1
Mirtazapine	3	3
Sertraline	2	1
Trazodone	1	0
Venlafaxine	1	1
Zopiclone	4	3

**TABLE 69** Number of times medications prescribed PRN for anxiety and depression in hospital wards

Name of medication	Control ward, <i>N</i> = 3 patients (total inpatient-weeks = 72)	Intervention ward, <i>N</i> = 8 patients (total inpatient-weeks = 94)
Antipsychotics		
Haloperidol (intramuscular injection) PRN	5	0
Risperidone PRN	0	1
Hypnotics and antidepressants		
Diazepam PRN	0	4
Lorazepam (oral) PRN	37	63
Lorazepam (intramuscular injection) PRN	2	5
Promethazine PRN	1	11
Zopiclone PRN	2	10
Un-named PRN medication	20	3

**TABLE 70** Number of patients prescribed medication on an ongoing basis for anxiety and depression in hospital wards

Name of medication	Control ward, <i>N</i> = 3 patients (total inpatient-weeks = 72)	Intervention ward, <i>N</i> = 8 patients (total inpatient-weeks = 94)
Antipsychotics		
Quetiapine	1	0
Risperidone	2	1
Hypnotics and antidepressants		
Diazepam	1	2
Lorazepam	0	1

**TABLE 71** Costs of antipsychotic and other drugs

Name of medication	Pack cost (generic unless stated) <sup>a</sup>	Daily cost (£)
Antipsychotics		
Amisulpride	15 mg, 28 tablets, £96.04	3.43
Haloperidol (intramuscular injection)	£0.36	0.36
Quetiapine	4 × 100 mg, 60 tablets, £113.10 (brand only @ 100 mg)	7.54
Olanzapine	2.5 mg, 28 tablets, £21.85 (brand only @ 2.5 mg)	0.78
Risperidone	1 mg, 20 tablets, £1.01 (brand £8.36)	0.05–0.42
Hypnotics and antidepressants		
Citalopram	10 mg, 28 tablets, £1.04	0.04
Diazepam	2 mg, 28 tablets, £0.96	0.03
Fluoxetine	20 mg, 30 tablets, £1.09	0.04
Lorazepam (oral)	1 mg, 28 tablets, £0.96	0.03
Lorazepam (intramuscular injection)	£0.35	0.35
Mirtazapine	45 mg, 28 tablets, £2.24	0.08
Promethazine	2 × 10 mg, 28 tablets, £2.96	0.11
Sertraline	50 mg, 28 tablets, £1.75 (brand £17.82)	0.06–0.64
Trazodone	50 mg, 84 tablets, £27.14	0.32
Venlafaxine	2 × 75 mg, 28 tablets, £22.08 (brand only @ 75 mg)	1.58
Zopiclone	7.5 mg, 28 tablets, £1.43	0.05

a All costs taken from *British National Formulary*.<sup>143</sup>

**TABLE 72** Total staff in focus groups and interviews for each site

Site	CH1	CH2	CH3	CH4	CH5	CH6	IW1	IW2	IW3	CW	Total
Staff in focus groups	3	0	4	0	0	2	7	5	2	3	26
Interviews	0	2	0	0	1	1	0	0	0	0	4
Total number of staff	3	2	4	0	1	3	7	5	2	3	30

CH, care home; CW, comparison ward.





## Appendix 2 Search strategies

### Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R)

Interface/URL: OvidSP.

Date range: 1946 to present.

Search date: 28 August 2012.

Retrieved records: 123.

#### Search strategy

1. dementia/ or alzheimer disease/ or aphasia, primary progressive/ (87,566)
2. (dementia or demented or confused).ti,ab. (69,187)
3. alzheimer\$1.ti,ab,jw. (80,263)
4. or/1-3 (140,560)
5. (life adj4 story\$).ti,ab. (471)
6. (life adj4 stories).ti,ab. (279)
7. (life adj4 review).ti,ab. (1831)
8. (life adj4 history).ti,ab. (9320)
9. (life adj4 histories).ti,ab. (1457)
10. (life adj4 narrative\$1).ti,ab. (280)
11. or/5-10 (12,965)
12. 4 and 11 (146)
13. animals/ not humans/ (3,678,892)
14. (rat or rats or mouse or mice or murine or rodent or rodents or hamster or hamsters or pig or pigs or porcine or rabbit or rabbits or dogs or dog or cat or cats or cow or cows or bovine or sheep or ovine or monkey or monkeys or horse or horses).ti. (1,686,732)
15. 12 not (13 or 14) (145)
16. limit 15 to english language (123)

### EMBASE

Interface/URL: OvidSP.

Date range: 1974 to week 34, 2012.

Search date: 28 August 2012.

Retrieved records: 171.

**Search strategy**

Bottom of form

1. dementia/ or alzheimer disease/ or primary progressive aphasia/ (154,081)
2. (dementia or demented or confused).ti,ab. (91,546)
3. alzheimer\$1.ti,ab,jw. (101,856)
4. or/1-3 (197,184)
5. (life adj4 story\$).ti,ab. (615)
6. (life adj4 stories).ti,ab. (340)
7. (life adj4 review).ti,ab. (2359)
8. (life adj4 history).ti,ab. (9774)
9. (life adj4 histories).ti,ab. (1506)
10. (life adj4 narrative\$1).ti,ab. (337)
11. or/5-10 (14,207)
12. 4 and 11 (212)
13. (Animal/ or Animal Experiment/ or Nonhuman/) not (exp Human/ or Human Experiment/) (4,807,439)
14. (rat or rats or mouse or mice or murine or rodent or rodents or hamster or hamsters or pig or pigs or porcine or rabbit or rabbits or dogs or dog or cat or cats or cow or cows or bovine or sheep or ovine or monkey or monkeys or horse or horses).ti. (1,926,871)
15. 12 not (13 or 14) (207)
16. limit 15 to english language (171)

**PsycINFO**

Interface/URL: OvidSP.

Date range: 1806 to August week 3, 2012.

Search date: 30 August 2012.

Retrieved records: 177.

**Search strategy**

1. dementia/ or alzheimer's disease/ or Aphasia/ (49,550)
2. (dementia or demented or confused).ti,ab,id. (43,618)
3. alzheimer\$1.ti,ab,jw,id. (35,455)
4. or/1-3 (69,379)
5. (life adj4 story\$).ti,ab,id. (1485)
6. (life adj4 stories).ti,ab,id. (1457)
7. (life adj4 review).ti,ab,id. (1716)
8. (life adj4 history).ti,ab,id. (4725)
9. (life adj4 histories).ti,ab,id. (1315)
10. (life adj4 narrative\$1).ti,ab,id. (1192)
11. or/5-10 (10,587)
12. 4 and 11 (194)
13. limit 12 to english language (177)

## Social Policy and Practice July 2012

Interface/URL: OvidSP.

Search date: 28 August 2012.

Retrieved records: 165.

### Search strategy

1. (dementia\$ or alzheimer\$ or aphasia or demented or confused).af. (11,546)
2. (life adj4 story\$).af. (975)
3. (life adj4 stories).af. (180)
4. (life adj4 review).af. (227)
5. (life adj4 history).af. (250)
6. (life adj4 histories).af. (112)
7. (life adj4 narrative\$1).af. (77)
8. or/2-7 (1638)
9. 1 and 8 (165)

## Cochrane Database of Systematic Reviews/Cochrane Central Register of Controlled Trials

Interface/URL: The Cochrane Library/Wiley Online Library. Issue 8 of 12 August 2012.

Search date: 29 August 2012.

Retrieved records:

Cochrane Database of Systematic Reviews: 2.

Cochrane Central Register of Controlled Trials: 6.

### Search strategy

#1	MeSH descriptor Dementia, this term only	1103
#2	MeSH descriptor Alzheimer Disease, this term only	1905
#3	MeSH descriptor Aphasia, Primary Progressive, this term only	5
#4	(dementia or demented or confused):ti,ab	4075
#5	alzheimer*:ti,ab,so	4044
#6	(#1 OR #2 OR #3 OR #4 OR #5)	6965
#7	(life near/4 story*):ti,ab	6
#8	(life near/4 stories):ti,ab	8
#9	(life near/4 review):ti,ab	121
#10	(life near/4 history):ti,ab	27
#11	(life near/4 histories):ti,ab	27
#12	(life near/4 narrative*):ti,ab	1
#13	(#7 OR #8 OR #9 OR #10 OR #11 OR #12)	153
#14	(#6 AND #13)	9

## Database of Abstracts of Reviews of Effects/Health Technology Assessment database

Interface/URL: The Cochrane Library/Wiley Online Library. Issue 8 of 12 August 2012.

Search date: 29 August 2012.

Retrieved records:

Database of Abstracts of Reviews of Effects: 6.

Health Technology Assessment: 1.

### Search strategy

#1	MeSH descriptor Dementia, this term only	1103
#2	MeSH descriptor Alzheimer Disease, this term only	1905
#3	MeSH descriptor Aphasia, Primary Progressive, this term only	5
#4	(dementia or demented or confused)	9481
#5	alzheimer*	4564
#6	(#1 OR #2 OR #3 OR #4 OR #5)	10565
#7	(life near/4 story*)	8
#8	(life near/4 stories)	10
#9	(life near/4 review)	505
#10	(life near/4 history)	96
#11	(life near/4 histories)	96
#12	(life near/4 narrative*)	20
#13	(#7 OR #8 OR #9 OR #10 OR #11 OR #12)	619
#14	(#6 AND #13)	62

## Science Citation Index Expanded, Social Sciences Citation Index, Conference Proceedings Citation Index – Science, Conference Proceedings Citation Index: Social Science & Humanities

Interface/URL: Web of Science.

Search date: 29 August 2012.

Retrieved records: 224.

### Search strategy

Lemmatization=Off

Timespan=All Years

# 11 224

(#3 and #10) AND Language=(English)

# 10 49,751

(#4 or #5 or #6 or #7 or #8 or #9) AND Language=(English)

# 9 859

(TS=(life near/4 narrative\*)) AND Language=(English)

# 8 5387

(TS=(life near/4 histories)) AND Language=(English)

# 7 41,397

(TS=(life near/4 history)) AND Language=(English)

# 6 2639

(TS=(life near/4 review)) AND Language=(English)

# 5 1030

(TS=(life near/4 stories)) AND Language=(English)

# 4 1162

(TS=(life near/4 story\*)) AND Language=(English)

# 3 178,943

(#1 or #2) AND Language=(English)

# 2 2826

(SO=alzheimer\*) AND Language=(English)

# 1 178,555

(TS=(dementia or alzheimer\* or "primary progressive aphasia" or demented or confused)) AND Language=(English)

## Cumulative Index to Nursing and Allied Health Literature

Interface/URL: EBSCOhost.

Search date: 30 August 2012.

Retrieved records: 104.

**Search strategy**

S11 (S1 or S2 or S3) and S10 104

S10 S4 OR S5 or S6 or S7 or S8 or S9 2318

S9 TI (life N4 narrative\*) or AB (life N4 narrative\*) 226

S8 TI (life N4 histories) or AB (life N4 histories) 162

S7 TI (life N4 history) or AB (life N4 history) 662

S6 TI (life N4 review) or AB (life N4 review) 792

S5 TI (life N4 stories\*) or AB (life N4 stories\*) 292

S4 TI (life N4 story\*) or AB (life N4 story\*) 406

S3 TI alzheimer\* or AB alzheimer\* or SO alzheimer\* 11,354

S2 TI (dementia or demented or confused) or AB (dementia or demented or confused) 18,798

S1 MH (dementia+ or Alzheimer's disease or aphasia+) 32,272

**Applied Social Sciences Index and Abstracts**

Interface/URL: ProQuest.

Search date: 30 August 2012.

Retrieved records: 33.

**Search strategy**

S15 S4 and S14 • 33\*

S14 S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 • 1950\*

S13 SU("Life narratives") • 63\*

S12 SU("Life histories") • 214\*

S11 SU("Life stories") • 117\*

S10 TI,AB(life NEAR/4 narrative\*) • 261\*

S9 TI,AB(life NEAR/4 histories) • 800\*

S8 TI,AB(life NEAR/4 history) • 800\*

S7 TI,AB(life NEAR/4 review) • 422\*

S6 TI,AB(life NEAR/4 stories) • 493\*

S5 TI,AB(life NEAR/4 story\*) • 273\*

S4 S1 or S2 or S3 • 6842\*

S3 TI,AB,PUB(alzheimer\*) • 2821\*

S2 TI,AB(dementia OR demented OR confused) • 4884\*

S1 SU.EXPLODE("Alcoholic dementia" OR "Alzheimer's disease" OR "Dementia" OR "Lewy body dementia" OR "Multi-infarct dementia" OR "Presenile Alzheimer's disease" OR "Presenile dementia" OR "Semantic dementia" OR "Senile dementia" OR "Subcortical dementia" OR "Vascular dementia" OR "Agraphia" OR "Anomic aphasia" OR "Aphasia" OR "Conduction aphasia" OR "Developmental dyscalculia" OR "Dyscalculia" OR "Peripheral agraphia") • 4550\*

\*Approximate result count without duplicates.

## Social Services Abstracts

Interface/URL: ProQuest.

Search date: 30 August 2012.

Retrieved records: 19.

### Search strategy

S14 S4 and S12 Limits applied 19\*

S13 S4 and S12 • 21\*

S12 S5 or S6 or S7 or S8 or S9 or S10 or S11 • 876\*

S11 SU("Life History") • 144\*

S10 TI,AB(life NEAR/4 narrative\*) • 138\*

S9 TI,AB(life NEAR/4 histories) • 336\*

S8 TI,AB(life NEAR/4 history) • 336\*

S7 TI,AB(life NEAR/4 review) • 169\*

S6 TI,AB(life NEAR/4 stories) • 253\*

S5 TI,AB(life NEAR/4 story\*) • 126\*

S4 S1 or S2 or S3 • 2294\*

S3 TI,AB,PUB(alzheimer\*) • 868\*

S2 TI,AB(dementia or demented or confused) • 1703\*

S1 SU("Senility" or "Alzheimer's disease" or "Aphasia") • 1211\*

\*Approximate result count without duplicates.



## Social Care Online

Interface/URL: [www.scie-socialcareonline.org.uk/](http://www.scie-socialcareonline.org.uk/).

Search date: 31 August 2012.

Retrieved records: 113.

### Search strategy

(freetext="dementia\*" or freetext="alzheimer\*" or freetext="aphasia" or freetext="demented" or freetext="confused") and (freetext="life stor\*" or freetext="life review" or freetext="life histor\*" or freetext="life narrativ\*")

## Research Register for Social Care

Interface/URL: [www.scie.org.uk/publications/researchresources/research-register-for-social-care](http://www.scie.org.uk/publications/researchresources/research-register-for-social-care) (closed April 2014).

Search date: 31 August 2012.

Retrieved records: 0.

### Search strategy

Free-text searches on following:

life stor\*

life history\*

life narrative\*

life review\*

## ClinicalTrials.gov

Interface/URL: [www.clinicaltrials.gov/](http://www.clinicaltrials.gov/).

Search date: 31 August 2012.

Retrieved records: 2.

### Search strategy

(dementia OR alzheimer OR aphasia) AND ("life story" OR "life stories" OR "life review" OR "life history" OR "life histories" OR "life narrative" OR "life narratives")

## NHS Evidence

Interface/URL: [www.evidence.nhs.uk/](http://www.evidence.nhs.uk/).

Search date: 31 August 2012.

Retrieved records: 53.

### Search strategy

dementia\* OR alzheimer\* OR aphasia) AND ("life story" OR "life stories" OR "life review" OR "life history" OR "life histories" OR "life narrative" OR "life narratives") = 53

[Search strategy limited by: Type of information: grey literature]

## OpenGrey

Interface/URL: [www.opengrey.eu/](http://www.opengrey.eu/).

Search date: 31 August 2012.

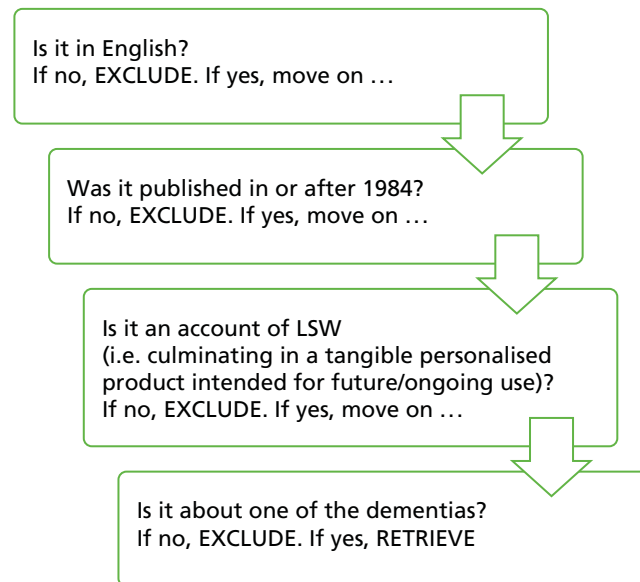
Retrieved records: 0.

### Search strategy

(dementia\* OR alzheimer\* OR aphasia) AND ("life story" OR "life stories" OR "life review" OR "life history" OR "life histories" OR "life narrative" OR "life narratives")



## Appendix 3 Algorithm for selection for relevance



### Notes for reviewers

- Be inclusive – if you are unsure at any stage, mark with a query and opt to retrieve. A decision can then be made based on a full reading.
- Data will be extracted only from written records – videos and podcasts should therefore be excluded.
- Exclude single case studies.



## Appendix 4 Instructions for selection for inclusion

**Include all accounts of life story work with people with dementia published in English in or after 1984.**

### Definition of ‘life story work’:

- **Must involve the creation of a tangible product about an individual with dementia’s life, or parts of their life** (This excludes narrative exercises followed by one off exhibitions or performances, and similarly it excludes life review conducted for therapeutic reasons with no book, box or other tangible record produced for future use as a result. There is no stipulation about what the ‘product’ is – could be a book, piece of art work or video, as long as it is tangible and remains with the individual, see next bullet point)
- **There must be an intention, explicit in the paper, that the life story product remains with the individual with dementia and is used in ongoing practice/care** (this could be in any setting – care homes, hospitals, or in a person’s home – and the people involved in the ongoing practice could again be anyone – family members, therapists, care staff, volunteers etc)

**Note:** while there are different ways of doing life story work, some of which may be considered to be better or worse practice (for example, those that don’t include the person the story is about directly), all accounts that claim to be life story work and meet the above definition should be included.

### Definition of ‘people with dementia’:

- If the paper claims to be about people with **dementia or Alzheimer’s disease** (including **confusion**’ or **memory problems**’) this will be **included**.
- If the paper is only about **another form of cognitive impairment, for example stroke, brain injury or learning disability, exclude** (unless it is also about people with dementia, as defined above, in which case an attempt will be made to separate the findings at the data extraction stage).

### Definition of ‘account’:

- **Includes all studies, including those about the process of life story work and those about its outcomes for any group, regardless of quality**
- **Includes theoretical accounts, guidance and training, descriptive and opinion pieces**
- **Include multi-component studies where one element of the intervention is life story work** (meeting the definition set out above).
- **Excludes single case studies, letters, editorials and book reviews** (in the case of the latter, any relevant books or articles referred to will be followed up separately).
- **Includes systematic reviews** (the citation lists from these will be used to pick up additional relevant material)

**EXCLUDE:**

- Foreign language
- Published before 1984
- Single case studies, letters, editorials and book reviews
- About people with another form of cognitive impairment, such as stroke or learning disability (unless dementia is also present)
- Data will only be extracted from written records – videos and podcasts should therefore be excluded.

**Note about PhD dissertations:** these will be included as potentially relevant in the first instance and a view will be taken jointly, once all other selections have been made, about whether to extract data from them.

## Appendix 5 Paperwork for focus groups

### Information sheets

#### *Focus groups with people with dementia*

THE UNIVERSITY *of York*

## Life Stories in Dementia Care

### Taking part in research





## **We Are Doing Some Research About Life Story Work - Can You Help?**

### **Our invitation to you**

We would like to invite you to take part in a focus group discussion about life story work with other people with dementia. This is part of a larger research project that will run from July 2012 – December 2014.

### **This leaflet**

This leaflet contains information about the research. Please read it all before agreeing to take part.

### **The research**

The research is being conducted by the Social Policy Research Unit, in partnership with Innovations in Dementia, and is funded by the National Institute for Health Research.

### **More information**

If you have any questions please contact Nada Savitch at Innovations in Dementia on 07549 921901 or email [nada@myid.org.uk](mailto:nada@myid.org.uk)

## What is Life Story work?

Life story work involves recording aspects of people's:

- past life
- present interests
- future wishes, hopes and dreams



This could be in a book, box or in any other way that the person wants – for example, with music.

The life story is owned by the person with dementia and is a living document that can be added to as life goes on.



## What is the research about?

We want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them.

We also want to learn when, how and with whom it is best to do life story work.

## Getting Involved

We want to hear what you and other people in your group think about life story work



### A group discussion will take place on:

Date \_\_\_\_\_

Time \_\_\_\_\_

Venue \_\_\_\_\_

### Please bring:

An object or picture that you would be happy to discuss with the group or your life story book/record, if you have one.

**Please note - you do not have to take part:** It is entirely up to you whether you take part in this study. Please discuss with Nada any questions or concerns you have. If you agree to take part, we will then ask you to sign a consent form.

**Tape recording:** We will tape record the discussion so that we can remember exactly what everybody said. The recording will be kept safe and confidential. **If you do not want to be tape recorded you will not be able to take part.**

## Changing your mind about taking part

You can change your mind about taking part at any time before or during the discussion. You do not have to give a reason.

If you change your mind once the discussion has started we will still keep a record of the things you said up till that point.

## Confidentiality

We will not tell anyone you have taken part in this study without your permission and we will not use your name in any reports we write.

We will keep everything you said in a safe place.



If you tell us that you or someone else is being hurt, we might have to tell someone, but we would try to talk to you first.

## Support to take part

If you would like someone, like a friend, support worker or family member, to be with you during the discussion, that's fine – please discuss this with Nada or the person who runs your group. If you need help to hear or speak, or any other support to take part, please let us know.

If you need help to travel to the discussion or home again we could help with this, please let us know.

## Expenses

We will reimburse your expenses for coming to the discussion. Please keep your travel tickets and receipts.



## Thank you

If you take part in the focus group, we will give you a gift of £20 to say thank you.



## Deciding whether to take part

Remember, you do not have to take part in the focus group.

When deciding whether or not to take part, it might help to talk to someone at home, or a friend,

Alternatively, you could speak to a member of staff at your group or someone else you trust.

## If you do not want to take part

You can still come to your group as usual - there will be other things for you to do

## After the focus group

The tape recording of the discussion will be typed up and analysed by researchers. Once this is done, Nada and a researcher will come back to the group to discuss what they have learnt and ask you what you think.

The project is due to be completed in January 2015, after which we will send a short summary of all the research findings to your group.

**This study is being conducted by the Social Policy Research Unit (University of York) and Innovations in Dementia.** It has been approved by the Social Care Research Ethics Committee for England

### Further information

If you would like further information about the focus group, please contact **Nada Savitch**: 07549 921901 [nada@myid.org.uk](mailto:nada@myid.org.uk) PO Box 616, Exeter EX1 9JB

If you would like to speak to the researcher on this project, please contact **Kate Gridley** at the Social Policy Research Unit, University of York, Heslington, York, YO10 5DD 01904 321988 [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

### Complaints

If you are concerned or would like to complain about this study, please contact: **Gillian Parker**, Director, Social Policy Research Unit, University of York, Heslington, York YO10 5DD  
Tel: 01904 321957 or email [spru-director@york.ac.uk](mailto:spru-director@york.ac.uk)

*Focus groups with family carers*

## Life Stories in Dementia Care

### Focus Groups

## Information Sheet - Family Carers

This sheet contains information for family carers of people with dementia considering taking part in a focus group about life story work in dementia care. Please read it all before consenting to take part in a focus group.

The research is being conducted by the Social Policy Research Unit, University of York, in partnership with Uniting Carers (part of Dementia UK), and is funded by the National Institute for Health Research.

### Our invitation to you

You have been contacted because you have experience of life story work and we would like to invite you to take part in a focus group discussion about this.

Before you decide whether or not to take part, you need to understand why the research is being done and what taking part in a focus group would involve. If you have any questions after reading this information sheet please contact Joy Watkins at Uniting Carers ([joy.watkins@dementiauk.org](mailto:joy.watkins@dementiauk.org) 0207 874 7209) who will be happy to discuss the project with you. If you do decide to take part in a focus group, there will be further opportunity to ask questions on the day.

### What do we mean by 'life story work'?

Life story work involves:

1. Recording aspects of people's:
  - past life
  - present interests
  - future wishes, hopes and dreams

This could be in a book, box, collage, or in any other way that the person wants.

Information Sheet, focus groups with family carers V1 Sept 2012



2. Using the life story to improve things (care, relationships, etc.) for the person with dementia and others.

### **What is the research about?**

We want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them. We also want to learn when, how and with whom it is best to do life story work.

There have been no large-scale, rigorous studies of life story work in dementia care so little is known about its effectiveness. It is not even clear, at this stage, what outcomes could or should be measured to assess its effectiveness.

The first step towards formal evaluation of life story work is to learn more about its potential outcomes and what the core elements of good practice are. We plan to do this by running focus groups with people with dementia, family carers and professionals with experience of life story work as well as bringing together all the research evidence already available on the subject and reviewing it in a systematic way.

### **Purpose of the focus groups**

The purpose of the focus groups will be to hear what outcomes you have experienced or would expect from life story work, for whom, under what circumstances, and the reasons for this. We also want to hear what you think are core elements of good practice in life story work, what challenges it might present and how these can be overcome.

### **What would taking part involve?**

If you would like to take part, please reply by email to Joy Watkins at [joy.watkins@dementiauk.org](mailto:joy.watkins@dementiauk.org). If you would like more information or have any questions please ring Joy Watkins on 0207 874 7209. Joy will give you further details of the focus groups, including dates and venues. Three focus group sessions for family carers have been planned in total, and where possible you will be given a choice of which one to attend.

Each focus group session will have no more than ten participants and will last about two hours, with fifteen minutes at the start and finish for questions. The discussion will be facilitated by Kate Gridley, a researcher at the Social Policy Research Unit, with support from Joy Watkins, and will cover an agreed list of topics. Please let Joy know if you would like to see a list of the topics in advance.

Focus group discussions will be audio-taped (with your consent) and transcribed so that we have a full record of everything said. **If you do not want to be tape recorded you will not be able to take part.** All recordings and transcripts will be kept on a secure drive and/or in a locked cabinet, and will only be seen/ listened to by the project team and transcribers.

We would like to give you a gift of £20 to say thank you for taking part in the focus group.

### **Support to take part**

We will cover your travel expenses to enable you to take part in the focus group. If you need to arrange for someone to support the person you care for in order for you to attend the focus group, please discuss this with Joy. Similarly, if you require any other support to attend a focus group, such as help with transport, this can be arranged. Please keep all tickets and receipts to enable us to reimburse you.

### **Do I have to take part?**

No. It is entirely up to you whether you take part in a focus group. We will talk through the study with you and discuss any concerns you have in advance. If you agree to take part, we will then ask you to sign a consent form.

### **What if I change my mind about taking part?**

You can withdraw from the study at any time before or during the focus group discussion without giving a reason. However, if you withdraw after the discussion has started, any contributions already made may be retained so as not to undermine the contributions of others.

### **Will my taking part in this study be kept confidential?**

We will not tell anyone you have taken part in this study without your permission. We may repeat or refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you without discussing this with you first.

As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you before passing on any information.

### What will happen to the results of the study?

After the focus group we will send you a summary of key points from the discussion. At this point you still have the opportunity to clarify specific issues by ringing us or sending an email. The data from all the focus groups will then be analysed thematically and considered together with the findings from the literature review to produce an account of what works, for whom, and in what circumstances, from the perspectives of people with dementia, carers and professionals. The next stage of the research will be a national survey of family carers and care providers, followed by a pilot study of costs and outcomes in care home and hospital settings.

The project is due to end in January 2015, after which time we will send you a short summary of all findings. If your contact details change in the meantime and you would still like a copy of the findings please do let us know so that we can update our records.

### Scientific and ethical review

This study has been scientifically reviewed as part of the National Institute for Health Research funding application process and the focus group methods have been approved by the Social Care Research Ethics Committee for England.

### Further information and contact details

If you would like to take part in a focus group, or would like further information about the carer focus groups, please contact:

#### Joy Watkins

Development Lead, Uniting Carers  
Dementia UK, 6 Camden High St, London, NW1 OJH  
Tel: 0207 874 7209 Email [joy.watkins@dementiauk.org](mailto:joy.watkins@dementiauk.org)

If you would like to speak to the researcher on the project please contact:

#### Kate Gridley

Social Policy Research Unit, University of York, Heslington, York, YO10 5DD  
Tel: 01904 321988 Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

If you are concerned or would like to complain about any aspect of this study, please contact the Director of the Social Policy Research Unit:

#### Gillian Parker

Social Policy Research Unit, University of York, Heslington, York, YO10 5DD  
Tel: 01904 321951 Email: [spru-director@york.ac.uk](mailto:spru-director@york.ac.uk)

*Focus groups with professionals*

THE UNIVERSITY of York



spru | Social Policy Research Unit

**Life Stories in Dementia Care****Focus Groups****Information Sheet - Professionals**

This sheet contains information for professionals considering taking part in a focus group about life story work in dementia care. Please read it all before consenting to take part in a focus group.

The research is being conducted by the Social Policy Research Unit (SPRU), University of York, and is funded by the National Institute for Health Research (NIHR).

**Our invitation to you**

The aim of this research is to understand more about the outcomes and costs of life story work for people with dementia, in order to plan a formal evaluation of the effectiveness of this approach. We also want to establish core elements of good practice in using and applying life story work with people with dementia. You have been contacted because we understand you are involved in life

story work in dementia care and we would like to invite you to take part in a focus group discussion with other professionals about this.

Before you decide whether or not to take part, you need to understand why the research is being done and what taking part in a focus group would involve. If you have any questions after reading this information sheet please contact Kate Gridley on 01904 321988 or email

[kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk). Kate will be happy to discuss the project with you. If you do decide to take part in a focus group, there will be further opportunities to ask questions on the day.

**Purpose of this research**

There have been no large-scale, rigorous studies of life story work in dementia care and we have little evidence about whether, in what

Information Sheet, Focus Groups with Professionals, V2, Oct 2012

ways or why life story work might improve care for people with dementia. It is not even clear, at this stage, what outcomes could or should be measured to assess the effectiveness of life story work. There is also little evidence about what might constitute good practice in life story work or how much it might cost to use life stories as a routine part of dementia care.

The purpose of this research is to carry out the preliminary investigations required to design a full evaluation of life story work for people with dementia. The first step towards this is to develop a theoretical model of life story work, including its potential outcomes, and establish core elements of good practice in using and applying the approach. We plan to do this by running focus groups with people with dementia, carers and professionals with experience of life story work as well as bringing together all the research evidence already available on the subject and reviewing it in a systematic way. You are being invited to take part in one of the focus groups with professionals.

The purpose of the focus groups will be to hear what outcomes are experienced or expected from life story work, for whom, under what circumstances, and the reasons for

this. We also want to hear what you think are core elements of good practice in life story work, what challenges it might present and how these can be overcome. In the professional focus groups we will also be asking what resources might be needed to make life story work a routine part of dementia care and what implications it might have for costs.

### **Do I have to take part?**

No. It is entirely up to you whether you take part in a focus group. We will talk through the study with you and discuss any concerns you have in advance. If you agree to take part, we will then ask you to sign a consent form. You can still withdraw after this point, but any contributions already made may be retained so as not to undermine the contributions of others.

### **What would taking part involve?**

If you would like to take part, or you want more information before making a decision, please contact Kate Gridley on 01904 321988 or email [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk). She will give you further details of the focus groups, including dates and venues, and can answer any remaining questions you have. Three focus group sessions for professionals have been planned in total, and where possible you will

be given a choice of which one to attend. Travel expenses incurred as a result of taking part in a focus group will be reimbursed if you keep all tickets and receipts.

Each focus group session will have no more than ten participants and will last no longer than two hours, with fifteen minutes at the start and finish for questions. The discussion will be facilitated by Kate Gridley and will cover an agreed list of topics. Please ask if you would like us to send this to you in advance.

Focus group discussions will be audio-taped (with your consent) and transcribed so that we have a full record of everything said. **If you do not want to be tape recorded you will not be able to take part.** All recordings and transcripts will be kept on a secure drive and/or in a locked cabinet, and will only be seen/ listened to by the project team and transcribers.

### **What if I change my mind about taking part?**

You can withdraw from the study at any time before or during the focus group discussion without giving a reason. However, if you withdraw after the discussion has started, any contributions already made may be retained so as not to

undermine the contributions of others.

### **Will my taking part in this study be kept confidential?**

We will not tell anyone you have taken part in this study without your permission. We may repeat or refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you without discussing this with you first.

As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you before passing on any information.

### **What will happen to the results of the study?**

After the focus group we will send you a summary of key points from the discussion. At this point you still have the opportunity to clarify specific issues by ringing us or sending an email. The data from all the focus groups will then be analysed thematically and considered together with the findings from the literature review to produce an account of what works, for whom, and in what circumstances, from the



perspectives of people with dementia, carers and professionals.

The next stage of the research will be a national survey of carers and care providers, followed by a pilot study of costs and outcomes in care home and hospital settings.

The project is due to end in January 2015, after which time we will send you a short summary of all findings. If your contact details change in the meantime and you would still like a copy of the findings please do let us know so that we can update our records.

### **Scientific and ethical review**

This study has been scientifically reviewed as part of the National Institute for Health Research funding application process and the focus group methods have been approved by the Social Care Research Ethics Committee for England.

### **Further information and contact details**

If you would like to take part in a focus group, or would like further information about any part of this research, please contact:

#### **Kate Gridley**

Social Policy Research Unit  
University of York  
Heslington  
York  
YO10 5DD  
Tel: 01904 321988

Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

If you are concerned or would like to complain about any aspects of this study please contact the director of the social Policy Research Unit:

#### **Professor Gillian Parker**

Social Policy Research Unit  
University of York  
Heslington  
York  
YO10 5DD  
Tel: 01904 321957

Email: [spru-director@york.ac.uk](mailto:spru-director@york.ac.uk)



## Consent forms

### People with dementia



## Life Story Focus Groups Consent Form

Thank you for thinking about taking part in this research. If you have any questions please talk to Kate Gridley or Nada Savitch before you agree to take part. Kate will keep a copy of this form, and give you a copy to keep.

Please tick the boxes and sign at the end	 Yes	 No
I have read the information leaflet		
I have had time to think about taking part in the research		
I have asked questions if I wanted to		
I know I do not have to take part in this research if I do not want to		
I agree to take part in a group discussion for the life stories research project		
I know I can change my mind before or during this discussion		
I agree that you can tape record the discussion		
I agree that you can keep a record that I took part in this research for five years after the project ends		

\_\_\_\_\_  
Participant name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature



**This research is being conducted by the Social Policy Research Unit, University of York, in partnership with Innovations in Dementia. It has been approved by the Social Care Research Ethics Committee for England. For more information please contact Nada Savitch on 07549 921901 or email [nada@myid.org.uk](mailto:nada@myid.org.uk)**



## Carers

## Life Story Focus Groups Consent Form for Carers

Thank you for thinking about taking part in this research. If you have any questions please talk to Kate Gridley or Joy Watkins before you agree to take part. Kate will keep a copy of this form, and give you a copy to keep.

Please tick the boxes and sign at the end	 Yes	 No
I have read the information leaflet		
I have had time to think about taking part in the research		
I have asked questions if I wanted to		
I know I do not have to take part in this research if I do not want to		
I agree to take part in a group discussion for the life stories research project		
I know I can change my mind before or during this discussion		
I agree that you can tape record the discussion		
I agree that you can keep my contact details and a record that I took part in this research for five years after the project ends		

_____	_____	_____
Participant name	Date	Signature
_____	_____	_____
Researcher name	Date	Signature



**This research is being conducted by the Social Policy Research Unit, University of York, in partnership with Uniting Carers (part of Dementia UK). It has been approved by the Social Care Research Ethics Committee for England. For more information please contact Joy Watkins at Dementia UK on 0207 8747209 or email [joy.watkins@dementiauk.org](mailto:joy.watkins@dementiauk.org)**

*Professionals*THE UNIVERSITY *of* York
 Social Policy  
Research Unit

## Life Story Focus Groups

### Consent Form for Professionals

Thank you for thinking about taking part in this research. If you have any questions please talk to Kate Gridley before you agree to take part. Kate will keep a copy of this form, and give you a copy to keep.

Please tick the boxes and sign at the end	 Yes	 No
I have read the information leaflet		
I have had time to think about taking part in the research		
I have asked questions if I wanted to		
I know I do not have to take part in this research if I do not want to		
I agree to take part in a group discussion for the life stories research project		
I know I can change my mind before or during this discussion		
I agree that you can tape record the discussion		
I agree that you can keep my contact details and a record that I took part in this research for five years after the project ends		

\_\_\_\_\_  
Participant name\_\_\_\_\_  
Date\_\_\_\_\_  
Signature\_\_\_\_\_  
Researcher name\_\_\_\_\_  
Date\_\_\_\_\_  
Signature

**This research is being conducted by the Social Policy Research Unit, University of York. It has been approved by the Social Care Research Ethics Committee for England. For more information please contact Kate Gridley at the Social Policy Research Unit on 01904 321988 [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)**

## Summary of findings



### Life Story Focus Groups Summary of findings

#### Thank you for taking part in this research

Earlier this year Kate and Nada visited your group to talk about your views and experiences of life story work.

We visited four groups and Kate also talked to groups of family carers and professionals.

#### What Kate found out

Lots of people thought the idea of recording things about their life story was a good idea. But people should think about:

- What they want to put into a life story?
- Who they would like to read about their lives?

Workers who help people with life story work should think about:

- Giving people information about doing life story work, but not forcing anyone to do it.
- Getting to know the person well – and sharing their own life experiences.
- Respecting the person's wishes about what goes in the life story and who will read it.
- Continuing to support people with their life story work as life goes on.
- Using different techniques – music or computers as well as words and pictures.
- Helping people to talk about difficult or upsetting memories.
- Helping people to think about what might be useful for other professionals and care workers to know about their life.

#### What happens next?

Kate will continue the research based on what she found out at the focus groups. She will look more closely at how life story work is used in care homes and hospitals.

This research is being conducted by the Social Policy Research Unit, University of York, in partnership with Innovations in Dementia.

For more information please contact Nada Savitch on 07549 921901 or email [nada@myid.or.uk](mailto:nada@myid.or.uk)

# Appendix 6 Topic guides for focus groups with carers/people with dementia/professionals

## Topic Guides

### *Focus groups with people with dementia*

#### Life Stories Focus Groups

##### Topic guide

##### People with dementia

##### Before the focus group begins:

- Check that all participants have read and understood the information leaflet and would like to take part. Answer any questions and reiterate that involvement is optional, and that they can change their minds at any time.
- Have arrangements in place (family/staff member, interpreter, communication aids etc) to ensure that all participants can make an informed decision about taking part, and participate in the focus group fully, if at all possible. If a participant cannot make an informed decision about taking part, even with support, then they will be excluded. (Arrangements will have been made in advance to ensure there are staff on hand to support people who decide at this stage to opt out, or who do not have capacity on the day to consent).
- Support those who would like to take part to sign a consent form (this will include consenting to the focus group being audio-recorded)
- Participants were asked on the information leaflet to bring along a copy of their 'life story' or another object of significance to them – find out informally (for example, while supporting participants to sign consent forms) what participants have brought and whether they are happy to talk to the group about them – this information will help to plan and facilitate the discussion

##### Explain to the group:

- a) That the discussion should be grounded in mutual respect (everyone's view is valid, it is important to listen and not interrupt etc.) and that we are not looking for consensus - people can have very different views and this is fine
- b) That everything said in the focus groups should be kept confidential/not talked about in a way that makes other people identifiable outside the room (but they can talk to people about what they themselves said/felt – and Nada and Kate will be available after the session if they do want to talk about anything that came up in the discussion)
- c) The tape recording of the discussion will be stored securely at SPRU and participants' names will not be included in any reports that come from it
- d) Participants are free to withdraw from the focus group at any time – there is a separate room they can go to
- e) It is fine for participants to ask questions or take breaks during the focus group

Topic guide for focus groups with people with dementia V1 Sept 2012

## Start

- START BY ASKING EACH PARTICIPANT TO INTRODUCE THEMSELVES (including how their dementia affects them day to day)

### TOPIC 1 – How does it feel to tell your story?

- ASK THE PEOPLE WHO HAVE BROUGHT IN AN OBJECT OR LIFE STORY TO TELL US A LITTLE BIT ABOUT IT.

#### Questions:

- What have you brought in today?
- What is the story behind it?
- How does it feel to tell these stories? (probe for positives and negatives)
- Is it important to talk about these things/that other people know about them? Why/why not?

### TOPIC 2 – Views on life story work

- SHOW EXAMPLES OF LIFE STORY BOOKS, BOXES, DIGITAL LIFE STORIES ETC (these will be mock-ups based on the Kate and Nada's lives)
- EXPLAIN HOW THEY CAN BE USED (in care settings, in the home etc)
- ANSWER ANY QUESTIONS PARTICIPANTS HAVE

#### Questions:

- What do they think of the life story books? (reasons)
- Why do they think someone might want to do a life story book/What might this achieve (and for who)?
- Why might someone not want to do one/what could go wrong?

### TOPIC 3 - Good practice

#### Questions:

- **When** (and **where**) would it be good to make a life story book?
- **How** should the life story be recorded? (What tool? What sort of process? What should/shouldn't go in?)
- **Who** should be involved?
- How should the life story record be used **once it's made**? (Is it ever finished?)

## TOPIC 4 - Messages for care staff/managers:

- What do they think care workers should know about doing life story work with people with dementia?
- What do they think managers/the people who plan services should know about this?

## Anything else?

## Finish

---

### After the focus group has finished:

- Thank all participants for their contribution
- Explain the next stages of the project (transcription, analysis, checking back with the group re interpretation etc)
- Ask if the group (or any particular members) have any questions or concerns
- Hand out thank you letters and £10 gift.
- Stay long enough to answer any concerns people still have about the way the focus group went or any issues that were raised. Ensure that further support is available to anyone who requires this before leaving. Point out that the letter has a number people can ring if they want to talk about any of the issues raised today.

*Focus groups with family carers***Life Stories Focus Groups****Topic guide****Family carers of people with dementia****Before the focus group begins:**

- Check that all participants have read and understood the information leaflet and would like to take part. Answer any remaining questions and reiterate that involvement is optional, and that they can change their minds at any time.
- Ask those who would like to take part to sign a consent form (this will include consenting to the focus group being audio-recorded)

**Explain to the group:**

- a) That the discussion should be grounded in mutual respect (everyone's view is valid, it is important to listen and not interrupt etc.) and that we are not looking for consensus - people can have very different views and this is fine
- b) That everything said in the focus groups should be kept confidential/not talked about in a way that makes other people identifiable outside the room (but they can talk to people about what they themselves said/felt – and Joy and Kate will be available after the session if they do want to talk about anything that came up in the discussion)
- c) The audio-recording of the discussion will be stored securely at SPRU and participants' names will not be included in any reports that come from it
- d) Participants are free to withdraw from the focus group at any time – there is a separate room they can go to
- e) It is fine for participants to ask questions or take breaks during the focus group

## Topics to cover

### 1. Experiences of life story work

What are their experiences of doing life story work?

Description:

- What did they/the person they care for do/make?
- When? Where? Who with?
- What happened (steps in the process)?
- How was it used after/is it used now?

Feelings:

- What was it like/how did it make them (the family carer) feel (during and after)?
- Positive bits? (probe for reasons)
- Negative bits? (probe for reasons)
- Could anything have made it better (ask for details)?

Outcomes:

- Has anything changed as a result?
- Do they think it has had an impact on anyone (professionals/carers working with them/the person with dementia/ family members/friends/other residents/themselves etc.)?

### 2. General views on life story work and good practice:

What do they think about life story work?

- Is it something people should do more of/less of (probe for reasons)?
- Are there any problems/challenges with it (ask for details)?

What is the best way to do life story work?

- How to record it (book, box, using a computer, collage etc)?
- Who with/when/where? (probe for reasons)

Potential outcomes/value of life story work:

- What could/should be achieved through life story work (how/why)?
- How should life stories be used?
- Who should use them/when/where?

Messages for care staff doing life story work and/or their managers:

Topic Guide for focus groups with family carers V2 Oct 2012



- What do they think care workers should know about doing life story work with people with dementia?
- What do they think managers/the people who plan services should know?

### 3. Anything else

- Any concerns not covered
- Any constructive suggestions

## Finish

---

### After the focus group has finished:

- Thank all participants for their contribution
- Explain the next stages of the project (transcription, analysis, checking back with the group re interpretation etc)
- Ask if the group (or any particular members) have any questions or concerns
- Hand out thank you letters and £20 gift
- Stay long enough to answer any concerns people still have about the way the focus group went or any issues that were raised.

*Focus groups with professionals***Life Stories Focus Groups****Topic guide****Professionals****Before the focus group begins:**

- Check that all participants have read and understood the information leaflet and would like to take part. Answer any remaining questions and reiterate that involvement is optional, and that they can change their minds at any time.
- Ask those who would like to take part to sign a consent form (this will include consenting to the focus group being audio-recorded)

**Explain to the group:**

- a) That the discussion should be grounded in mutual respect (everyone's view is valid, it is important to listen and not interrupt etc.) and that we are not looking for consensus - people can have very different views and this is fine
- b) That everything said in the focus groups should be kept confidential/not talked about in a way that makes other people identifiable outside the room (but they can talk to people about what they themselves said/felt – Kate will be available after the session if they do want to talk about anything that came up in the discussion)
- c) The audio-recording of the discussion will be stored securely at SPRU and participants' names will not be included in any reports that come from it
- d) Participants are free to withdraw from the focus group at any time – there is a separate room they can go to
- e) It is fine for participants to ask questions or take breaks during the focus group

## Topics to cover

### 1. PERSONAL EXPERIENCE OF LIFE STORY WORK

What are their experiences of doing life story work?

Description:

- Where/what setting/when/Who with?
- Routine part of work or a one-off?
- Approach to recording the life story (what tool/type of record, who else was involved, what was the process)?
- How was/is the life story record used once made?

Outcomes:

- Has anything changed as a result?
- Has it had an impact on anyone (professionals/carers working with them/the person with dementia/ family members/friends/other residents/themselves etc.)?

Challenges of life story work:

- Have they ever had any problems doing life story work (probe for details, possible reasons and solutions/ways of avoiding such problems)

### 2. GENERAL VIEWS ON LIFE STORY WORK

What do they think about life story work?

- Is it something people should do more of/less of (probe for reasons)?
- What are/could be the outcomes of doing life story work?

What could be the problems/challenges with it?

- Description of problem?
- For who?
- Reasons for it being problematic?
- Possible solutions/ways of avoiding such problems?

### 3. GOOD PRACTICE

When/in what circumstances, would it be good to do life story work?

- Early or later in the dementia journey? (reasons)
- When someone uses a particular service/ moves into a particular setting? (reasons)
- Other times/circumstances?

Topic Guide for focus groups with professionals V1 Sept 2012

How should the life story be recorded?

- What tool/format? (Book? Box? Collage? Computer? Other?)
- What sort of process? (One off? Over several sessions? On-going process?)
- How detailed should it be/what should go in?
- Who should be involved?

How should the life story book be used once it's made?

Are there any challenges to this (probe for details, possible reasons and solutions/ways of avoiding such problems)?

#### 4. ORGANISATIONAL ISSUES AND COSTS

What would be necessary in order to make life story work a routine part of dementia care?

- What resources (including staff time, skills, equipment etc)?
- What training?
- Any changes to organisational culture/management approach?

Can you think of any other costs of life story work?

- To the organisation?
- To people with dementia?
- To families/friends?

How might the outcomes of life story work impact on costs?

- Changes to prescribing patterns?
- Changes to service use?
- Changes to demands upon staff?

#### 5. SUMMARY

What is the best way of doing life story work with people with dementia?

What could help or hinder people to work in this way?

#### Anything else?

- Any concerns not covered
- Any constructive suggestions

**Finish**

---

**After the focus group has finished:**

- Thank all participants for their contribution
- Explain the next stages of the project (transcription, analysis, checking back with the group re interpretation etc)
- Ask if the group (or any particular members) have any questions or concerns
- Hand out Thank You letters
- Stay long enough to answer any concerns people still have about the way the focus group went or any issues that were raised.

## Appendix 7 'I Am' Fluency Task

### The feasibility of using the 'I Am' Fluency Task with people with dementia living in care homes

The 'I Am' Fluency Task is an adapted version of the Twenty Statements Task<sup>125</sup> that was developed to examine the accessibility of self-concept statements (e.g. I am generous, I am a mother, I am a psychologist). The original Twenty Statements Task asks participants to describe their sense of self by responding open endedly to the question 'Who am I?'. This task was modified such that participants were given 2 minutes to generate as many statements as possible beginning with the phrase *I am*, the assumption being that the ability to generate statements in a given time reflects accessibility to self-concept.

Fourteen people with dementia living in care homes were approached to complete the 'I Am' Fluency Task. Of these 14 participants, 11 were able to generate self-concept statements that described aspects of their identity, with the number of 'I am' statements generated in 2 minutes ranging from 2 to 10. Of the remaining three participants, two presented with language difficulties consistent with anomic aphasia and were therefore unable to generate any statements in response to the task instructions, and one participant, whose spoken language was consistent with Wernicke's aphasia, gave responses that were inconsistent with the task. Overall, those without language deficits were able to complete the task. Some individuals commented that they were not used to thinking about themselves in such a way, and others tended to talk in detail about their statements, and this prevented them from generating many in the given time frame. Such observations might explain the small number of statements generated by some participants, as correlational analysis demonstrates that an inability to generate many statements in the allotted time is not attributable to a general fluency deficit.

It was anticipated that people with dementia would find it difficult to complete the 'I Am' Fluency Task and so the 'Me/Not Me' task was also designed for the purposes of this research. The 'Me/Not Me' task presents participants with a list of 30 words (e.g. grandmother, loving, retired) and asks participants to rate each for self-descriptiveness. This is done by selecting one of three responses: 'me', 'not me' or 'sometimes me'. All 11 participants who completed the 'I Am' Fluency Task were able to complete this task, and most of them completed it with ease. However, a couple of the participants did not engage with the forced choice element of the task; they would speak for several minutes regarding their answer and would then have to be guided by the experimenter towards selecting the most appropriate of the three responses (e.g. when given the statement 'happy' one participant spoke in depth about being happy most days but also feeling down on occasions; this participant was subsequently guided to give the response 'sometimes me'). This tendency to give an embellished response to each item is reflected in the finding that it took participants an average of 7 minutes and 48 seconds to respond to all 30 items in the 'Me/Not Me' task.

Aphasic participants were also able to respond to some items on the 'Me/Not Me' task. Ability on this task varied for those with aphasia; the most extremely aphasic participant responded to 13 of the 30 statements, for instance in response to being asked if she was a driver she responded 'no I don't drive'. The second participant who presented with anomic aphasia responded to most items (27/30) despite very limited language ability. The participant who presented with language consistent with Wernicke's aphasia responded to all items, yet it was not clear that she responded appropriately to all items; for instance, in response to being asked if she was a good listener she replied 'yes, I like to know everything' and yet when asked if she was an aunt, she replied 'they are all right'.

In an attempt to examine the accessibility of autobiographical memory, the Autobiographical Fluency Task<sup>147</sup> was administered to participants. This task examines the ability of participants to generate both personal semantic (names of people known to them) and personal incident (personally experienced events) memories for three lifetime periods: childhood, early adult life and recent life. Participants were given 2 minutes to generate as much information as possible for each of the six components of this task. Nine of the 14 participants who were approached to take part in this research were able to complete this task; two withdrew from taking part at this stage and the task was not attempted with the three aphasic participants.

Overall, most participants were able to generate names and events from across the lifespan, with events from early adulthood and names from childhood being most accessible. When asking about recent times a number of participants were disorientated to time and generated event memories from more than 5 years ago (e.g. finishing the army in 1947). These memories were not included in the analysis.

The pattern of findings from the autobiographical fluency task replicates that of Addis and Tippett,<sup>126</sup> who also found that individuals with Alzheimer's disease were impaired on both personal semantic and personal incident memory relative to a control group of aged matched individuals without dementia. Suggesting that the findings from individuals in the present research likely indicates impaired autobiographical memory. Indeed, it was clear from administering this task that participants found it difficult to recall information from across their lifespan, yet the data that were collected suggest that, nevertheless, they engaged with the task and understood the task instructions.

## Appendix 8 Text version of provider survey

Life Stories Services Questionnaire Final

Q1 Life Story Work in Dementia Care

Q2 Survey of Services Provided for People with Dementia

Q3 Thank you for taking the time to complete this questionnaire. We are interested in your service, whether it uses Life Story Work and, if so, how it does this. Even if `{{e://Field/NameOfService}}` does not use Life Story Work currently, we are interested in your answers. Please remember that participation is optional. The answers you give will be kept secure and confidential and data will be anonymous. Findings will be used only to inform the research project about Life Story Work. The questionnaire usually takes around 15 minutes to complete, but could take less or more time, depending on how much you have to say. Most of the questions have tick box answers. You do not have to complete the whole questionnaire in one session: you can close the page at any time and your answers will save automatically. You can come back to the page and add more answers for up to a week after starting the questionnaire, as long as you are on the same computer. You can also move backwards and forwards between the pages. If you are happy to continue please click on 'Next page' below to start the questionnaire.

Q4 What do we mean by 'Life Story Work'? When we say 'Life Story Work', we mean: making something that records aspects of the life of a person with dementia, including their past life, their present interests, and their future wishes, hopes and dreams AND using these records to improve things (for example, care, relationships) for the person with dementia and those around them. The record of the life story can be a book, a box, a collage, on a computer or in any other format that the person wants. Some people may have several different types of record of their life story, for example a photo album, a collage on the wall, and a written record for care staff. We are interested in all types of Life Story Work. We are also interested in hearing about services that do not do Life Story Work or have never come across it.



Q5 Have you ever heard of Life Story Work for people with dementia?

- ☐ Yes (1)
- ☐ No (2)

If No Is Selected, Then Skip To Would like to know more about LSW (all)

Q6 Does \${e://Field/NameOfService} do Life Story Work with people with dementia currently?

- ☐ Yes, do Life Story Work currently (1)
- ☐ Have done Life Story Work in the past, but not now (2)
- ☐ No, have never done Life Story Work (3)
- ☐ No, but we refer on to another place or service where Life Story Work is done (4)

If Yes, do life story work cur... Is Selected, Then Skip To End of Block

Answer If Types of record A written summary Is Selected

Q7 Please write in the name and contact details of the place or service where you refer people to

Answer If Service ever done life story work (current) Have done life story work in the past, but not now Is Selected Or Service ever done life story work (current) No, have never done life story work Is Selected

Q8 People have different views about how helpful it is to do Life Story Work. Do you think Life Story Work could help the people who use \${e://Field/NameOfService}?

- ☐ Yes (1)
- ☐ No (2)
- ☐ Don't know (3)

Answer If Service ever done life story work Have done life story work in the past, but not now Is Selected Or Service ever done life story work No, have never done life story work Is Selected

Q9 Why do you think that? (Please write in below)

Q10 Would you like to know more about Life Story Work?

- ☐ Yes (1)
- ☐ No (2)

Q12 People with dementia can do Life Story Work at different times. How soon after a person with dementia comes to  $\{e://Field/NameOfService\}$  do you start doing Life Story Work with them?

- ☐ Immediately (1)
- ☐ Within a month (2)
- ☐ Between one and three months after they come to  $\{e://Field/NameOfService\}$  (3)
- ☐ More than three months after they come to  $\{e://Field/NameOfService\}$  (4)
- ☐ It depends (please give details below) (5) \_\_\_\_\_

Q13 A person's life story can be recorded in different ways. What kind of record(s) of a life story do you create in  $\{e://Field/NameOfService\}$  with people with dementia? (please tick all that apply)

- ☐ A photo album just containing photographs (1)
- ☐ A photo album with written comments or stories (2)
- ☐ A book with a mixture of photos and stories (3)
- ☐ A written summary (4)
- ☐ A box containing important objects or memories (5)
- ☐ A collage to put up on a wall (6)
- ☐ A DVD or film (7)
- ☐ A poem (8)
- ☐ Something else (please give details below) (9) \_\_\_\_\_

Q14 Life Story Work can be done in different ways, for example, in a group or one-to-one. In what ways do you do Life Story Work in  $\{e://Field/NameOfService\}$  when working with people with dementia? (please tick all that apply)

- ☐ In a group (1)
- ☐ One-to-one (2)
- ☐ Other (please give details below) (3) \_\_\_\_\_

Q15 Different people can be involved in doing Life Story Work. Who is involved in doing Life Story Work with people with dementia in  $\{e://Field/NameOfService\}$ ? (please tick all that apply)

- ☐ The person with dementia (1)
- ☐ Family members or others close to the person with dementia (3)
- ☐ A volunteer who does Life Story Work (7)
- ☐ A person/people employed specifically to do Life Story Work (5)
- ☐ A person/people employed to provide care more generally (6)
- ☐ Someone else (please give details below) (8) \_\_\_\_\_

Q16 People have different ideas about what life stories can be used for. Thinking about all the types of life story records that people with dementia in your service have, how is their life story used? (please tick all that apply)

	In \${e://Field/NameOfService}
	we use life stories (1)
To help the person with dementia remember important parts of their life (1)	<input type="checkbox"/>
To give the person with dementia pleasure when they look at it (2)	<input type="checkbox"/>
To help soothe or calm the person with dementia (3)	<input type="checkbox"/>
To help staff see the person behind the dementia (4)	<input type="checkbox"/>
As something for staff and people with dementia to enjoy looking at together (5)	<input type="checkbox"/>
As something for people with dementia to enjoy looking at with family members or other people close to them (6)	<input type="checkbox"/>
So that health or social care workers in other places or services can provide better care (7)	<input type="checkbox"/>
For other reasons (8)	<input type="checkbox"/>

Answer If How LSW used For other reasons - In \${e://Field/NameOfService} - we use life stories Is Selected

Q17 What other ways do you use life story records? (please write in below)

Answer If How LSW used To help the person with dementia remember important parts of their life - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used To give the person with dementia pleasure when they look at it - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used To help soothe or calm the person with dementia - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used To help staff see the person behind the dementia - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used As something for staff and people with dementia to enjoy looking at together - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used As something for people with dementia to enjoy looking at with family members or other people close to them - In \${e://Field/NameOfService} we use life stories - Use of life story Is Selected Or How LSW used So that health or

social care workers in other places or services can provide better care - In  
 \${e://Field/NameOfService} we use life stories - Use of life story Is Selected

Q18 You said that these were the different ways that you used life stories in your service. Please choose the one that you think is the most important (please tick ONE)

Q19 Different sorts of information or clues about a person's life can be included in a life story. These next four questions are about the different types of information that can be used to create a life story. For each question, please tick the answers closest to what you do in \${e://Field/NameOfService}.

Q20 Thinking about all the types of life story records that people with dementia have in \${e://Field/NameOfService}, what information is included about family and other people who are close to them?

	We always include this information in the life story (4)	We sometimes include this information in the life story (5)	We do not include this information in the life story (6)
The names of family members and other people close to them (31)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Details about or descriptions of family members and other people close to them (32)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their reactions to family members and other people close to them (33)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anything else about family or other close people (please write in - the box will expand as you write) (34)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

## Q21 And what information is included about the person's life?

	We always include this information in the life story (1)	We sometimes include this information in the life story (2)	We do not include this information in the life story (3)
A list of important events, dates, places or stages in their life (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Details about important events, dates, places or stages in their life (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Their feelings about important events, dates, places or stages in their life (6)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anything else about the person's life? (please write in - the box will expand as you write) (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q22 And what information is included about the likes and dislikes and preferences of the person with dementia?

	We always include this information in the life story (1)	We sometimes include this information in the life story (2)	We never include this information in the life story (3)
What they like to eat (7)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What they like to wear (8)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
What they like doing (interests, hobbies, activities) (9)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Things they like to talk about (10)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Things they do not like to talk about (11)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Anything else about their likes and dislikes? (please write in - the box will expand as you write) (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q23 And finally in this section, thinking about all the types of life story records that people with dementia have, what information is included about their needs?

	We always include this information in the life story (1)	We sometimes include this information in the life story (2)	We never include this information in the life story (3)
Medical or care information (12)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Spiritual and cultural needs or preferences (13)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any other information about their needs (please write in - the box will expand as you write) (14)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q24 Sometimes certain information about the person with dementia, or a particular time in their life is left out of their life story. Does this happen when people with dementia do their life stories in your service? (please tick one)

- ☐ Yes (1)  
☐ No (2)  
☐ Don't know (3)

If No Is Selected, Then Skip To One-off or things added  
If Don't know Is Selected, Then Skip To One-off or things added

Q25 Why are certain things left out of life stories? (please tick all that apply)

- ☐ Some things are too private to include (2)  
☐ Some things are too upsetting to include (3)  
☐ Any other reason (please give details below) (4) \_\_\_\_\_

Q26 Who makes the decision to leave certain things out of the life story? (please tick all that apply)

- ☐ The person with dementia (1)  
☐ A family member, or someone close to the person with dementia (3)  
☐ A volunteer who does life story work (7)  
☐ A person/people employed specifically to do life story work (6)  
☐ A person/people employed to provide care more generally (4)  
☐ Someone else (please write in this person's job title) (5) \_\_\_\_\_

Q27 Doing a life story can be a one-off event or it can be something that is added to as new memories come to light or new events take place. How would you describe Life Story Work for people with dementia in {e://Field/NameOfService}?

- ☐ It is a one-off thing and nothing is added to it once it is finished (1)
- ☐ Photos, descriptions, or other items about the past are added along the way (2)
- ☐ Photos, descriptions or other items about recent events are added as they happen (3)

Q28 Life stories can be about the past, the present and the future. Thinking about all the types of life story record that people living with dementia in {e://Field/NameOfService} have, how would you describe these life stories? (please tick all that apply)

	Always (18)	Very Often (19)	Occasionally (20)	Never (21)
The life stories include general information about the past that are not specific to the individual person (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The life stories include memories and information about the person's past (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The life stories include current information about the person (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The life stories include the person's hopes and views about the future (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



Q29 People have different views about who should be able to look at a person's life story. Who is able to look at the life story of a person with dementia in {e://Field/NameOfService}? (please tick all that apply)

- ☐ The person with dementia (1)
- ☐ Family members, friends and people close to the person with dementia (3)
- ☐ Some selected staff who work here (4)
- ☐ Any staff who work here (5)
- ☐ Health or social care staff who work elsewhere (7)
- ☐ Others (please give details below) (6) \_\_\_\_\_

Q30 Do you ask the person with dementia to give their permission about which people can look at their life story? (please tick one)

- ☐ Yes, always (1)
- ☐ Sometimes (4)
- ☐ No (2)
- ☐ Don't know (3)

Answer If Does person give permission who can look at LS No Is Selected Or Does person give permission who can look at LS Sometimes Is Selected

Q31 In what circumstances would the person with dementia NOT be asked to give their permission about which people can look at their life story? Please write your answer here.

Q32 Do family members or others close to the person with dementia give their permission about which people can look at the life story of the person? (please tick one)

- ☐ Yes, always when there is a family member/other close person to ask (1)
- ☐ Yes, sometimes when there is a family member/other close person to ask (4)
- ☐ No (2)
- ☐ Don't know (3)

Answer If Have you given permission who can look at LS No Is Selected Or Have you given permission who can look at LS Yes, sometimes when there is a family member/other close person to ask Is Selected

Q33 In what circumstances would family members or others close to the person with dementia NOT be asked to give their permission about which people can look at the life story? Please write your answer here.

Q34 Does the life story of the person with dementia have a statement in it that says in what circumstances other people can look at it? (please tick one)

- ☐ Yes, always (1)
- ☐ Sometimes (4)
- ☐ No (2)
- ☐ Don't know (3)

Q35 Where is the life story usually kept? (please tick all that apply)

- ☐ The person with dementia keeps it (1)
- ☐ A family member or someone close to the person with dementia keeps it (7)
- ☐ In an office or other secure place in your service (2)
- ☐ In the care record of the person living with dementia (3)
- ☐ On display (please write in where) (5) \_\_\_\_\_
- ☐ Somewhere else (please write in where) (6) \_\_\_\_\_

Q36 How often do people normally look at or use the life story? (please tick one box in each row below)

	How often does this person use or look at the life story?						
	Every day (1)	A few times a week (2)	A few times a month (3)	Less than once a month (4)	Never (5)	Don't know (6)	Not applicable (7)
The person with dementia (19)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Family or other people close to the person with dementia (23)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Staff who work in $\{e://Field/NameOfService\}$ (20)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Volunteers who work in $\{e://Field/NameOfService\}$ (21)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Health or social care staff who work somewhere else (22)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other people (please give details) (24)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q37 This section is about your policies and practice for Life Story Work.

Q38 Below are some statements about policies and practice in {e://Field/NameOfService}. Please tick the answer closest to what happens in your service.

	No (16)	Yes (17)
We offer everyone the opportunity to do Life Story Work, no matter how severe their dementia (1)	<input type="radio"/>	<input type="radio"/>
Staff/volunteers who do Life Story Work do their own life story before they work with service users (2)	<input type="radio"/>	<input type="radio"/>
We use a template to guide Life Story Work from start to finish (3)	<input type="radio"/>	<input type="radio"/>
Staff/volunteers doing Life Story Work learn to do it 'on the job' rather than through special training (4)	<input type="radio"/>	<input type="radio"/>
Staff/volunteers doing Life Story Work get regular supervision from senior or more experienced staff (5)	<input type="radio"/>	<input type="radio"/>
Decisions about the format and look of the life story are made mainly by staff/volunteers who do the Life Story Work (6)	<input type="radio"/>	<input type="radio"/>
People with dementia who also have a visual impairment are offered the opportunity to do Life Story Work (7)	<input type="radio"/>	<input type="radio"/>
We train family members or other people close to the person with dementia before they do Life Story Work (8)	<input type="radio"/>	<input type="radio"/>
Everyone who works or volunteers in my service knows what Life Story work is (9)	<input type="radio"/>	<input type="radio"/>
Everyone who works or volunteers in my service	<input type="radio"/>	<input type="radio"/>

knows how to use a life story to improve the care of the person with dementia (10)		
We adjust how we do Life Story Work, depending on the needs and strengths of the person with dementia (11)	○	○

Q39 Below are some statements about the time and resources that are available for Life Story Work. Please tick the answer closest to what happens in  $\{e://Field/NameOfService\}$ .

	Strongly Agree (22)	Agree (23)	Disagree (24)	Strongly Disagree (25)
Life Story Work is done in spare moments in the care routine (1)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The time spent doing Life Story Work makes it difficult to get other care work done (3)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
We have dedicated and protected time for doing Life Story Work (2)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Senior staff in the service are fully committed to Life Story Work being done (4)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Any member of staff who wants to do Life Story Work with a person with dementia will have time freed up from other duties (5)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q40 Have there been any problems with doing Life Story Work with people with dementia in \${e://Field/NameOfService}?

Q41 What have been the best things about doing Life Story Work with people with dementia in \${e://Field/NameOfService}?

Q42 Is there anything else you would like to tell us about Life Story Work for people with dementia?

Q43 About your service It helps us to understand answers if we know a bit about the service you are telling us about.

Q44 What type of service does \${e://Field/NameOfService} provide? (please tick one)

- ☐ Memory clinic/memory assessment service based in an out-patient setting (1)
- ☐ In-patient dementia mental health assessment unit (3)
- ☐ Community care provider providing services to people with dementia (4)
- ☐ Specialist dementia care nursing or residential care home (2)
- ☐ Non-specialist nursing or residential care home providing care to people living with dementia (5)
- ☐ Other, please write in (6) \_\_\_\_\_

Answer If What type of service does \${e://Field/NameOfService} provide? (please tick one) Memory clinic/memory assessment service based in an out-patient setting Is Selected Or What type of service does \${e://Field/NameOfService} provide? (please tick one) Community care provider providing services to people with dementia Is Selected Or What type of service does \${e://Field/NameOfService} provide? (please tick one) Other, please write in Is Selected

Q45 Typically, how many people with dementia does \${e://Field/NameOfService} see each week? (write number in box)

- ☐ 1-10 (1)
- ☐ 11-20 (2)
- ☐ 21-30 (3)
- ☐ 31-40 (4)
- ☐ 41-50 (5)
- ☐ 51-60 (6)
- ☐ More than 60 (please write in number) (7) \_\_\_\_\_

Answer If On average, how many people with dementia live in your nursing or residential care home? (please write in number) Is Selected Or On average, how many people with dementia live in your nursing or residential care home? (please write in number) Is Selected

Q46 Typically, how many people with dementia live in \${e://Field/NameOfService}? (write number in box)

- ☐ 1-10 (1)
- ☐ 11-20 (2)
- ☐ 21-30 (3)
- ☐ 31-40 (4)
- ☐ 41-50 (5)
- ☐ 51-60 (6)
- ☐ More than 60 (please write in number) (7) \_\_\_\_\_

Answer If What type of service does \${e://Field/NameOfService} provide? (please tick one) In-patient dementia mental health assessment unit Is Selected

Q57 Typically, how many people with dementia are in-patients in \${e://Field/NameOfService} each week? (write number in box)

- ☐ 1-10 (1)
- ☐ 11-20 (2)
- ☐ 21-30 (3)
- ☐ 31-40 (4)
- ☐ 41-50 (5)
- ☐ 51-60 (6)
- ☐ More than 60 (please write in number) (7) \_\_\_\_\_

Q47 About yoult helps us to analyze our survey results if we know a bit about you. This final section asks for some simple personal details. If you would rather not give any of this information, please just skip the question(s).

Q48 What is your sex?

- ☐ Male (1)
- ☐ Female (2)

Q49 Which of the following age bands do you fit into?

- ☐ 16-24 (1)
- ☐ 25-34 (2)
- ☐ 35-44 (3)
- ☐ 45-54 (4)
- ☐ 55-64 (5)
- ☐ 65 or over (6)

Q50 What is your ethnic group? Please choose one option that best describes your ethnic group or background.

- ☐ White (1)
- ☐ Mixed / Multiple ethnic groups (2)
- ☐ Asian / Asian British (3)
- ☐ Black / African / Caribbean / Black British (4)
- ☐ Other ethnic group (5)

Q51 What is your job title?

Answer If Service ever done life story work Yes, do Life Story Work currently Is Selected Or Service ever done life story work Have done Life Story Work in the past, but not now Is Selected Or Service ever done life story work No, but we refer on to another place or service where Life Story Work is done Is Selected

Q52 You can find more about Life Story Work training and resources by visiting the Life Story Network website. The link to the website will be in the 'thank you' email that we will send you.

Answer If Service ever done life story work No, have never done Life Story Work Is Selected And Would like to know more about LSW Yes Is Selected

Q53 You can find out more about Life Story Work by visiting the Life Story Network website. The link to the website will be in the 'thank you' email that we will send you.

Q54 When you are happy with all your answers, please click '&#39;Next page&#39;' to submit your response. Once you have done this you will not be able to return to the questionnaire.

Q55 Thank you for helping us with our research. If you would like to receive a summary of our findings later this year, please tick the box below.

- ☐ I would like to receive a summary of the findings (1)





## Appendix 9 Paperwork for carer survey

# LIFE STORIES SURVEY

**If you would like the opportunity to take part in a survey about life story work, read on...**

Uniting Carers have teamed up with the University of York Social Policy Research Unit to look into the ways that life story work is being used in dementia care.

We are inviting you to get involved by completing a short survey about life story work. Both current and former carers are invited to take part and you do not have to have any experience of life story work to answer the questions: **we are equally interested in hearing from carers who have never done any life story work as we are from those who have.** Please see the attached leaflet for more information.

To complete the online survey just follow this link: [\[insert link\]](#)

We understand that carers lead busy lives, so this survey has been designed to take no more than [\[insert\]](#) minutes to complete, and it could take considerably less.

If you have any questions or would like to request a paper copy of the survey please contact Kate Gridley at the [\[redacted\]](#)

For a large print or translated version of the information leaflet and questionnaire, please contact Kate Gridley at the [\[redacted\]](#)



## Life Story Work in Dementia Care

### Survey of Family Carers

This leaflet contains important information for carers of people with dementia considering taking part in the University of York survey about life story work. Please read it before completing the questionnaire.

The research is being conducted by the Social Policy Research Unit (part of the University of York) in partnership with Uniting Carers (part of Dementia UK), and is funded by the National Institute for Health Research.

#### You are invited to take part in a survey about life story work

You are invited to take part in a survey about life story work. You do not have to have any experience of life story work in order to take part: we are just as interested in hearing from carers who have never done any life story work as we are from those who have. If you have any questions after reading this information leaflet please contact Kate Gridley at the [REDACTED] who will be happy to discuss the project further.

#### What do we mean by 'life story work'?

In this research, when we say 'life story work', we mean:

1. Recording aspects of a person with dementia's:
  - past life
  - present interests
  - future wishes, hopes and dreams

This could be in a book, box, collage, or in any other way that the person wants.

2. Using the life story to improve things (care, relationships, etc.) for the person with dementia and others.

The aim of this survey is to find out from family carers (current and former) whether the people they care(d) for have life story documents and learn more about how these are used in care.

This is part of a larger study looking at the benefits and challenges of life story work in dementia care. For more information visit the project webpage at <http://php.york.ac.uk/inst/spru/research/summs/life.php>

### **Do I have to take part?**

No. It is entirely up to you whether you take part in this survey. If you do not want to take part please ignore this email and the follow-up email that you will receive in two weeks' time.

### **What would taking part involve?**

If you would like to take part in the survey, please click on the link in the email which will take you to an online survey. If you would prefer to complete the survey on paper, please contact Kate Gridley at the [REDACTED] and she will send you a paper copy with a prepaid return envelope.

The survey takes up to 30 minutes to complete, but it could take considerably less time depending on the answers you give.

The questions you will be asked in the survey cover:

- Some background information about you and the person you care(d)
- Whether the person with dementia has or had any life story documents
- What these are or were like
- How they are or were used
- What you think about this

Your answers will be kept safe and confidential on a password protected computer drive and/or in a locked cabinet, and will only be seen by the research team. Any information that is included in our final report or other publications will be completely anonymous.

The deadline for completing the survey is [insert date].

### **What if I change my mind about taking part?**

You can change your mind about completing the survey any time up until you press 'submit' on the online survey or you put a completed paper copy of the survey in the post. If you change your mind after this point you can still contact us to see if it is possible to withdraw your answers, but we cannot

guarantee this after submission as some calculations may have already been made that include your answers.

### **Will my taking part in this study be kept confidential?**

We will not ask for your name or tell anyone you have taken part in this study without your permission. We may repeat or refer to the answers you gave in reports, articles or presentations, but you will not be named and no details will be given that could identify you without discussing this with you first.

As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you before passing on any information.

### **What will happen to the results of the study?**

The information from all the completed questionnaires will be analysed and used to understand more about how life story work is used in dementia care. This will be considered together with information from a national survey of dementia care service providers. The project is due to report in spring 2015, after which time we will circulate a summary of the findings to everyone on the Uniting Carers email list.

### **Scientific and ethical review**

This study has been reviewed and funded by the National Institute for Health Research and the survey has been approved by the Social Care Research Ethics Committee for England.

### **Further information and contact details**

If you would like further information about the survey or would like to discuss any aspect of this research please contact: **Kate Gridley**

[REDACTED]  
[REDACTED]

If you are concerned or would like to complain about any aspect of this study, please contact the Director of the Social Policy Research Unit:

**Gillian Parker** [REDACTED]  
[REDACTED]

## Life Stories - Carers questionnaire - Version 3

### Life Story Work in Dementia Care. Survey of Family Carers

Thank you for taking the time to complete this questionnaire. Please remember that participation is optional. The questionnaire is anonymous and the answers you give will be kept secure and confidential. They will only be used to inform the research project about life story work described in the information leaflet you were sent by Uniting Carers [hyperlink to information sheet]. The questionnaire should take no more than 30 minutes to complete. Most of the questions have tick box answers, but there is space at the end for you to add your own comments. You do not have to complete the whole questionnaire in one session: you can close the webpage at any time and your answers will save automatically. You can come back to the webpage and add more answers for up to a week after starting the questionnaire, as long as you are on the same computer. If you have any questions or would like any help filling in the questionnaire, please email [redacted]

[redacted] and ask to speak to Kate Gridley or Linda Cusworth. If you are happy to continue please click on 'Next page' below to start the questionnaire.

### Part 1: Background information

It helps us to understand people's answers if we know a bit about them. This part of the questionnaire is about you and the person you care(d) for.

#### About you

1. What is your sex?

- ☐ Male
- ☐ Female

2. Which of the following age bands do you fit into?

- ☐ 16-24
- ☐ 25-34
- ☐ 35-44
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75+

3. What is your ethnic group? Please choose one option that best describes your ethnic group or background.

- ☐ White
- ☐ Mixed / Multiple ethnic groups
- ☐ Asian / Asian British
- ☐ Black / African / Caribbean / Black British
- ☐ Other ethnic group

4. Are you currently caring for someone with dementia?

- ☐ Yes  
☐ No

**Answer If 4. Are you currently caring for someone with dementia? Yes Is Selected**

If you care for more than one person with dementia, please choose the person you provide most care for and complete the rest of the questionnaire about that person.

**Answer If 4. Are you currently caring for someone with dementia? No Is Selected**

If you have cared for more than one person with dementia, please choose the person you provided most care for and complete the rest of the questionnaire about that person.

**About the person you care for**

6. What relationship to you is the person you care for? (please tick one)

- ☐ Spouse / partner  
☐ Parent  
☐ Parent-in-law  
☐ Grand-parent  
☐ Other relative  
☐ Friend or neighbour  
☐ Other (please specify) \_\_\_\_\_

7. What is their sex?

- ☐ Male  
☐ Female

8. What is the ethnic group of the person you care for? Please choose one option that best describes their ethnic origin or background.

- ☐ White  
☐ Mixed / Multiple ethnic groups  
☐ Asian / Asian British  
☐ Black / African / Caribbean / Black British  
☐ Other ethnic group

9. Which of the following age bands does the person you care for fit into? (please tick one)

- ☐ Under 45
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75-84
- ☐ 85-94
- ☐ 95 or over

10. Roughly how long have you been aware of the memory problems of the person you care for? (please tick one)

- ☐ Under 1 year
- ☐ 1-5 years
- ☐ 6-10 years
- ☐ 11 years or more

11. At the moment, where does the person you care for usually live? (please tick one)

- ☐ At home with me
- ☐ At home with others (e.g. spouse, other relative)
- ☐ At home alone
- ☐ In supported living accommodation
- ☐ In sheltered or very sheltered housing or housing with care
- ☐ In a residential or care home
- ☐ In a nursing home
- ☐ Other (please specify) \_\_\_\_\_

## Part 2: Life story work

What do we mean by 'life story work'? In this questionnaire, when we say 'life story work', we mean: - making something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams. AND - using these records to improve things (for example, care, relationships) for the person living with dementia and those around them. The record of the life story can be a book, a box, a collage, on a computer or in any other format that the person wants. Some people may have several different types of record of their life story, for example a photo album, a collage on the wall, and a written record for care staff. We are interested in all types of life story work. We are also interested in finding out how many people have not done life story work or have never come across it.



12. Have you ever heard of life story work for people living with dementia?

- ☐ Yes  
☐ No

If No Is Selected, Then Skip To Could life story work help (current)

13. How did you hear about life story work for people living with dementia? (please tick all that apply)

- ☐ I heard about it from another carer  
☐ I heard about it from a voluntary organisation (e.g. Dementia UK, Alzheimer's Society, Age UK)  
☐ I heard about it from a health or care professional/member of staff  
☐ I heard about it from a leaflet, magazine or other publication  
☐ I found out about it on the internet  
☐ Other (please specify) \_\_\_\_\_

14. Has the person you care for done any life story work - either on their own or with some help?

- ☐ Yes  
☐ No

If Yes Is Selected, Then Skip To End of Block

15. Not everyone gets the chance to do life story work and not everyone wants to do it. Why do you think the person you care for not has not done any life story work? (please tick all that apply)

- ☐ Life story work has never been offered to the person I care for  
☐ Life story work was offered but the person I care for was not interested in doing it  
☐ Life story work was offered but I was not sure of the benefits of doing it  
☐ Life story work was offered but I was worried about it raising painful memories for the person I care for  
☐ Life story work was offered but another family member or someone close to the person I care for was worried about it raising painful memories  
☐ Another reason \_\_\_\_\_

Answer If Ever heard of life story work (current) No Is Selected

13. People have different views about how helpful it is to do life story work. Do you think life story work could help the person you care for?

- ☐ Yes  
☐ No  
☐ Don't know

**Answer If Could life story work help (current) Yes Is Selected**

14. People can receive information about life story work at different times. When do you think it would be best for people to receive information about life story work?

- ☐ Before they show any signs of memory loss
- ☐ Soon after they show signs of memory loss (within 12 months)
- ☐ Later than this
- ☐ Not sure

16. A person's life story can be recorded in different ways. What kind of record(s) of their life story does the person you care for have? (please tick all that apply)

- ☐ A photo album just containing photographs
- ☐ A photo album with written comments or stories
- ☐ A book with a mixture of photos and stories
- ☐ A written summary
- ☐ A box containing important objects or memories
- ☐ A collage to put up on a wall
- ☐ A DVD or film
- ☐ A poem
- ☐ Something else (please specify) \_\_\_\_\_

17. Life story work can be done in different ways, for example, in a group or one-to-one. In what ways has the person you care for done their life story work? (please tick all that apply)

- ☐ In a group
- ☐ One-to-one
- ☐ Other (please specify) \_\_\_\_\_

18. Where has the person you care for done their life story work? (please tick all that apply)

- ☐ At home
- ☐ On a post-diagnostic course or group
- ☐ At a support group
- ☐ At a day centre, memory cafe or other community service
- ☐ In the care or nursing home where they live
- ☐ Somewhere else (please specify) \_\_\_\_\_

19. Different people can be involved in doing life story work. Who has been involved in doing life story work with the person you care for? (please tick all that apply)

- ☐ The person you care for
- ☐ You
- ☐ Another family member
- ☐ Someone else close to the person you care for (e.g. a friend or neighbour)
- ☐ A person paid to do life story work
- ☐ A person paid to provide care more generally
- ☐ A volunteer who does life story work
- ☐ Someone else (please specify) \_\_\_\_\_

20. People have different ideas about what life stories can be used for.

a) Thinking about all the types of life story records that the person you care for has, how is their life story used? (please tick all that apply)

b) Which aspect is most important to you (please tick one)

	a)	b)
	All that apply	Most important
It is something to help the person I care for remember important parts of their life	<input type="checkbox"/>	<input type="radio"/>
It is something to give the person I care for pleasure when they look at it	<input type="checkbox"/>	<input type="radio"/>
It is something that helps to soothe or calm the person I care for	<input type="checkbox"/>	<input type="radio"/>
It is something to help me remember the person I care for	<input type="checkbox"/>	<input type="radio"/>
It is something we enjoy looking at together	<input type="checkbox"/>	<input type="radio"/>
It is something to share with family members or other people close to the person I care for	<input type="checkbox"/>	<input type="radio"/>
It is something for health or social workers to use so that they can provide better care	<input type="checkbox"/>	<input type="radio"/>
Something else (please specify)	<input type="checkbox"/>	<input type="radio"/>

21. Different sorts of information or clues about a person's life can be included in a life story. Thinking about all the types of life story records that the person you care for has, what information is included in their life story? (please tick all that apply).

- ☐ The names of family member and other people close to them
- ☐ Details about or descriptions of family members and other people close to them
- ☐ Their reactions to family members and other people close to them
- ☐ A list of important events, dates, places or stages in their life
- ☐ Details about important events, dates, places or stages in their life
- ☐ Their feelings about important events, dates, places or stages in their life
- ☐ What they like to eat
- ☐ What they like to wear
- ☐ What they like doing (interests, hobbies, activities)
- ☐ Things they like to talk about
- ☐ Things they do not like to talk about
- ☐ Medical or care information
- ☐ Spiritual and cultural needs or preferences
- ☐ Something else \_\_\_\_\_

22. Sometimes certain information about the person with dementia, or a particular time in their life is left out of their life story. Did this happen when the person you care for did their life story? (please tick one)

- ☐ Yes
- ☐ No

If No [ROUTE FORWARDS] Is Selected, Then Skip To 25. How would you describe the life s ...

23. Why have certain things been left out of their life story? (please tick all that apply)

- ☐ Wanted the life story to be positive
- ☐ Some things would have been too private to include
- ☐ Some things would have been too upsetting to include
- ☐ Another reason (please specify) \_\_\_\_\_

24. Who made the decision to leave certain things out of the life story? (please tick all that apply)

- ☐ The person I care for
- ☐ Me
- ☐ Another family member, or someone close to the person I care for
- ☐ A health or social care worker
- ☐ Someone else (please specify) \_\_\_\_\_

25. Doing a life story can be a one-off event or it can be something that is added to as new memories come to light or new events take place. How would you describe the life story work of the person you care for? (please tick one)

- ☐ It was a one-off thing and nothing has been added to it since
- ☐ Photos, descriptions, or other items about the past have been added along the way
- ☐ Photos, descriptions or other items about recent events have been added as they happened

26. Life story work can be done at different points in the journey with dementia. When did the person you care for first do life story work? (please tick one)

- ☐ Before they showed any signs of memory problems
- ☐ Soon after they first showed signs of memory problems (within 12 months)
- ☐ Between a year and five years after they first showed signs of memory problems
- ☐ More than five years after they first showed signs of memory problems

27. Life stories can be about the past, the present and the future. Thinking about all the types of life story records that the person you care for has, how would you describe their life story? (please tick all that apply)

- ☐ The life story includes memories and information about the past
- ☐ The life story includes current information
- ☐ The life story includes hopes and views about the future

28. People have different views about who should be able to look at a person's life story. Who is able to look at the life story of the person you care for? (please tick all that apply)

- ☐ The person I care for
- ☐ Me
- ☐ Other family members, friends and people close to the person I care for
- ☐ Some selected health or social care staff
- ☐ Any health or social care staff
- ☐ Others (please specify) \_\_\_\_\_

29. Has the person you care for given their permission about which people can look at their life story? (please tick one)

- ☐ Yes
- ☐ No
- ☐ Don't know/Can't remember

30. Have you given your permission about which people can look at the life story of the person you care for? (please tick one)

- ☐ Yes  
☐ No  
☐ Don't know/Can't remember

31. Does the life story have a statement in it that says in which circumstances other people can look at it? (please tick one)

- ☐ Yes  
☐ No  
☐ Don't know/Can't remember

32. Where is the life story usually kept? (please tick all that apply)

- ☐ At the home of the person I care for  
☐ At my home (if the person you care for does not live with you)  
☐ At the day centre where the person I care for attends  
☐ At the care home or nursing home where the person I care for lives  
☐ Somewhere else (please specify) \_\_\_\_\_

33. How often do you, the person you care for, and care professionals or members of staff look at or use the life story? (please tick one box in each row)

	How often?					
	Every day	Once or twice a week	Once or twice a month	Less than once a month	Never	Don't know
You	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The person you care for	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care professionals/staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

34. Have there been any problems with the person you care for making and/or using their life story?

35. What have been the best things about the person you care for making and/or using their life story?

**About the person you cared for**

6. What relationship to you was the person you cared for? (please tick one)

- ☐ Spouse / partner
- ☐ Parent
- ☐ Parent-in-law
- ☐ Grand-parent
- ☐ Other relative
- ☐ Friend or neighbour
- ☐ Other (please specify) \_\_\_\_\_

7. What was their sex?

- ☐ Male
- ☐ Female

8. What was the ethnic group of the person you cared for? Please choose one option that best described their ethnic origin or background.

- ☐ White
- ☐ Mixed / Multiple ethnic groups
- ☐ Asian / Asian British
- ☐ Black / African / Caribbean / Black British
- ☐ Other ethnic group

9. How old was the person you cared for when you first became aware of their memory problems? (please tick one?)

- ☐ Under 45
- ☐ 45-54
- ☐ 55-64
- ☐ 65-74
- ☐ 75-84
- ☐ 85-94
- ☐ 95 or over

10. Roughly how long did you care for this person for? (please tick one)

- ☐ Under 1 year
- ☐ 1-5 years
- ☐ 6-10 years
- ☐ 11 years or more

## Part 2: Life story work

What do we mean by 'life story work'? In this questionnaire, when we say 'life story work', we mean: - making something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams. AND - using these records to improve things (for example, care, relationships) for the person living with dementia and those around them. The record of the life story can be a book, a box, a collage, on a computer or in any other format that the person wants. Some people may have several different types of record of their life story, for example a photo album, a collage on the wall, and a written record for care staff. We are interested in all types of life story work. We are also interested in finding out how many people have not done life story work or have never come across it.

12. Have you ever heard of life story work for people living with dementia?

☐ Yes

☐ No

If No Is Selected, Then Skip To Could LSW have helped person cared for...

13. How did you hear about life story work for people living with dementia? (please tick all that apply)

☐ I heard about it from another carer

☐ I heard about it from a voluntary organisation (e.g. Dementia UK, Alzheimer's Society, Age UK)

☐ I heard about it from a health or care professional/member of staff

☐ I heard about it from a leaflet, magazine or other publication

☐ I found out about it on the internet

☐ Other (please specify) \_\_\_\_\_

14. Did the person you cared for ever do any life story work - either on their own or with some help?

☐ Yes

☐ No

If Yes Is Selected, Then Skip To End of Block



15. Not everyone gets the chance to do life story work and not everyone wants to do it. Why do you think the person you cared for did not do any life story work? (please tick all that apply)

- ☐ Life story work was never offered to the person I cared for
- ☐ Life story work was offered but the person I cared for was not interested in doing it
- ☐ Life story work was offered but I was not sure of the benefits of doing it
- ☐ Life story work was offered but I was worried about it raising painful memories for the person I cared for
- ☐ Life story work was offered but another family member or someone close to the person I cared for was worried about it raising painful memories
- ☐ Another reason \_\_\_\_\_

#### Answer If Heard of LSW (ex) No Is Selected

13. People have different views about how helpful it is to do life story work. Do you think life story work could have helped the person you cared for? (please tick one)

- ☐ Yes
- ☐ No
- ☐ Don't know

#### Answer If Could LSW have helped person cared for (ex) Yes Is Selected

14. People can receive information about life story work at different times. When do you think it would be best for people to receive information about life story work? (please tick one)

- ☐ Before they show any signs of memory problems
- ☐ Soon after they show signs of memory problems (within 12 months)
- ☐ Later than this
- ☐ Not sure

16. A person's life story can be recorded in different ways. What kind of record(s) of their life story did the person you cared for have? (please tick all that apply)

- ☐ A photo album just containing photographs
- ☐ A photo album with written comments or stories
- ☐ A book with a mixture of photos and stories
- ☐ A written summary
- ☐ A box containing important objects or memories
- ☐ A collage to put up on a wall
- ☐ A DVD or film
- ☐ A poem
- ☐ Something else (please specify) \_\_\_\_\_

17. Life story work can be done in different ways, for example, in a group or one-to-one. How did the person you cared for do their life story work? (please tick all that apply)

- ☐ In a group
- ☐ One-to-one
- ☐ Other (please specify) \_\_\_\_\_

18. Where did the person you cared for do their life story work? (please tick all that apply)

- ☐ At home
- ☐ On a post-diagnostic course or group
- ☐ At a support group
- ☐ At a day centre, memory cafe or other community service
- ☐ In the care or nursing home where they live
- ☐ Somewhere else (please specify) \_\_\_\_\_

19. Different people can be involved in doing life story work. Who was involved in doing life story work with the person you cared for? (please tick all that apply)

- ☐ The person you cared for
- ☐ You
- ☐ Another family member
- ☐ Someone else close to the person you cared for (e.g. a friend or neighbour)
- ☐ A person paid to do life story work
- ☐ A person paid to provide care more generally
- ☐ A volunteer who does life story work
- ☐ Someone else (please specify) \_\_\_\_\_

20. People have different ideas about what life stories can be used for. a) Thinking about all the types of life story records that the person you cared for had, how was their life story used? (please tick all that apply) b) Which aspect was most important to you (please tick one)

	a)	b)
	All that apply	Most important
It was something to help the person I cared for remember important parts of their life	<input type="checkbox"/>	<input type="radio"/>
It was something to give the person I cared for pleasure when they looked at it	<input type="checkbox"/>	<input type="radio"/>
It was something that helped to soothe or calm the person I cared for	<input type="checkbox"/>	<input type="radio"/>
It was something to help me remember the person I cared for	<input type="checkbox"/>	<input type="radio"/>
It was something we enjoyed looking at together	<input type="checkbox"/>	<input type="radio"/>
It was something to share with family members or other people close to the person I cared for	<input type="checkbox"/>	<input type="radio"/>
It was something for health or social workers to use so that they could provide better care	<input type="checkbox"/>	<input type="radio"/>
Something else (please specify)	<input type="checkbox"/>	<input type="radio"/>

21. Different sorts of information or clues about a person's life can be included in a life story. Thinking about all the types of life story records that the person you cared for had, what information was included in their life story? (please tick all that apply).

- ☐ The names of family members and other people close to them
- ☐ Details about or descriptions of family members and other people close to them
- ☐ Their reactions to family members and other people close to them
- ☐ A list of important events, dates, places or stages in their life
- ☐ Details about important events, dates, places or stages in their life
- ☐ Their feelings about important events, dates, places or stages in their life
- ☐ What they liked to eat
- ☐ What they liked to wear
- ☐ What they liked doing (interests, hobbies, activities)
- ☐ Things they liked to talk about
- ☐ Things they did not like to talk about
- ☐ Medical or care information
- ☐ Spiritual and cultural needs or preferences
- ☐ Something else \_\_\_\_\_

22. Sometimes certain information about the person with dementia, or a particular time in their life is left out of their life story. Did this happen when the person you cared for did life story work? (please tick one)

- ☐ Yes
- ☐ No

If No [ROUTE FORWARDS] Is Selected, Then Skip To 25. How would you describe the life s...

23. Why were certain things left out of their life story? (please tick all that apply)

- ☐ Wanted the life story to be positive
- ☐ Some things would have been too private to include
- ☐ Some things would have been too upsetting to include
- ☐ Another reason (please specify) \_\_\_\_\_

24. Who made the decision to leave certain things out of the life story? (please tick all that apply)

- ☐ The person I cared for
- ☐ Me
- ☐ Another family member, or someone close to the person I cared for
- ☐ A health or social care worker
- ☐ Someone else (please specify) \_\_\_\_\_

25. Doing a life story can be a one-off event or it can be something that is added to as new memories come to light or new events take place. How would you describe the life story work of the person you cared for? (please tick one)

- ☐ It was a one-off thing and nothing else has been added to it since
- ☐ Photos, descriptions, or other items about the past were added along the way
- ☐ Photos, descriptions or other items about recent events were added as they happened

26. Life story work can be done at different points in the journey with dementia. When did the person you cared for first do life story work? (please tick one)

- ☐ Before they showed any signs of memory problems
- ☐ Soon after they first showed signs of memory problems (within 12 months)
- ☐ Between a year and five years after they first showed signs of memory problems
- ☐ More than five years after they first showed signs of memory problems

27. Life stories can be about the past, the present and the future. Thinking about all the types of life story records that the person you cared for had, how would you describe their life story? (please tick all that apply)

- ☐ The life story included memories and information about the past
- ☐ The life story included current information
- ☐ The life story included hopes and views about the future

28. People have different views about who should be able to look at a person's life story. Who was able to look at the life story of the person you cared for? (please tick all that apply)

- ☐ The person I cared for
- ☐ Me
- ☐ Other family members, friends and people close to the person I cared for
- ☐ Some selected health or social care staff
- ☐ Any health or social care staff
- ☐ Others (please specify) \_\_\_\_\_

29. Did the person you cared for give their permission about which people could look at their life story? (please tick one)

- ☐ Yes
- ☐ No
- ☐ Don't know/Can't remember

30. Did you give your permission about which people could look at the life story of the person you cared for? (please tick one)

- ☐ Yes  
☐ No  
☐ Don't know/Can't remember

31. Did the life story have a statement in it that said in which circumstances other people could look at it? (please tick one)

- ☐ Yes  
☐ No  
☐ Don't know/Can't remember

32. Where was the life story usually kept? (please tick all that apply)

- ☐ At the home of the person I cared for  
☐ At my home (if the person you cared for did not live with you)  
☐ At the day centre where the person I cared for attended  
☐ At the care home or nursing home where the person I card for lived  
☐ Somewhere else (please specify) \_\_\_\_\_

33. How often did you, the person you cared for, and care professionals or members of staff look at or use the life story? (please tick one box in each row)

	How often?					
	Every day	Once or twice a week	Once or twice a month	Less than once a month	Never	Don't know
You	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The person you cared for	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Care professionals/staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

34. Were there any problems with the person you cared for making and/or using their life story?

35. What were the best things about the person you cared for making and/or using their life story?

Is there anything else you would like to tell us about life story work for people living with dementia?

Would you like to know more about life story work?

- ☐ Yes  
☐ No

Answer If Would you like to know more about life story work? No [ROUTE TO ending 2 below] Is Selected

If you have any questions about this questionnaire or research project, please email [REDACTED] or ring [REDACTED] and ask to speak to Kate Gridley or Linda Cusworth. If you have concerns about any of the issues raised in this questionnaire and would like to talk to someone, please contact Admiral Nursing Direct on [REDACTED]

Answer If Would you like to know more about life story work? Yes [ ROUTE TO ending 1 BELOW] Is Selected

If you have any questions about this questionnaire or research project, please email [REDACTED] and ask to speak to Kate Gridley or Linda Cusworth. If you have concerns about any of the issues raised in this questionnaire and would like to talk to someone, please contact Admiral Nursing Direct on [REDACTED] You can find out more about life story work by visiting the Life Story Network website (<http://www.lifestorynetwork.org.uk>)

Thank you for completing this questionnaire. Please click 'Next page' to submit your response

## Appendix 10 Paperwork for feasibility study

### Information sheets

#### Care homes: people with dementia

THE UNIVERSITY *of York*



## Life Stories in Dementia Care

### Taking part in research



Information Sheet PWD – Care Homes V2 Nov 2013



## **We are doing some research about life story work – Can You Help?**

### **Would you like to take part in some research?**

You are invited to take part in some research about life story work

### **What is life story work?**

Life story work involves recording aspects of a person's:

- past life
- present interests
- future wishes, hopes and dreams.



This could be in a book, box or in any other way that the person prefers – for example, on a computer.

The life story is owned by the person who made it and is a living document that can be added to as life goes on.

### **Research into life story work**

We want to find out how life story work affects people's lives.

Does it make things better or worse? Or do they stay the same?

Please read this leaflet if you are interested in taking part.

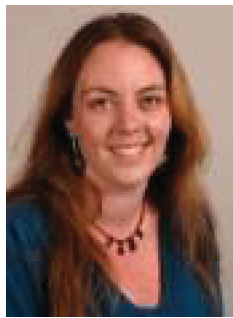
## Who we are

The research is being carried out by two researchers from the University of York Social Policy Research Unit:



Kate Gridley

and



Jenni Brooks

## What is the research about?

██████ want to give their residents the opportunity to make a life story. The workers in your care home will soon be offering help to some people to record their life stories.



Kate and Jenni are doing some research to see whether making a life story makes a difference to people's lives. They would like to gather some information from people who make life stories and the people who support them.

Information Sheet PWD – Care Homes V2 Nov 2013

## Why have I been given this leaflet?

You have been randomly selected to take part in this study.

## What will happen if I take part?

**SOME QUESTIONS:** Kate or Jenni will visit you before you start making your life story and three times after to ask you some questions. The questionnaires they will use are about how you feel ('quality of life') and your relationships with others. They will keep all your answers confidential.



## AN INTERVIEW



Kate and Jenni will interview some of the people who take part in this research. The interviews will be informal conversations about making a life story. These will be tape recorded and written up. If you do not want to take part in a tape recorded interview that is fine, you can still take part in the rest of the research.

Information Sheet PWD – Care Homes V2 Nov 2013

## What other information will they collect?

Jenni and Kate would also like to collect information about what medication you are on, how often you use different services and whether you had any falls or other problems before and after making the life story. If you agree to take part in the research they will collect this information from your care records (they may use your NHS number for this).

## Deciding whether to take part

You do not have to take part in this research. It is entirely up to you. Please discuss any questions or concerns you have with Kate or Jenni. You can also talk to someone else about it – like a family member or friend.

## What if I do not want to take part?

That's fine - nothing will change.

## Support to take part

If you would like someone, like a friend, care worker or family member to be with you when we visit you, that's fine – please discuss this with a member of staff.



If you need help to hear or speak, or any other support to take part, please let us know.

Information Sheet PWD – Care Homes V2 Nov 2013

## Agreeing to take part

If you would like to take part, we will ask you to sign a consent form. Someone else can sign this form for you if you prefer.

## Changing your mind about taking part

You can change your mind about taking part in the study at any time. You do not have to give a reason.

If you change your mind halfway through, we will still keep a record of the things we've learnt up to that point, but we will not ask you anything else.

## Confidentiality

We will not tell anyone you have taken part in this study without your permission and we will not use your name in any reports we write.

We will keep everything you say in a safe place for 5 years.



The only time we might have to speak to someone else is if you tell us that you or someone else is being hurt, but we would always try to speak to you about this first.

## How will the research be used?



We want to find out if life story work could make things better for people with dementia. The findings of this small study will be used to help plan a larger study about this. We will write a report for the National Institute of Health Research and talk about the research at conferences and in articles, but we will not use your name.

When the research is finished we will come back to the care home to talk to you about what we have learnt.

**This study is being conducted by the Social Policy Research Unit (University of York) and [REDACTED].** It was funded by the National Institute for Health Research and has been approved by the Social Care Research Ethics Committee for England

## Independent advice

If you would like to discuss this project with an organisation that supports people with dementia to get involved in research please contact:

**Nada Savitch** at Innovations in Dementia

Telephone: 07549 921901

Email: [nada@myid.org.uk](mailto:nada@myid.org.uk)

Information Sheet PWD – Care Homes V2 Nov 2013

## Further information

If you would like more information about this research please contact **Kate Gridley** at the Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Telephone: 01904 321988

Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

If you would like to speak to someone at [REDACTED] about their involvement in this study, please contact:



## Complaints

If you are concerned or would like to complain about this study, please contact: **Gillian Parker**, Director, Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Telephone: 01904 321957

Email: [spru-director@york.ac.uk](mailto:spru-director@york.ac.uk)



*Comparison hospital: people with dementia*THE UNIVERSITY *of York*

[Insert comparison site logo here]

# Improving Care for People with Dementia

## Taking part in research



Information Sheet PWD – COMPARISON hospital V2 Nov 2013



## **We are doing some research about life for people with dementia – Can You Help?**

### **Would you like to take part in some research?**

The hospital that provides your care is taking part in a research project. Would you like to get involved?

Who we are?

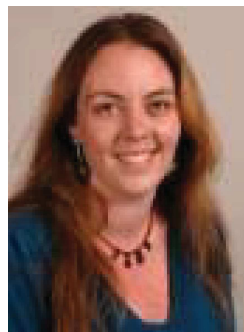
### **Who we are**

The research is being carried out by two researchers from the University of York Social Policy Research Unit:



Kate Gridley

and



Jenni Brooks

Information Sheet PWD – COMPARISON hospital V2 Nov 2013



## What is the research about?

We want to understand how people at your hospital feel while they are in hospital and afterwards. We will compare this with information about people in another hospital. At the other hospital they do something called 'life story work', whereas at your hospital they don't. We want to find out which approach is best.

Kate and Jenni would like to gather some information from some patients on your ward and from some family carers.

**They would like to invite you to take part in this study.**

## What will happen if I take part?

### SOME QUESTIONS

Kate or Jenni will visit you at the start of the project, and three more times after, to ask you some questions. The questionnaires they will use are about how you feel ('quality of life') and your relationships with others. They will keep all your answers confidential.

Information Sheet PWD – COMPARISON hospital V2 Nov 2013

## What other information will they collect?

Jenni and Kate would also like to collect information about what medication you are on, how often you use different services and whether you had any falls or other problems. They will collect this information from health records (they may use your NHS number for this).

## Deciding whether to take part

You do not have to take part in this research. It is entirely up to you. Please discuss any questions or concerns you have with Kate or Jenni. You can also talk to someone else about it – like a family member or friend.

## What if I do not want to take part?

That's fine - nothing will change.

## Support to take part

If you would like someone, like a friend, care worker or family member to be with you when we visit you, that's fine – please discuss this with a member of staff.



If you need help to hear or speak, or any other support to take part, please let us know.

## Agreeing to take part

If you would like to take part, we will ask you to sign a consent form. Someone else can sign this form for you if you prefer.

## Changing your mind about taking part

You can change your mind about taking part in the study at any time. You do not have to give a reason.

If you change your mind halfway through, we will still keep a record of the things we've learnt up to that point, but we will not ask you anything else.

## Confidentiality

We will not tell anyone you have taken part in this study without your permission and we will not use your name in any reports we write.

We will keep everything you say in a safe place for 5 years.



Information Sheet PWD – COMPARISON hospital V2 Nov 2013

The only time we might have to speak to someone else is if you tell us that you or someone else is being hurt, but we would always try to speak to you about this first.

## How will the research be used?



We want to find out if life story work could make things better for people with dementia. The findings of this small study will be used to help plan a larger study about this. We will write a report for the National Institute of Health Research and talk about the research at conferences and in articles, but we will not use your name.

If you would like them to send you a summary of what we have learnt, please let us know who to send this to.

**This study is being conducted by the Social Policy Research Unit (University of York).** It was funded by the National Institute for Health Research and has been approved by the Social Care Research Ethics Committee for England.

## Further information

If you would like more information about this research please contact **Kate Gridley** at the Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Telephone: 01904 321988

Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

## Independent advice

If you would like to discuss this project with an organisation that supports people with dementia to get involved in research please contact:

**Nada Savitch** at Innovations in Dementia

Telephone: 07549 921901

Email: [nada@myid.org.uk](mailto:nada@myid.org.uk)

## Complaints

If you are concerned or would like to complain about this study, please contact: **Gillian Parker**, Director, Social Policy Research Unit, University of York, Heslington, York YO10 5DD

Telephone: 01904 321957

Email: [spru-director@york.ac.uk](mailto:spru-director@york.ac.uk)

Information Sheet PWD – COMPARISON hospital V2 Nov 2013

*Care homes: family carers*

## Life Stories in Dementia Care Feasibility Study

### Information leaflet for unpaid carers

This leaflet contains information for unpaid carers of people with dementia who are being invited to take part in research about life story work. Please read it all before deciding whether to take part.

The research is being conducted by the Social Policy Research Unit, University of York, in partnership with [REDACTED], and is funded by the National Institute for Health Research.

#### Our invitation to you

[REDACTED] has teamed up with the University of York to do some research about life story work. They want to understand whether life story work makes a difference for people with dementia and those who care for them, and whether this difference can be measured.

You have been contacted because the person you care for was randomly selected to take part in the study. We are inviting you to join the study as well as we are interested in whether their involvement in life story work makes a difference for you. Both you and they are free to say no or yes to this invitation.

If you have any questions after reading this leaflet, please contact Kate Gridley in the research team on 01904 3212988 [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk) or speak to your care home manager.

### When we say 'life story work', we mean:

- Creating something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams.

AND

- Using these records to improve things (for example, care, relationships) for the person living with dementia and those around them.

The record of the life story can be a book, a box, a collage, on a computer or in any other way that the person wants. Some people may have several different types of record of their life story.

### Who are the researchers?

The research is being carried out by two researchers from the University of York Social Policy Research Unit: Kate Gridley (left) and Dr Jenni Brooks (right).



### What is the research about?

██████ want to give their residents with dementia the opportunity to make a life story. The workers in the care home have had some extra training in life story work and will soon be offering help to some of the residents with dementia to record their life stories.

We want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them. There have been no large-scale, in-depth studies of life story work in dementia care so little is known about whether it makes a difference, how it makes a difference, or even how to measure this.

This study is a pilot study which will inform future evaluations of life story work. Kate and Jenni will try out a range of ways of assessing the impact of life story work in six ██████ care homes, including the home the person you care for lives in. They

Life Story Information Sheet for Feasibility Study, Carers V1 Oct 2013



will use some questionnaires which measure things like quality of life and the relationships between people. They will also interview and observe some (but not all) of the people involved. Then they will write a report about what they have learnt for the National Institute for Health Research, who will use it to decide whether to do a full scale study of the effectiveness of life story work. They may also learn things about good practice that they can feed back to staff who work in and design services, as well as other people involved in the research, to help improve care.

### What would taking part involve?

If you decide to take part, Jenni or Kate will ask you to complete a short questionnaire about your quality of life and another one about your relationship with the person you care for. The information you provide will be kept confidential and will be stored in a safe place (see below). They will ask you to complete these questionnaires again 1 month, 2 months and 6 months after you first completed them.

Some of the people taking part in this study will also be invited to take part in an interview. This would be an informal conversation about your views on life story work and your experiences of taking part in the research. Interviews will be tape recorded and transcribed to ensure that the researchers do not forget anything that is said. No-one outside the research team (and no-one at [REDACTED]) will hear the interviews or see the notes we make of interviews. **If you do not want to take part in an interview you can still take part in the rest of the research.**

### How do I consent to take part?

If you are interested in taking part, please contact Kate Gridley (see contact details below) or ask a member of staff to pass on your contact details to Kate or Jenni. They will contact you to answer any questions you have, and if you want to proceed they will ask you to sign a consent form. There is a separate box on the consent form to indicate whether you would like to take part in a tape recorded interview. If you choose not to tick this box you can still take part in the rest of the study.

### Do I have to take part?

No. It is entirely up to you whether you take part in this study. The person you care for can still take part in the study even if you decide not to yourself. If you choose not to take part it will not affect the care of the person you care for in any way.

### Support for you

If you require any support to take part in this study, such as help with transport to meet with the researchers at the care home, this can be arranged. Please keep all tickets and receipts to enable us to reimburse you. Similarly, if you need any help to

Life Story Information Sheet for Feasibility Study, Carers V1 Oct 2013

communicate such as an interpreter or help to fill in the questionnaires, please let us know.

### **What if I change my mind about taking part?**

You can withdraw from the study at any time without giving a reason. However, if you withdraw after the study has started, the information you have already given may still be used for the research.

### **Will my taking part in this study be kept confidential?**

Yes, we will keep the information you provide safe and secure and it will not be shared with anyone without your permission. We may repeat or refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you without discussing this with you first. The information you provide, including your contact details, will be held by the University of York for 5 years as required by our funder.

As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

### **What will happen to the results of the study?**

The information from the study will be used to see if life story work has made a difference for the people involved. We will write a report about everything we learn for the National Institute of Health Research which will be circulated widely. We will also talk about what we have learnt at conferences and in academic papers. No names will be used in anything we produce. The report should be available in spring 2015. If you would like to be sent a copy, please give your preferred contact details to a member of the research team.

### **Further information and contact details**

If you would like further information or have questions about this study please contact: **Kate Gridley** Social Policy Research Unit, University of York, Heslington, York, YO10 5DD tel: 01904 321988 Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

### **Independent advice**

If you would like to discuss this project with an organisation that supports carers to get involved in research please contact: **Joy Watkins** at Uniting Carers  
Tel: 07967 685979 Email: [watkinsjoya@yahoo.com](mailto:watkinsjoya@yahoo.com)

*Comparison hospital: family carers*

[Insert comparison site logo here]

## Improving Care for People with Dementia Taking part in research

### Information leaflet for unpaid carers

This leaflet contains information for unpaid carers of people with dementia who are being invited to take part in a research project. Please read it all before deciding whether to take part.

The research is being conducted by the Social Policy Research Unit, University of York, in partnership with [comparison site], and is funded by the National Institute for Health Research.

If you have any questions after reading this leaflet, please contact Kate Gridley in the research team ([kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk) Tel: 01904 3212988) or speak to your ward manager.

### Our invitation to you

[Comparison site] has teamed up with the University of York to do some research about life story work. You have been contacted because the person you care for was selected to take part in the study. We are inviting you to join the study as well as. Both you and they are free to say no or yes to this invitation.

### Who are the researchers?

The research is being carried out by two researchers from the University of York Social Policy Research Unit: Kate Gridley (left) and Dr Jenni Brooks (right).



## What is the life stories research about?

In some hospitals, support to make a life story is a routine part of care. At present, [\[Comparison site\]](#) do not offer life story work to any patients. [\[Comparison site\]](#) would like to learn more about the well-being of patients who do not get support to make a life story, and about the well-being and satisfaction of the people who care for them.

There have been no large-scale, in-depth studies of life story work in dementia care so little is known about whether it makes a difference, how it makes a difference, or even how to measure this. Researchers at the University of York want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them.

This study is a small preliminary study which we will use to design a bigger study. Kate and Jenni will try out a range of ways of assessing the difference between outcomes for people on wards that do and do not do life story work. The person you care for is **on a ward that does not do life story work**. If you take part in this research you would therefore be in the comparison group.

### When we say 'life story work', we mean:

- Creating something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams.

### AND

- Using these records to improve things (for example, care, relationships) for the person living with dementia and those around them.

The record of the life story can be a book, a box, a collage, on a computer or in any other way that the person wants. Some people may have several different types of record of their life story.

## What would taking part involve?

If you decide to take part, Jenni or Kate will ask you to complete a short questionnaire about your quality of life and another one about your relationship with the person you care for. They will also ask you about your satisfaction with the care provided at the hospital. The information you give will be kept confidential and will

Life Story Information Sheet for HOSPITAL Feasibility Study, Carers V1 Oct 2013

be stored in a safe place (see below). They will ask you to complete these questionnaires again 1 month, 2 months and 6 months after you first completed them.

### **How do I consent to take part?**

If you are interested in taking part, please contact Kate Gridley (see contact details below) or ask a member of staff to pass on your contact details to Kate or Jenni. They will contact you to answer any questions you have, and if you want to proceed they will ask you to sign a consent form.

### **Do I have to take part?**

No. It is entirely up to you whether you take part in this study. The person you care for can still take part in the study even if you decide not to yourself. If you choose not to take part it will not affect the care of the person you care for in any way.

### **Support for you**

If you require any support to take part in this study, such as help with transport to meet with the researchers at the hospital, this can be arranged. Please keep all tickets and receipts to enable us to reimburse you. Similarly, if you need any help to communicate such as an interpreter or help to fill in the questionnaires, please let us know.

### **What if I change my mind about taking part?**

You can withdraw from the study at any time without giving a reason. However, if you withdraw after the study has started, the information you have already given may still be used for the research.

### **Will my taking part in this study be kept confidential?**

We will keep the information you provide safe and secure and it will not be shared with anyone without your permission. We may repeat or refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you without discussing this with you first. The information you provide, including your contact details, will be held by the University of York for 5 years as required by our funder.

As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

## What will happen to the results of the study?

We will write a report about everything we learn for the National Institute of Health Research which will be circulated widely. We will also talk about what we have learnt at conferences and in academic journals. No names will be used in anything we produce. The report should be available in spring 2015. If you would like to be sent a copy, please give your preferred contact details to a member of the research team.

## Further information and contact details

If you would like further information or have questions about this study please contact: **Kate Gridley** Social Policy Research Unit, University of York, Heslington, York, YO10 5DD; Tel: 01904 321988; Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

## Independent advice

If you would like to discuss this project with an organisation that supports carers to get involved in research please contact: **Joy Watkins** at Uniting Carers

Tel: 0207 874 7209 Email: [joy.watkins@dementiauk.org](mailto:joy.watkins@dementiauk.org)

*Care homes: consultees*

## Life Stories Research

### Information Leaflet for Consultees

#### Background

■■■■■ has teamed up with the University of York to do some research about life story work. They want to understand whether life story work makes a difference for people with dementia and those who care for them, and whether this difference can be measured. The research is being conducted by the Social Policy Research Unit, (University of York), in partnership with ■■■■■, and is funded by the National Institute for Health Research.

#### Who are the researchers?

The research is being carried out by two researchers from the University of York Social Policy Research Unit: Kate Gridley (left) and Dr Jenni Brooks (right).



#### Why have I been contacted?

We believe that .....is unable to make an informed decision about getting involved in a research project taking place in some ■■■■■ care homes. We are contacting you for advice on whether you think he/she would want to take part – if you agree to give this advice, this would make you a 'consultee'.

This information leaflet explains what the research is about and what it means to be a consultee.

Life Story Information Sheet for Feasibility Study, Care Home CONSULTTEES V1 Oct 2013



## What does it mean to be a consultee?

A consultee is someone who knows a person well and is willing and able to offer an opinion as to what that person's wishes would be. A consultee is not asked for their personal views about the research but what they think the person's wishes would have been if they were able to make a decision.

## Why have I been asked to be a consultee?

You have been contacted because the person you care for was randomly selected to take part in the study and we are seeking your advice as to whether you think they would agree to take part if they had the capacity to do so.

### Personal consultees

You may have been chosen because you know the person personally and they would trust you to help with this decision. This would make you a 'personal consultee'.

### Nominated consultees

Or, you may be a member of the care team who looks after the person and have their best interests in mind, in which case you are a 'nominated consultee'.

## Do I have to be a consultee?

No, you do not have to act as a consultee if you do not want to. Please let us know (see contact details below) if you do not want to act as a consultee and we will find an alternative.

## What is the life stories research about?

██████ want to give their residents with dementia the opportunity to make a life story. The workers in the care home have had some extra training in life story work and will soon be offering help to some of the residents with dementia to record their life stories.

Researchers at the University of York want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them. There have been no large-scale, in-depth studies of life story work in dementia care so little is known about whether it makes a difference, how it makes a difference, or even how to measure this.

This study is a small preliminary study which we will use to design a bigger study. Kate and Jenni will try out a range of ways of assessing the impact of life story work in six ██████ care homes across the country, including the home of the person you are being consulted about.

Life Story Information Sheet for Feasibility Study, Care Home CONSULTTEES V1 Oct 2013



**When we say 'life story work', we mean:**

- Creating something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams.

**AND**

- Using these records to improve things (for example, care, relationships) for the person living with dementia and those around them.

The record of the life story can be a book, a box, a collage, on a computer or in any other way that the person wants. Some people may have several different types of record of their life story.

**What would taking part involve for the person I am a consultee for?**

Kate and Jenni would like to collect some information about the person from the care home and the person's main carer, and ask the person themselves some questions (if they are able to answer). The information they collect will be kept confidential and will be stored in a safe place (see below).

Kate or Jenni will visit the care home on four occasions over a 6 month period to collect this information (once before they do any life story work, then 1 month, 2 months and 6 months afterwards).

**Assessing quality of life:**

We would like to assess the person's quality of life before and after they start doing life story work. We could do this by asking them directly, or if they are unable to understand and answer questions we will ask a family member or friend to answer on their behalf.

**Asking about relationships:**

If they are able to answer questions we will also ask them about their relationship to their main carer (if they have one). Again, if they are unable to answer these questions we will only ask the carer.

**Information from care records:**

We would like to collect information about the medication the person takes, the sorts of care they have received and whether anything untoward like a fall or an admission to hospital has happened to them. This information will be collected from care records by care home staff (no-one from the research team will have access to the person's records directly). It may require the use of the person's NHS number.

**Does the person have to take part?**

No. We are asking you whether you think the person would want to take part. If you think they would prefer not to that is fine, they will not be included. This will not alter the care they receive in any way.

**Support for the person**

If you think that the person could take a more active role in the research if they had some support, such as a communication aid, or the help of a friend or interpreter, then please let us know.

**Will information be kept secure and confidential?**

We will keep the information we collect safe and secure and it will not be shared with anyone without your permission. We may refer to information about the person in reports, articles or presentations, but they will not be named and no details will be given that could identify them. The information about them, including that you acted as their consultee, will be held by the University of York for 5 years as required by our funder.

As with all assurances of confidentiality, we may still have to pass on information if it appears that the person, or someone else, is at risk of serious harm. In such a situation, we would try to talk to you before passing on any information.

**What will happen to the results of the study?**

We will write a report about everything we learn for the National Institute of Health Research, (part of the NHS) which will be circulated widely. We will also talk about what we have learnt at conferences and in academic papers. No names will be used in anything we produce. The report should be available in spring 2015. If you would like to be sent a copy, please give your preferred contact details to a member of the research team.

### How do I respond to this consultation?

Please contact Kate Gridley on 01904 3212988 [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk) to let her know whether you would be happy to act as a consultee, or ask a member of staff at the care home to pass on your contact details so that Kate or Jenni can contact you. They will answer any questions you have over the phone or in person. If you think the person would have no objections to taking part in the research, you will be asked to sign a 'record of consultation' form.

**If you feel unable to give advice about the person's wishes, please say so.**

### What if I change my mind?

You can withdraw the person from the study at any time. This will not affect the care that they receive. If you withdraw them after the study has started, any information already provided will be retained, but no more will be collected.

### Further information and contact details

If you would like further information or have questions about this study please contact: **Kate Gridley** Social Policy Research Unit, University of York, Heslington, York, YO10 5DD tel: 01904 321988 Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

### Independent advice

If you would like to discuss this project with an organisation that supports people with dementia to get involved in research please contact:

Nada Savitch at Innovations in Dementia, Tel: 07549 921901 [nada@myid.org.uk](mailto:nada@myid.org.uk)

**Comparison hospital: consultees**

[Insert logo of comparison site]

## Life Stories Research

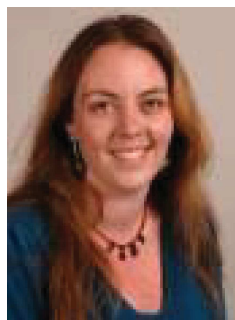
### Information Leaflet for Consultees

#### Background

[Comparison site] has teamed up with the University of York to do some research about life story work. They want to understand whether life story work makes a difference for people with dementia and those who care for them, and whether this difference can be measured. The research is being conducted by the Social Policy Research Unit, (University of York), in partnership with [Comparison site], and is funded by the National Institute for Health Research.

#### Who are the researchers?

The research is being carried out by two researchers from the University of York Social Policy Research Unit: Kate Gridley (left) and Dr Jenni Brooks (right).



#### Why have I been contacted?

We believe that .....is unable to make an informed decision about getting involved in a research project taking place on Jubilee Ward. We are contacting you for advice on whether you think he/she would want to take part – if you agree to give this advice, this would make you a 'consultee'.

This information leaflet explains what the research is about and what it means to be a consultee.

Life Story Information Sheet for Feasibility Study, COMPARISON GROUP CONSULTYES V1 Oct 2013

## What does it mean to be a consultee?

A consultee is someone who knows a person well and is willing and able to offer an opinion as to what that person's wishes would be. A consultee is not asked for their personal views about the research but what they think the person's wishes would have been if they were able to make a decision.

## Why have I been asked to be a consultee?

You have been contacted because the person you care for is eligible to take part in the study and we are seeking your advice as to whether you think they would have agreed to take part if they had the capacity to do so.

### Personal consultees

You may have been chosen because you know the person personally and they would trust you to help with this decision. This would make you a 'personal consultee'.

### Nominated consultees

Or, you may be a member of the care team who looks after the person and have their best interests in mind, in which case you are a 'nominated consultee'.

## Do I have to be a consultee?

No, you do not have to act as a consultee if you do not want to. Please let us know (see contact details below) if you do not want to act as a consultee and we will find an alternative.

## What is the life stories research about?

In some hospitals, support to make a life story is a routine part of care. At present, [Comparison site] do not offer life story work to any patients. [Comparison site] would like to learn more about the well-being of patients who do not get support to make a life story.

There have been no large-scale, in-depth studies of life story work in dementia care so little is known about whether it makes a difference, how it makes a difference, or even how to measure this. Researchers at the University of York want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them.

This study is a small preliminary study which we will use to design a bigger piece of research. Kate and Jenni will try out a range of ways of assessing the difference between outcomes for people on wards that do and do not do life story work. The person you are a consultee for is **on a ward that does not do life story work**. If they take part in this research they would therefore be in the comparison group.

#### When we say 'life story work', we mean:

- Creating something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams.

AND

- Using these records to improve things (for example, care, relationships) for the person living with dementia and those around them.

The record of the life story can be a book, a box, a collage, on a computer or in any other way that the person wants. Some people may have several different types of record of their life story.

#### What would taking part involve for the person I am a consultee for?

Kate and Jenni would like to collect some information about the person from their medical records and their main carer, and ask the person with dementia themselves some questions (if they are able to answer). The information they collect will be kept confidential and will be stored in a safe place (see below).

Kate or Jenni will visit the person on four occasions over a 6 month period to collect this information (once at the start of the project, and again 1 month, 2 months and 6 months afterwards).

#### Assessing quality of life:

We would like to assess the person's quality of life. We could do this by asking them directly, or if they are unable to understand and answer questions we will ask a family member or friend to answer on their behalf.

**Asking about relationships:**

If they are able to answer questions we will also ask them about their relationship to their main carer (if they have one). Again, if they are unable to answer these questions we will only ask the carer.

**Information from medical records:**

We would like to collect information about the medication the person takes, the sorts of care they have received and whether anything untoward (like a fall) has happened to them. This information will be collected from medical records by hospital staff (no-one from the research team will have access to the person's records directly). It may require the use of the person's NHS number.

**Does the person have to take part?**

No. We are asking you whether you think the person would want to take part. If you think they would prefer not to that is fine, they will not be included. This will not alter the care they receive in any way.

**Support for the person**

If you think that the person could take a more active role in the research if they had some support, such as a communication aid, or the help of a friend or interpreter, then please let us know.

**Will information be kept secure and confidential?**

We will keep the information we collect safe and secure and it will not be shared with anyone without your permission. We may refer to information about the person in reports, articles or presentations, but they will not be named and no details will be given that could identify them. The information about them, including that you acted as their consultee, will be held by the University of York for 5 years as required by our funder.

As with all assurances of confidentiality, we may still have to pass on information if it appears that the person, or someone else, is at risk of serious harm. In such a situation, we would try to talk to you before passing on any information.

**What will happen to the results of the study?**

We will write a report about everything we learn for the National Institute of Health Research, (part of the NHS) which will be circulated widely. We will also talk about what we have learnt at conferences and in academic papers. No names will be used in anything we produce. The report should be available in spring 2015. If you

would like to be sent a copy, please give your preferred contact details to a member of the research team.

### How do I respond to this consultation?

Please contact Kate Gridley on 01904 3212988 [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk) to let her know whether you would be happy to act as a consultee, or ask a member of staff at the care home to pass on your contact details so that Kate or Jenni can contact you. They will answer any questions you have over the phone or in person. If you think the person would have no objections to taking part in the research, you will be asked to sign a 'record of consultation' form.

**If you feel unable to give advice about the person's wishes, please say so.**

### What if I change my mind?

You can withdraw the person from the study at any time. This will not affect the care that they receive. If you withdraw them after the study has started, any information already provided will be retained, but no more will be collected.

### Further information and contact details

If you would like further information or have questions about this study please contact: **Kate Gridley** Social Policy Research Unit, University of York, Heslington, York, YO10 5DD tel: 01904 321988 Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

### Independent advice

If you would like to discuss this project with an organisation that supports people with dementia to get involved in research please contact:

**Nada Savitch** at Innovations in Dementia, Tel: 07549 921901

Email: [nada@myid.org.uk](mailto:nada@myid.org.uk)



*Care homes: staff*

## Life Stories in Dementia Care Feasibility Research

### Information leaflet for staff

This leaflet contains information for staff in [REDACTED] care homes who are being invited to take part in research about life story work. Please read it all before deciding whether to take part.

The research is being conducted by the Social Policy Research Unit, University of York, in partnership with [REDACTED], and is funded by the National Institute for Health Research.

#### Our invitation to you

[REDACTED] has teamed up with the University of York to do some research about life story work. They want to understand whether life story work makes a difference for people with dementia and those who care for them, and whether this difference can be measured.

Ten people with dementia in your care home will be randomly selected to take part in the research. We are inviting you to join the research as well, as we are interested in learning how life story work might affect the staff supporting people with dementia. You are free to say no or yes to this invitation.

If you have any questions after reading this leaflet, please contact Kate Gridley in the research team on 01904 3212988 [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk) or speak to your care home manager.

### When we say 'life story work', we mean:

- Creating something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams.

AND

- Using these records to improve things (for example, care, relationships) for the person living with dementia and those around them.

The record of the life story can be a book, a box, a collage, on a computer or in any other way that the person wants. Some people may have several different types of record of their life story.

### Who are the researchers?

The research is being carried out by two researchers from the University of York Social Policy Research Unit: Kate Gridley (left) and Dr Jenni Brooks (right).



### What is the research about?

We want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them, including paid staff. There have been no large-scale, in-depth studies of life story work in dementia care so little is known about whether it makes a difference, how it makes a difference, or even how to measure this.

This study is a pilot study which will inform future evaluations of life story work. Kate and Jenni will try out a range of ways of assessing the impact of life story work in six care homes, including the home you work in.

### What would taking part involve?

If you decide to take part, Jenni or Kate will ask you to complete three short questionnaires: one about personhood and dementia; one about your approaches

Life Story Information Sheet for Feasibility Research, STAFF V1 Oct 2013

to working with people with dementia and one about whether you are experiencing 'burnout'. The information you provide will be kept confidential and will be stored in a safe place (see below) – no-one else at the care home will see it, and we will not share the findings with your manager. You will be asked to complete these questionnaires again 1 month, 2 months and 6 months after you first completed them.

Towards the end of the research we will also invite you to come to a focus group discussion about the research, and about your views on life story work. This will be an opportunity to feed back to the research team about your experiences of taking part in the project, and to tell us your views on life story work. The focus group session will be tape recorded but all tapes and transcripts will be kept secure and confidential. **If you do not want to take part in a focus group you can still take part in the research.**

### **How do I consent to take part?**

If you would like to take part, please tick all the boxes on the consent form and sign it. There is a separate box on the consent form to indicate whether you would like to take part in a tape recorded focus. If you choose not to tick this box you can still take part in the rest of the research.

### **Do I have to take part?**

No. It is entirely up to you whether you take part in this research. If you choose not to take part it will not affect your job or the work that you do in any way.

### **What if I change my mind about taking part?**

You can withdraw from the research at any time without giving a reason. However, if you withdraw after the research has started, the information you have already given may still be used.

### **Will my taking part in this research be kept confidential?**

Yes, we will keep the information you provide safe and secure and it will not be shared with anyone without your permission. We may refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you. The information you provide will be held by the University of York for 5 years as required by our funder.

As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

## What will happen to the results of the research?

The information from the research will be used to see if life story work has made a difference for the people involved, including staff. We will write a report about everything we learn for the National Institute of Health Research which will be circulated widely. We will also talk about what we have learnt at conferences and in academic papers. No names will be used in anything we produce. The report should be available in spring 2015. If you would like to be sent a copy, please give your preferred contact details to a member of the research team.

## Scientific and ethical review

This research has been scientifically reviewed as part of the National Institute for Health Research funding process and the methods and materials have been approved by the Social Care Research Ethics Committee for England (REC reference 13/IEC08/0046).

## Further information and contact details

If you would like further information or have questions about this research please contact: **Kate Gridley** Social Policy Research Unit, University of York, Heslington, York, YO10 5DD Tel: 01904 321988 Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

If you would like to speak to someone at [REDACTED] about the organisation's involvement in this study, please contact: [REDACTED]  
[REDACTED]

*Comparison hospital: staff*

[Insert logo here]

## Life Stories in Dementia Care

### Feasibility Research

### Information leaflet for staff

This leaflet contains information for staff in [comparison site] ward who are being invited to take part in research about life story work. Please read it all before deciding whether to take part.

The research is being conducted by the Social Policy Research Unit, University of York, in partnership with [comparison site], and is funded by the National Institute for Health Research.

#### Our invitation to you

[Comparison site] has teamed up with the University of York to do some research about life story work. You have been contacted because you work with people with dementia on a ward here the research will take place.

#### Who are the researchers?

The research is being carried out by two researchers from the University of York Social Policy Research Unit: Kate Gridley (left) and Dr Jenni Brooks (right).



## What is the life stories research about?

In some hospitals, support to make a life story is a routine part of care. At present, [\[Comparison site\]](#) do not offer life story work to any patients. [\[Comparison site\]](#) would like to learn more about the well-being of patients who do not get support to make a life story, and about the well-being and satisfaction of the people who care for them, including staff.

There have been no large-scale, in-depth studies of life story work in dementia care so little is known about whether it makes a difference, how it makes a difference, or even how to measure this. Researchers at the University of York want to see if doing life story work makes a difference for people with dementia, their families and other people who care for them.

This study is a small preliminary study which we will use to inform future evaluations of dementia care. Kate and Jenni will try out a range of ways of assessing the difference between outcomes for people on wards that do and do not do life story work. You work **on a ward that does not do life story work**. If you take part in this research you would therefore be in the comparison group.

### When we say 'life story work', we mean:

- Creating something that records aspects of the life of a person living with dementia, including their past life, their present interests, and their future wishes, hopes and dreams.

### AND

- Using these records to improve things (for example, care, relationships) for the person living with dementia and those around them.

The record of the life story can be a book, a box, a collage, on a computer or in any other way that the person wants. Some people may have several different types of record of their life story.

### What would taking part involve?

If you decide to take part, Jenni or Kate will ask you to complete three short questionnaires: one about personhood and dementia; one about your approaches to working with people with dementia and one about whether you are experiencing 'burnout'. The information you provide will be kept confidential and will be stored in a safe place (see below) – no-one else will see it, and we will not share the findings with your manager..

Towards the end of the research we will also invite you to come to a focus group discussion about the research, and about your views on life story work. This will be an opportunity to feed back to the research team about your experiences of taking part in the project. The focus group session will be tape recorded but all tapes and transcripts will be kept secure and confidential. **If you do not want to take part in a focus group you can still take part in the research.**

### How do I consent to take part?

If you would like to take part, please tick all the boxes on the consent form and sign it. There is a separate box on the consent form to indicate whether you would like to take part in a tape recorded focus. If you choose not to tick this box you can still take part in the rest of the research.

### Do I have to take part?

No. It is entirely up to you whether you take part in this research. If you choose not to take part it will not affect your job or the work that you do in any way.

### What if I change my mind about taking part?

You can withdraw from the research at any time without giving a reason. However, if you withdraw after the research has started, the information you have already given may still be used.

### Will my taking part in this research be kept confidential?

Yes, we will keep the information you provide safe and secure and it will not be shared with anyone without your permission. We may refer to what you have said in reports, articles or presentations, but you will not be named and no details will be given that could identify you. The information you provide will be held by the University of York for 5 years as required by our funder.

As with all assurances of confidentiality, we may still have to pass on information if you indicate that you or someone else is at risk of serious harm. In such a situation, we would try to talk to you first.

### What will happen to the results of the research?

The information from the research will be used to see if life story work has made a difference for the people involved, including staff. We will write a report about everything we learn for the National Institute of Health Research which will be circulated widely. We will also talk about what we have learnt at conferences and in academic papers. No names will be used in anything we produce. The report will be available 2015. If you would like to be sent a copy, please give your preferred contact details to a member of the research team.

### Scientific and ethical review

This research has been scientifically reviewed as part of the National Institute for Health Research funding process and the methods and materials have been approved by the Social Care Research Ethics Committee for England (REC reference 13/IEC08/0046).

### Further information and contact details

If you would like further information or have questions about this research please contact: **Kate Gridley** Social Policy Research Unit, University of York, Heslington, York, YO10 5DD tel: 01904 321988 Email: [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)

If you would like to speak to someone at [comparison site] about the organisation's involvement in this study, please contact: [contact name] Tel: [phone number] Email: [email]



## Consent forms



### People with dementia

THE UNIVERSITY of York

spru | Social Policy  
Research Unit

[Insert logo here]

## Life Story Research Consent Form

Please tick the boxes and sign at the end	 Yes	 No
I have read the information leaflet and had time to think about it		
I know I do not have to take part in this research if I do not want to		
I have asked all the questions I want to and understand the answers		
<b>I agree to take part in this research</b>		
I agree to let the researchers have information from my care records		
I know that the University of York will keep the information from this research for five years after the project ends		
I know I can change my mind and stop taking part at any time and this will not affect the care I receive in any way		

\_\_\_\_\_  
Name Date Signature

\_\_\_\_\_  
Researcher name Date Signature

**If verbal or non-verbal consent is being witnessed**, the person witnessing should sign here:

Witness name \_\_\_\_\_ Signature \_\_\_\_\_ Date \_\_\_\_\_

Relationship of witness to person consenting (e.g. relative/member of staff) \_\_\_\_\_

Means of communication (verbal/non-verbal - please specify) \_\_\_\_\_

**This research is being conducted by the Social Policy Research Unit, University of York. It has been approved by the Social Care Research Ethics Committee for England. For more information please contact Kate Gridley on 01904 321988 [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)**



Consent form for feasibility study all settings PWD V2 Nov 2013

## Carers



[Insert logo here]

## Life Story Research Consent Form

Please tick the boxes and sign at the end	 Yes	 No
I have read the information leaflet and had time to think about it		
I know I do not have to take part in this research if I do not want to		
I have asked all the questions I want to and understand the answers		
<b>I agree to take part in this research</b>		
<b>I would be happy to be contacted about taking part in an interview towards the end of the study</b> (Please note that you are free to decide not to do the interview when we re-contact you)		
I know that the University of York will keep the information from this research for five years after the project ends		
I know I can change my mind and stop taking part at any time and this will not affect the care I receive in any way		

_____	_____	_____
Name	Date	Signature
_____	_____	_____
Researcher name	Date	Signature



**This research is being conducted by the Social Policy Research Unit, University of York. It has been approved by the Social Care Research Ethics Committee for England. For more information please contact Kate Gridley on 01904 321988 [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)**

Consent form for feasibility study CARERS V2 Nov 2013

## Consultees

**Life Stories Research  
Record of Consultation for Consultees**

Name of individual: \_\_\_\_\_ Study Site \_\_\_\_\_

Please tick the boxes and sign at the end	 Yes	 No
I have been consulted about the above named individual's participation in this research. I confirm that I have read and understood the Information Leaflet for Consultees and have had the opportunity to ask questions. I understand what is involved.		
In my opinion the individual named above would have no objection to taking part in the above study.		
I understand that their participation is voluntary and that I am free to withdraw them at any time, without giving any reason, without their care or legal rights being affected.		
I understand that they will be asked to answer some questions but that if they are unable to do this, I or another carer, will be asked to answer these questions as a proxy.		
I understand that information may be collected from their care records and given to researchers, where this is relevant to their taking part in this research, for example what medication they take and what health services they have used.		
I understand that all information will be used anonymously, that information will remain confidential and only be used for research.		

_____ Name of Personal Consultee	_____ Date	_____ Signature
_____ Relationship to individual	_____ Date	_____ Signature
_____ Name of researcher	_____ Date	_____ Signature



**This research is being conducted by the Social Policy Research Unit, University of York. It has been approved by the Social Care Research Ethics Committee for England. For more information please contact Kate Gridley at the Social Policy Research Unit on 01904 321988 [kate.gridley@york.ac.uk](mailto:kate.gridley@york.ac.uk)**

## Staff



[Insert logo here]

## Life Story Research Consent Form

If you would like to take part in this research, please tick each box and sign at the end:	 Yes	 No
I have read the information leaflet and had time to think about it		
I know I do not have to take part in this research if I do not want to		
I have asked all the questions I want to and understand the answers		
<b>I agree to take part in this research</b>		
I know that the University of York will keep the information from this research for five years after the project ends		
I know I can change my mind and stop taking part at any time and this will not affect the care I receive in any way		

If you would like to take part in a focus group, please tick here:	Yes	No
I would like to take part in a tape recorded focus group about my involvement in this research		

_____	_____	_____
Name	Date	Signature
_____	_____	_____
Researcher name	Date	Signature

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Consent form for feasibility study STAFF V2 Dec 2013





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