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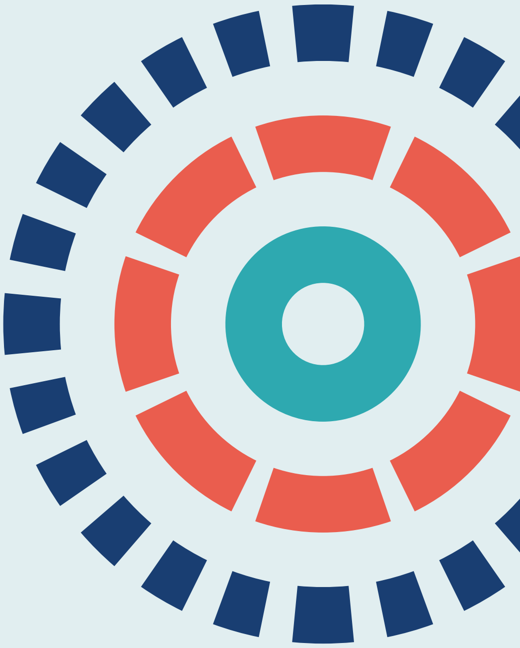

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Supporting good quality, community-based end-of-life care for people living with dementia: the SEED research programme including feasibility RCT

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Abstract

Supporting good quality, community-based end-of-life care for people living with dementia: the SEED research programme including feasibility RCT

Louise Robinson,[1]* Marie Poole,[1] Emma McLellan,[1] Richard Lee,[2] Sarah Amador,[3] Nawaraj Bhattarai,[1] Andrew Bryant,[1] Dorothy Coe,[4] Anne Corbett,[5] Catherine Exley,[1] Claire Goodman,[6] Zoe Gotts,[7] Karen Harrison-Dening,[8] Sarah Hill,[1] Denise Howel,[1] Susan Hrisos,[1] Julian Hughes,[9] Ashleigh Kernohan,[1] Alastair Macdonald,[10] Helen Mason,[11] Christopher Massey,[7] Sandra Neves,[10] Paul Paes,[12] Katherine Rennie,[13] Stephen Rice,[1] Tomos Robinson,[1] Elizabeth Sampson,[14] Susan Tucker,[15] Dimitrios Tzelis,[1] Luke Vale[1] and Claire Bamford[1]

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Background: In the UK, most people with dementia die in the community and they often receive poorer end-of-life care than people with cancer.

Objective: The overall aim of this programme was to support professionals to deliver good-quality, community-based care towards, and at, the end of life for people living with dementia and their families.

Design: The Supporting Excellence in End-of-life care in Dementia (SEED) programme comprised six interlinked workstreams. Workstream 1 examined existing guidance and outcome measures using systematic reviews, identified good practice through a national e-survey and explored outcomes of end-of-life care valued by people with dementia and family carers ($n = 57$) using a Q-sort study.

Workstream 2 explored good-quality end-of-life care in dementia from the perspectives of a range of stakeholders using qualitative methods (119 interviews, 12 focus groups and 256 observation hours). Using data from workstreams 1 and 2, workstream 3 used co-design methods with key stakeholders to develop the SEED intervention. Worksteam 4 was a pilot study of the SEED intervention with an embedded process evaluation. Using a cluster design, we assessed the feasibility and acceptability of recruitment and retention, outcome measures and our intervention. Four general practices were recruited in North East England: two were allocated to the intervention and two provided usual care. Patient recruitment was via general practitioner dementia registers. Outcome data were collected at baseline, 4, 8 and 12 months. Workstream 5 involved economic modelling studies that assessed the potential value of the SEED intervention using a contingent valuation survey of the general public ($n = 1002$). These data informed an economic decision model to explore how the SEED intervention might influence care. Results of the model were presented in terms of the costs and consequences (e.g. hospitalisations) and, using the contingent valuation data, a cost–benefit analysis. Workstream 6 examined commissioning of end-of-life care in dementia through a narrative review of policy and practice literature, combined with indepth interviews with a national sample of service commissioners ($n = 20$).

Setting: The workstream 1 survey and workstream 2 included services throughout England. The workstream 1 Q-sort study and workstream 4 pilot trial took place in North East England. For workstream 4, four general practices were recruited; two received the intervention and two provided usual care.

Results: Currently, dementia care and end-of-life care are commissioned separately, with commissioners receiving little formal guidance and training. Examples of good practice rely on non-recurrent funding and leadership from an interested clinician. Seven key components are required for good end-of-life care in dementia: timely planning discussions, recognising end of life and providing supportive care, co-ordinating care, effective working with primary care, managing hospitalisation, continuing care after death, and valuing staff and ongoing learning. Using co-design methods and the theory of change, the seven components were operationalised as a primary care-based, dementia nurse specialist intervention, with a care resource kit to help the dementia nurse specialist improve the knowledge of family and professional carers. The SEED intervention proved feasible and acceptable to all stakeholders, and being located in the general practice was considered beneficial. None of the outcome measures was suitable as the primary outcome for a future trial. The contingent valuation showed that the SEED intervention was valued, with a wider package of care valued more than selected features in isolation. The SEED intervention is unlikely to reduce costs, but this may be offset by the value placed on the SEED intervention by the general public.

Limitations: The biggest challenge to the successful delivery and completion of this research programme was translating the ‘theoretical’ complex intervention into practice in an ever-changing policy and service landscape at national and local levels. A major limitation for a future trial is the lack of a valid and relevant primary outcome measure to evaluate the effectiveness of a complex intervention that influences outcomes for both individuals and systems.

Conclusions: Although the dementia nurse specialist intervention was acceptable, feasible and integrated well with existing care, it is unlikely to reduce costs of care; however, it was highly valued by all stakeholders (professionals, people with dementia and their families) and has the potential to influence outcomes at both an individual and a systems level.

Future work: There is no plan to progress to a full randomised controlled trial of the SEED intervention in its current form. In view of new National Institute for Health and Care Excellence dementia guidance, which now recommends a care co-ordinator for all people with dementia, the feasibility of providing the SEED intervention throughout the illness trajectory should be explored. Appropriate outcome measures to evaluate the effectiveness of such a complex intervention are needed urgently.

Trial registration: Current Controlled Trials ISRCTN21390601.

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Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

List of abbreviations

ACP	advance care planning
CAD-EOLD	Comfort Assessment in Dying with Dementia
CCG	Clinical Commissioning Group
CFAS	Cognitive Function and Ageing Studies
CI	confidence interval
CONSORT	Consolidated Standards of Reporting Trials
CPG	care planning guide
DNACPR	do not attempt cardiopulmonary resuscitation
DNS	dementia nurse specialist
EAPC	European Association for Palliative Care
EOL	end of life
EOLC	end-of-life care
EQ-5D-5L	EuroQol-5 Dimensions, five-level version
ESC	External Steering Committee
FAQ	Functional Activities Questionnaire
FAST	Functional Assessment Staging Tool
GP	general practitioner
GSF	Gold Standards Framework
HADS	Hospital Anxiety and Depression Scale
HoNOS	Health of the Nation Outcome Scales
ICP	integrated care pathway
IT	information technology
LCP	Liverpool Care Pathway for the Dying Patient
MCDP	Marie Curie Dementia Programme
MDT	multidisciplinary team
MMSE	Mini Mental State Examination
MOOC	massive open online course
MRC	Medical Research Council
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health Research
NPI	Neuropsychiatric Inventory
NPI-Q	Neuropsychiatric Inventory Questionnaire
NPT	normalisation process theory
PAINAD	Pain Assessment in Advanced Dementia
PIS	participant information sheet
PPAB	patient and public advisory board
PPI	patient and public involvement
QALY	quality-adjusted life-year
QoL	quality of life
QUALID	Quality of Life in Late-stage Dementia
RCT	randomised controlled trial
REC	Research Ethics Committee
SBAR	situation, background, assessment, recommendation
SEED	Supporting Excellence in End-of-life care in Dementia
SM-EOLD	Symptom Management at the End Of Life in Dementia
SWC-EOLD	Satisfaction with Care at the End of Life in Dementia
WS	workstream
WTP	willingness to pay

Plain English summary

In the UK, two-thirds of people with dementia die in the community. Compared with people with cancer, the end-of-life care for people with dementia is relatively poor. The aim of this programme was to support professionals to deliver better community-based care towards, and at, the end of life for people with dementia and their families.

First, we looked at current care by reviewing existing guidance and research. We also looked at the commissioning of dementia and end-of-life care. Second, we worked with people with dementia, their families, service providers and commissioners to identify good end-of-life care in dementia, challenges to service delivery and possible solutions. Seven components of end-of-life care were key:

1. timely planning discussions
2. recognising end of life and providing supportive care
3. co-ordinating care
4. effective working with primary care
5. managing hospitalisation
6. continuing care after death
7. valuing staff and ongoing learning.

These informed the intervention, which was a primary care-based dementia nurse specialist and associated resources. The dementia nurse specialist provided direct care to people with dementia and their families, while also supporting professionals to make system changes.

The intervention was piloted in two general practices in North East England, and two other practices acted as controls, providing usual care. We achieved the recruitment target of 11 people with dementia per practice; 12 people with dementia died over the 12-month follow-up period. One-year outcome data were successfully collected for 41 (66%) people with dementia.

The dementia nurse specialist intervention was feasible, acceptable and highly valued by all participants. Key components of the role were providing proactive care, continuity and co-ordination. Unfortunately, it is unlikely to reduce care costs. It is a possible solution to delivering the single, named care co-ordinator role recommended in the recent National Institute for Health and Care Excellence dementia guidance.

Scientific summary

Background

Two-thirds of people with dementia die in the community, usually in nursing or residential care settings, and often in receipt of suboptimal end-of-life care compared with the care of cancer patients. Meeting the health-care needs of the majority of people with dementia from diagnosis through to death will usually be the responsibility of the general practitioner and associated community care teams.

Aim and objectives

The overall aim of the Supporting Excellence in End-of-life care in Dementia (SEED) programme was to support professionals to deliver good-quality, community-based care towards, and at, the end of life for people living with dementia and their families. Specific objectives included to:

- identify which aspects of existing care towards, and at, the end of life in dementia are effective and efficient
- develop, implement and evaluate an evidence-based intervention, and associated resources, to support the provision of good-quality care towards, and at, the end of life in dementia
- determine how community-based end-of-life care in dementia should be organised and commissioned.

Programme design

We followed the Medical Research Council framework for the development and evaluation of complex interventions, beginning with systematic reviews of existing evidence and in-depth exploration of current care. The SEED programme comprised six separate and interlinked workstreams:

- workstream 1 – mapping current evidence and identifying quality indicators and outcome measures for end-of-life care in dementia (March 2014 to July 2015)
- workstream 2 – qualitative studies to identify components of good end-of-life care in dementia (October 2013 to January 2016)
- workstream 3 – development of the SEED intervention using data from workstreams 1 and 2 and the Marie Curie Dementia Programme (August 2015 to November 2016)
- workstream 4 – pilot trial of the SEED intervention, with process evaluation, to ascertain feasibility and acceptability (August 2016 to July 2018)
- workstream 5 – economic modelling of the SEED intervention including a willingness-to-pay exercise to explore cost versus consequences (October 2013 to May 2018)
- workstream 6 – commissioning good-quality, community-based end-of-life care in dementia (October 2014 to September 2018).

Patient and public involvement

Patient and public involvement has been pivotal to the creation, development and delivery of the SEED programme. The initial idea for this research originated from Alzheimer's Society's Research Network carer groups. Continuity of patient and public involvement was ensured by (1) a member of the original Alzheimer's Society Research Network carer groups becoming programme patient and public involvement co-lead and (2) some members joining our external patient and public advisory board.

The patient and public advisory board met a total of seven times throughout the programme. A second, locally based, patient and public involvement group was also established to provide more in-depth, ongoing input to individual workstreams; therefore, each workstream benefited from regular insightful feedback grounded in the views and experiences of families living with dementia. Examples of such specific and tailored patient and public involvement included (1) piloting of the Q-sort methods in workstream 1 and (2) providing constructive comments on topic guides in workstreams 2 and 4. The extensive patient and public involvement also strongly influenced the dissemination strategy, for example the patient and public involvement group's recommendation to use the data and key findings to develop practical tools, such as a massive open online learning course for family carers.

Workstream methods and results

Workstreams 1 and 2 addressed the core work required for the development phase of the Medical Research Council complex intervention guidance, identifying the evidence base (workstream 1) and developing an understanding of existing practice and possible mechanisms for change (workstream 2).

Workstream 1: mapping existing guidance/care pathways and identification of quality indicators and/or outcome measures

Methods

This comprised the following:

- a series of updated systematic reviews to identify existing relevant guidelines, quality indicators and/or outcome measures
- an online survey (updated 2008 National Council for Palliative Care survey) to identify national examples of good, and sustainable, practice (to inform workstream 2 sampling)
- a Q-sort study, with 57 participants (14 people with dementia, 21 carers and 22 bereaved carers), to explore which outcomes for end-of-life care were important to people with dementia and their families.

Results and key findings

Examples of national good practice rely on non-commissioned, non-recurrent funding and leadership from an interested clinician. We had previously found a number of existing systematic reviews of outcome measures for end-of-life care for people with dementia; therefore, we did not repeat this work, but instead focused on quality indicators. Existing guidelines recommended that care towards, and at, the end of life for people with dementia be community based for as long as possible. No dementia guidelines included any quality indicators to drive improvement in palliative care. However, current palliative care quality indicators are not entirely suitable, as they do not incorporate key aspects of dementia, such as person-centred care or behaviours that challenge. People with dementia and their families consider compassionate care and informed shared decision-making as important outcomes for end-of-life care.

Workstream 2: qualitative studies to define and determine what constitutes good-quality care towards, and at, end of life in dementia

Methods

The views of national experts, service managers, front-line staff, people with dementia and family carers were explored using a range of qualitative methods (i.e. semistructured interviews, focus groups and observations of routine care). The large data set comprised 119 interviews, 12 focus groups and 256 hours of observation. Each data set was initially analysed thematically, prior to an integrative analysis, which drew out key themes across stakeholder groups.

Results

The integrative analysis identified seven key components required for the delivery of good end-of-life care for people with dementia: timely planning discussions, recognising end of life and providing supportive care, co-ordinating care, effective working with primary care, managing hospitalisation, continuing care after death, and valuing staff and ongoing learning. These factors span the entire illness trajectory, from planning at a relatively early stage in the illness to continuing care after death. Some components were more important to professionals (i.e. national experts, service managers and front-line staff) than to people with dementia and their families, for example future care planning and recognition of the end-of-life phase.

Workstream 3: development of the SEED intervention using data from workstreams 1 and 2 and the Marie Curie Dementia Programme

Methods

Innovative co-design methods, and the theory of change, were employed to synthesise data and key findings from workstreams 1 and 2 and the Marie Curie Dementia Programme. Intervention development took place in two distinct phases. The first phase comprised a series of workshops with the full SEED programme team to generate and prioritise ideas for possible interventions. In the second phase, the broad concept of the intervention was operationalised through small group co-design workshops with key stakeholders (patient and public involvement group members, clinical specialists and service providers), thus enabling continuous, integrated user involvement.

Results

The seven key components identified in workstream 2 were operationalised as a primary care-based, dementia nurse specialist intervention. From a theoretical perspective, we utilised the theory of change as it allows a collaborative and iterative process and focuses on desired outcomes. A training and supervision programme was developed, along with an intervention manual. Findings also indicated the need for a care resource kit to help the dementia nurse specialist deliver the intervention, work more effectively with people with dementia and their families, and improve the knowledge and skills of family and professional carers. As an extensive review of existing resources identified few resources for both family carers and professional carers on advanced dementia, we developed a massive open online course, titled *Dementia Care: Living Well as Dementia Progresses*, to address this gap (this course was winner of the 'outstanding care resource' category at the 10th National Dementia Care Awards, 2019).

Workstream 4: pilot trial of the SEED intervention with process evaluation

Methods

A cluster design was used to assess the feasibility and acceptability of recruitment and retention, the SEED intervention, and the chosen outcome measures. Four general practices were recruited in North East England: two were allocated to receive the intervention and the other two provided usual care. Patients on the general practice dementia register were screened, eligible patients were approached, and a family carer and, for those in care homes, a key informant were identified. Outcome data were collected at baseline and at 4, 8 and 12 months. A process evaluation used interviews, observation and dementia nurse specialist activity logs to collect stakeholder views of the intervention and to capture whether and how the intervention was delivered.

Results

The SEED intervention proved feasible and acceptable to all stakeholders, and being located in general practice was considered particularly beneficial. The intervention was seen as distinct from existing services. Improving the local context for end-of-life care was achieved through, for example, the development of training for care home staff and the implementation of a template for annual dementia reviews. Extending the intervention to all people with dementia, from the point of diagnosis, was widely recommended by stakeholders. Although some issues concerning outcome measurement were resolved, none of the outcome measures used was found to be suitable as the primary outcome measure for a future trial. In the light of these remaining uncertainties, we do not intend to proceed to a definitive trial of the SEED intervention at this stage.

Workstream 5: economic modelling of the SEED intervention, including a willingness-to-pay exercise to explore cost versus consequence

Methods

The economic evaluation compared the SEED intervention with alternative ways of providing care, including an example of current practice. The potential value of the SEED intervention was assessed using a contingent valuation survey of 1002 members of the general public. These data were used in an economic decision model. The economic model describes what happens to a person with dementia over time and how the SEED intervention might change this. The results of the model were presented in terms of the costs and consequences (e.g. hospitalisations) and, using the contingent valuation data, a cost–benefit analysis.

Results

The contingent valuation showed that the SEED intervention was valued, with a wider package of care valued more than selected features in isolation. Individuals with experience of dementia placed a higher value on the SEED intervention than those without such experience, but there was no evidence of a difference in the value by gender, household size or health status. Based on the economic modelling study, the SEED intervention is unlikely to reduce costs, but this may be offset by the value placed on the SEED intervention by the general public. The SEED intervention may benefit people with dementia and carers, but the impact on services is mixed.

Workstream 6: commissioning good-quality, community-based end-of-life care in dementia

Methods

To determine how current care in this area was commissioned and organised, a narrative review of policy and practice literature was undertaken, followed by in-depth interviews with service commissioners ($n = 20$). Owing to an update of the National Institute for Health and Care Excellence dementia care guidance, the development of programme-specific commissioning guidance was postponed. When new National Institute for Health and Care Excellence guidance was released (in 2018), key findings from the programme were compared with this guidance. The results of this analysis were disseminated to commissioners at a national workshop.

Results

Commissioners receive little formal guidance and training. In addition, they work in a context of persistent uncertainty owing to a constantly changing policy and organisational landscape. Dementia care and end-of-life care are usually commissioned separately, and a more integrated, joined-up commissioning approach is urgently required.

Limitations

The biggest challenge to the successful delivery and completion of this research programme was the translation of a theoretical, co-developed complex intervention into practice in a constantly changing organisational landscape of health and social care at both national and local levels. The introduction of new commissioning structures, especially in primary and community care, with a considerable and continuous period of change and reorganisation, led to difficulty identifying and recruiting participants (workstreams 2 and 6) and delays in securing governance approvals. A further major limitation, especially for a future trial, is the lack of valid and relevant primary outcome measures to evaluate the effectiveness of complex interventions to improve care at the end of life in dementia. Such measures need to capture

changes in outcomes for individuals (e.g. improved comfort at end of life for a person with dementia) and system-level changes (e.g. introduction of robust systems for discussing and documenting advance care planning). Two of the potential future primary outcome measures performed well: Symptom Management at the End Of Life in Dementia and Comfort Assessment in Dying with Dementia, however, the Satisfaction with Care at the End of Life in Dementia measure was criticised by participants. It may be that, for dementia care in general, new measures for evaluating the success of complex interventions need to be developed that better reflect outcomes that (1) are important to people with dementia and their families and (2) more accurately reflect the complexity of symptoms in advanced dementia.

Conclusions

Extending existing evidence and using new empirical data, we followed the Medical Research Council framework for complex interventions to co-design a primary care-led, dementia nurse specialist intervention to enable community-based professionals to deliver co-ordinated and proactive end-of-life care to people with dementia and their families and pilot it in practice. Seven components of care were key to the dementia nurse specialist role: timely planning discussions, recognising end of life and providing supportive care, co-ordinating care, effective working with primary care, managing hospitalisation, continuing care after death and valuing staff and ongoing learning. The intervention was acceptable, feasible and shown to integrate well with existing care. The dementia nurse specialist was highly valued by all stakeholders, both in real life and hypothetically in the contingent valuation study; however, the economic evaluation (cost–consequence analysis and cost–benefit analysis) showed that it is unlikely to reduce the costs of care.

Future work

Based on the key findings to date, we do not plan to progress to a full randomised trial of the SEED intervention in its current form. In view of the introduction of updated National Institute for Health and Care Excellence dementia guidance, and a steady and unplanned shift of post-diagnostic dementia care to primary care, further research is needed to:

- determine the feasibility of providing the SEED intervention throughout the illness trajectory, that is to all people with dementia from point of diagnosis to death, and if, and how, it would need to be adapted
- identify appropriate, and/or develop, new outcome measures to evaluate the effectiveness of such a complex intervention that has the potential to influence both patient- and carer-reported outcomes and system-level processes, outcomes and structures.

In the absence of a future trial that would incorporate a more accurate and detailed cost-effective analysis, it would be worth exploring whether or not specialist micro- and macro-simulation economic modelling techniques could inform translation of the SEED intervention into an efficient model for practice.

Trial registration

This trial is registered as ISRCTN21390601.

Funding

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SYNOPSIS

Background

Our ageing societies and prevalence of dementia

The number of people living with dementia is predicted to double by 2040.[1,2] Dementia has the greatest disease burden of all long-term illnesses.[1,3] Nationally, the cost of dementia care is estimated to be £26B, with community care costs accounting for almost half of this.[2,4] More older people are experiencing a slower, more unpredictable, dying pathway[5,6] as a result of multimorbidity,[7] age-related illnesses such as dementia[8,9] and frailty, leading to an increased need for better-integrated community care, especially if the preferred final outcome is death in the usual place of care.[5,10–12]

Dying with dementia

In the UK, the National Institute for Health and Care Excellence (NICE) considers end-of-life care (EOLC) to include all health and social care provided in all settings to the following groups of people: those who are likely to die within 12 months, those with advanced, progressive, incurable conditions, and those with life-threatening acute conditions.[13–15] EOLC also covers support for families and carers. More recently, NICE has provided separate evidence-based care recommendations for patients whom professionals consider to be in the last few days of their life, when more intensive support is needed.[13,14] Because of the unpredictable dying trajectory in dementia, professionals often find it difficult to predict when a person is dying.[16,17] EOLC can, therefore, be considered more than the last few days of life: the term 'supportive care' was coined to reflect the need for sustained care throughout the illness trajectory.[18] In terms of the quality of care, evidence consistently shows that people with advanced dementia experience poorer EOLC than those with cancer, with increased hospitalisation, inadequate pain control and fewer palliative care interventions.[19–21] In addition, family carers of people with advanced dementia require more emotional support prior to the person's death than afterwards;[22] many do not consider dementia as a terminal illness and know little about the symptoms and prognosis of the advanced illness.[23] With respect to place of death for people with dementia in the UK, few people die at home. Nearly half die in care homes and around one-third die in hospital;[24–26] very few people with a primary diagnosis of dementia use hospice care.[27]

Palliative care in dementia

Palliative care is defined as:

> *An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*
>
> *World Health Organization.[28] © Copyright World Health Organization (WHO), 2020. All Rights Reserved. URL: www.who.int/cancer/palliative/definition/en/*

People with advanced dementia experience symptoms that are comparable to the symptoms of those dying with cancer.[12] Professionals experience a number of difficulties in meeting the palliative care needs of people with advanced dementia; for example, pain and symptom management is particularly difficult, as people with dementia may not be able to verbalise their symptoms. Despite this, however, the use of evidence-based pain assessment tools in community settings is low.[29] In addition, some professionals do not consider dementia a terminal illness[30] and find prognostication difficult.[20,21,31] Both medical and nursing home staff consistently overestimate prognosis in advanced dementia. In one US study,[31] only 1% of care home residents at admission were thought to have a life expectancy of < 6 months, yet 71% died in that period. A palliative care approach as dementia progresses is recommended both nationally[29,32] and internationally;[33] however, the evidence base to inform translation of these recommendations into practice is still limited.

End-of-life care in dementia in the UK: current service provision and commissioning

In the UK, access to specialist palliative care by families caring for people with advanced dementia is limited.[34] The quality of EOLC, in general, has been strongly influenced by the introduction of a national End of Life Care Strategy and programme,[35] with associated quality markers to measure care outcomes.[36] These include the use of advance care planning (ACP), to promote patient choice, and EOLC pathways, for example the Liverpool Care Pathway for the Dying Patient (LCP)[37] and the Gold Standards Framework (GSF).[38] However, the national End of Life Care Strategy[35] was developed from cancer care, and directly transferring interventions may not be appropriate in dementia, for which the dying trajectory is longer and more unpredictable.[39,40] In a UK population, median survival time in dementia is 4.1 years from diagnosis,[41] but this can be up to 7–10 years in younger age groups (60–69 years),[42] or as low as 1.3 years in an older care home population.[43] Evidence has been slow to emerge of the effectiveness of ACP in dementia care[44–46] in terms of reducing potentially harmful interventions such as hospitalisation, but few families living with dementia seem to want to complete formal ACP documents.[47–49]

In England, guidance on commissioning dementia services is available from several sources,[50] and NICE reiterated the need to follow other relevant existing guidance.[32,51] Currently, health and well-being boards in England do not prioritise EOLC in their strategies.[52] The Department of Health has developed dementia commissioning resources on early diagnosis and intervention, better care in acute hospitals and support for people in the community,[53] but none of these documents covers EOLC in detail.

End-of-life care in dementia in the UK: research to date

Despite increasing international research, there has been little UK research in this area,[20,54–56] even though EOLC was highlighted as a national research priority.[57] The Marie Curie, Alzheimer's Society James Lind Alliance Priority Setting partnerships, which worked with the public, have also prioritised research in this area.[58,59]

One UK-based study explored what constituted good EOLC in dementia with bereaved carers and professionals.[47] Family carers felt that people with dementia should die free from pain and surrounded by their relatives, whereas professional carers identified physical needs, emotional and spiritual issues, and care planning. However, general practitioners (GPs), who provide most of the EOLC in dementia,[60] were not included.

England still has a high rate of hospital death in dementia (40%),[61] and few people with dementia die at home.[35,62] Avoiding care transitions is important, but policy has focused mainly on promoting death in the usual place of care, rather than on the quality of dying.[35] Carers and people with dementia report comfort and QoL as the main goals of care.[43] Updated NICE dementia guidance states that people with dementia should receive flexible, needs-based palliative care that addresses the unpredictable progression,[29] but models of how to achieve this in practice are lacking. Recent (2013–18) UK research has found high levels of persistent pain in care home residents with severe dementia,[63] increasing anguish for carers,[64,65] and rising numbers of people with dementia attending emergency departments in the last year of life.[66] Realist methods have increased understanding of integration[67] and the barriers to and facilitators of good dementia palliative care,[68,69] but significant research gaps remain. These include the following:

- development/testing of new interventions for primary care, as opposed to specialist care[70]
- research focused on people dying at home rather than in care homes[43,63,71]
- management of more complex dementia patients, namely those with multimorbidity
- health economic evaluations.

Programme aim and objectives

The overall aim of the Supporting Excellence in End-of-life care in Dementia (SEED) programme was to support professionals to deliver good-quality, community-based care towards, and at, the end of life (EOL) for people living with dementia and their families. Specific objectives were to:

- identify which aspects of existing care towards, and at, EOL in dementia are effective and efficient
- develop, implement and evaluate an evidence-based intervention, and associated resources, to support good-quality care towards, and at, EOL in dementia
- determine how community-based EOLC in dementia should be organised and commissioned.

Programme design and methods

The SEED programme comprised six separate and interlinked workstreams (WSs); *Figure 1* illustrates the relationship between individual WSs. We utilised the Medical Research Council (MRC) guidance on the development, piloting, implementation and evaluation of complex interventions.[72–74] The intervention

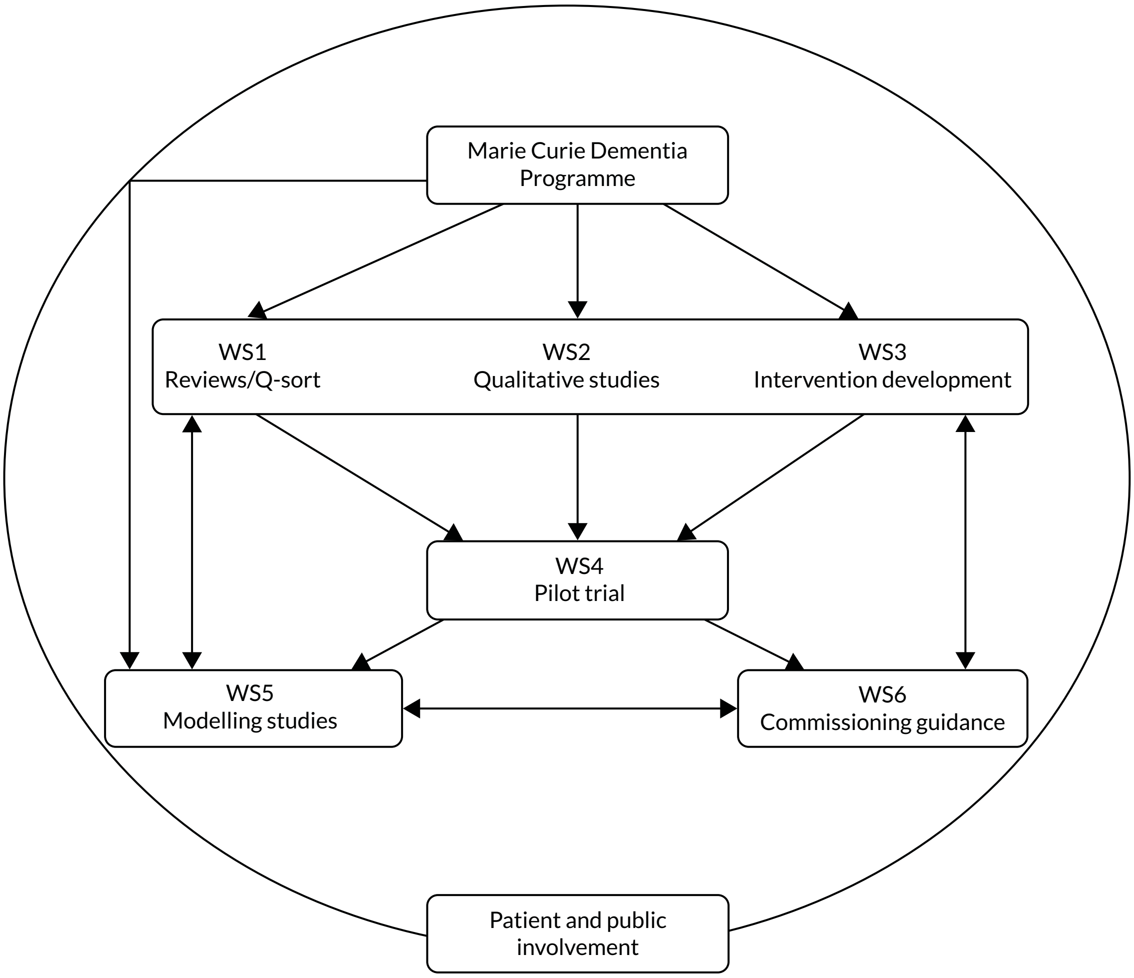


FIGURE 1 Inter-relationship of WSs in the SEED programme.

development phrase comprised evidence synthesis (WS1) and a qualitative exploration of current care (WS2) to describe core processes, structures and outcomes. Individual WSs comprised the following:

- WS1 – mapping current evidence and identifying quality indicators and/or outcome measures for EOLC in dementia
- WS2 – qualitative studies to identify components of good EOLC in dementia
- WS3 – development of the SEED intervention using data from WSs 1 and 2 and the Marie Curie Dementia Programme (MCDP)
- WS4 – pilot trial of the SEED intervention, with process evaluation, to ascertain feasibility and acceptability
- WS5 – economic modelling of the SEED intervention, including a willingness-to-pay (WTP) exercise to explore cost versus consequences
- WS6 – commissioning good-quality, community-based EOLC in dementia.

Patient and public involvement

Patient and public involvement (PPI) has been pivotal to the creation and subsequent development of this programme. The initial idea for this research originated from Alzheimer's Society's Research Network carer groups. A series of collaborative workshops between several representatives from these carer groups and the programme leads ensued to further develop the programme. To ensure that this level of PPI continued throughout the programme, one of the members of the original Alzheimer's Society Research Network carer groups (ST) became programme co-lead for PPI. In addition, some of the carer group members also joined the external patient and public advisory board (PPAB).

The PPAB met a total of seven times throughout the programme: the initial two meetings were held in the first 6 months, subsequent meetings were held annually and two meetings were held in the final year. Alzheimer's Society Research Network volunteers already receive training in basic dementia science, research methodologies, ethics and governance and reviewing funding bids. The first meeting was an educational session on EOLC in dementia and the purpose of the group. The second meeting focused on enhancing knowledge and the PPAB management role in terms of:

- individual members' roles and responsibilities
- monitoring individual WSs
- provision of ongoing support for members.

As required by the National Institute for Health Research (NIHR), we established an External Steering Committee (ESC), which also included PPI representation. This group met a total of five times during the programme to review progress and provide critical advice. We also had a local PPI group, which provided more in-depth ongoing input, for example providing constructive comments on topic guides. Therefore, each WS benefited from regular insightful feedback grounded in the views and experiences of families living with dementia. The PPI contributions to individual WSs are described in the specific WS sections. The continuing engagement and enthusiasm of PPAB and PPI group members is demonstrated by their contributions to the development and piloting of the massive open online course (MOOC) and their agreement to join new projects.

Major changes to the proposed programme

Workstream 3

The original proposal aimed to develop and evaluate an integrated care pathway (ICP) for professionals to use with people dying from, or with, dementia in community settings. This was grounded in the palliative care intervention, the LCP,[37] which provided professionals with advice on how to provide better care in the last days of life. The LCP had been widely implemented on a national level. However, following the recommendation of a national review in 2013, the LCP was withdrawn from practice.[75] The SEED programme team, advised by the ESC, thus avoided any future use of the phrase 'care pathway for the dying', or ICP, and developed the intervention from the empirical data.

Workstream 6

In 2015, NICE announced that its dementia care guidelines were to be updated. As this national guidance was anticipated to include evidence-based recommendations on care towards, and at, the EOL in dementia, the ESC recommended postponing the development of any guidance for commissioners based on the SEED intervention findings until the updated guidance was published (in June 2018).[29]

Workstream 1: mapping current evidence and identifying quality indicators and/or outcome measures for end-of-life care in dementia

Overview

We utilised the MRC guidance on the development and evaluation of complex interventions[72–74] to inform intervention development, beginning with evidence synthesis (WS1). This WS comprised (1) updated systematic reviews to identify existing relevant guidelines, quality indicators and outcome measures, (2) a national online survey to identify current examples of good and sustainable practice (to inform WS2 sampling), and (3) a Q-sort study, with people with dementia, current carers and bereaved carers ($n = 57$), to explore their views on important outcomes for EOLC. Existing guidelines recommended that care towards, and at, the EOL for people with dementia be community based for as long as possible. As we had identified a number of existing, recent reviews of outcome measures for EOLC in dementia, we did not repeat this work; our article on the systematic review of quality indicators has now been published.[76] No dementia guidelines included any quality indicators to measure, and thus drive, improvement in this area of care. However, current palliative care quality indicators are not entirely suitable as they do not incorporate key aspects of dementia, such as person-centred care or behaviours that challenge. Results from the national survey showed that examples of current good practice rely heavily on (1) non-commissioned, non-recurrent funding and (2) leadership from an interested clinician or 'local champion'. People with dementia and their families consider compassionate care and informed shared decision-making as important outcomes of good-quality EOLC.

Patient and public involvement

Significant PPI contributions to WS1 included discussion of the content and format of the relevance of existing outcome measures and/or quality indicators, testing the Q-methodology approach and advising on statements to be used, and informing the participant sampling frame for the Q-sort.

Research aim

To inform the development of the SEED intervention, WS1 sought to determine what is already known about the organisation and provision of EOLC for people with dementia and their families. Specific objectives were to:

i. map the evidence base for existing EOLC guidance and care pathways in dementia
ii. identify national examples of good and sustainable practice
iii. identify outcome measures and indicators to measure good-quality EOLC in dementia
iv. elicit the views of people with mild dementia and carers on the elements of the care pathway(s) and outcomes important to them.

Existing end-of-life care guidance and models of care in dementia

Further details of existing EOLC guidance and models of care in dementia are provided in *Appendix 1*.

Methods

We built on a previous systematic review of dementia practice guidelines.[77] The original review retrieved 27 sets of dementia practice guidelines, 12 of which were eligible for inclusion [i.e. scored at least four on the Appraisal of Guidelines for REsearch and Evaluation II (AGREE II) instrument[78]]. Of these, five guidelines specifically addressed palliative care and EOLC:

1. *Clinical Practice Guidelines and Care Pathways for People with Dementia Living in the Community*[79] (Queensland University of Technology, 2008)
2. guideline on supporting people with dementia and their carers in health and social care[80] [NICE–Social Care Institute for Excellence (SCIE), 2007]
3. *Guideline for Alzheimer's Disease Management*[81] (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008)
4. Ministry of Health's *Dementia: MOH Clinical Practice Guidelines*[82] (Singapore, 2013)
5. Ministry of Health's *Clinical Practice Guidelines, Management of Dementia*, 2nd edition[83] (Malaysia, 2009).

In collaboration with WS5, we further examined the content in each guideline, looking specifically at setting, content, timing, care model(s), staff and resource implications, and clinical audit parameters. This exercise helped inform WS5 in terms of cost estimation and subsequent modelling.

Key findings

Existing guidelines recommended that people with dementia be managed as far as possible in the community. Recommendations varied as to when palliative care for people with dementia should be introduced, ranging from as early as diagnosis through to < 6 months to live. Only UK guidelines did not make any clear recommendations on the timing of the introduction of palliative care. Guidelines covered a range of aspects of palliative dementia care, including assessment, access to services, ACP and symptom management. Guidelines varied in the level of primary care involvement and support, and included shared care and case management models. Finally, no guideline incorporated any quality indicators/outcomes specific to the palliative care phase of the dementia care trajectory.

Mapping UK end-of-life care services in dementia

This study has been published as Amador *et al.*[84] For a full-text version of this paper see *Appendix 2*.

Methods

To map national initiatives, including examples of good and sustainable practice in EOLC in dementia, we updated and repeated the National Council for Palliative Care 2008 local practice online survey from October 2014 to the end of February 2015. We enquired about (1) general information regarding the service (i.e. title, contact information and location), (2) service activities and referral criteria, (3) team size and composition, (4) situation, funding mechanisms and sectors of operation and (5) dissemination and evaluation activities.[84] More than 60 services, set up specifically to provide EOLC to people with dementia, were purposively sampled via targeted e-mail invitation, in addition to open-call invitations.

Key findings

Fifteen respondents representing discrete service initiatives responded. Two-thirds of returns were received in response to targeted e-mail invitations, and one-third in response to open calls. Initiatives engaged in a wide range of activities, predominantly providing direct care and workforce development/advisory or educational activities. Findings suggested that sustainability of services was reliant on

(1) enthusiastic clinicians with a leadership role, (2) wider system support through reliable funding mechanisms and (3) a minimum level of integration with normal service provision. More recent initiatives were largely built on the expertise of the nursing professions, and driven mainly by charity and hospice sector funding.

Identifying quality indicators/outcome measures to measure good-quality care

This work has been published as Amador *et al.*[76] (see *Acknowledgements*, *Publications*).

Quality indicators are defined as measurable elements of work/practice performance for which there is evidence or consensus that they can be used for assessing and changing the quality of care being provided. Quality indicators can be related to three key elements of care: process, outcomes and structure.[85,86] Outcome measures, more specifically patient- or public-related outcome measures, assess changes at an individual level in terms of health status or health-related QoL. Both types of measures were considered to be equally important when assessing the impact of a complex, community-based intervention that could potentially affect service users (i.e. patients and their families) as well as service providers and commissioners.

Methods

We had previously identified a number of existing systematic reviews of outcome measures for EOLC in dementia and, therefore, did not repeat this work.[87–89] To identify quality indicators to measure good-quality EOLC in dementia, we built on a previous systematic review of quality indicators for palliative care by de Roo *et al.*[90] The original review identified 17 sets of quality indicators for palliative care, containing 326 unique indicators. After screening, we excluded over half of the indicators because they were not applicable to long-term care settings, lacked procedural relevance or were specific to a particular scale. In addition, other indicators excluded at this stage were not applicable to UK care settings or lacked conceptual clarity. The remaining indicators ($n = 156$) were mapped against the European Association for Palliative Care (EAPC) framework for optimal palliative care in older people with dementia, which was developed through a rigorous international consensus process.[33] The framework comprises 11 domains:

1. applicability of palliative care
2. person-centred care, communication and shared decision-making
3. setting care goals and ACP
4. continuity of care
5. prognostication and timely recognition of dying
6. avoid aggressive treatment
7. comfort and optimal symptom treatment
8. psychosocial and spiritual support
9. family carer involvement
10. education of the health-care team
11. societal and ethical issues.

Key findings

Overall, quality indicators available to assess optimal palliative care in older people with dementia covered some of the EAPC domains, including ACP (domain 3), continuity of care (domain 4), prognostication and timely recognition of dying phase (domain 5) and family carer involvement (domain 9). However, existing indicators would need to be further developed in order for each to comprise the necessary elements (i.e. numerator, denominator and performance standard) and have its fundamental properties assessed (i.e. feasibility, acceptability, reliability, sensitivity to change and predictive validity).

There were major gaps in existing quality indicators in the following areas: (1) person-centred care, especially in specific aspects of dementia care (behaviour that challenges), (2) non-pharmacological interventions, (3) the appropriateness of pharmacological and other interventions at EOL (i.e. use of restraints, tube nutrition and the use of antibiotics), (4) the need for appropriate skill mix in health-care teams, including specialist nursing care and dementia care to support optimal symptom management, and (5) the quality of the dying environment.

Developing person-centred outcome measures: views of people with mild/moderate dementia and carers

This work has been published as Hill *et al.*[91] (see *Acknowledgements*, *Publications*).

Methods

Q-methodology is a mixed-methods approach combining qualitative and quantitative techniques to study subjectivity.[92] In this study, it was used to identify the views of people with mild dementia, family carers and bereaved carers on what is important (or unimportant) to them about the care provided to people with dementia approaching the EOL. In the first stage, participants ranked in order, from the most important to the least important, a set of 24 cards printed with statements about the type of care patients could receive (the statements are available in *Report Supplementary Material 1*). By-person factor analysis was used to identify clusters of respondents who completed the Q-sort in a similar way,[92] and these clusters helped define the different factors. Short interviews were conducted following the card sort to provide additional information to aid interpretation of the factors.

Key findings

Four distinct viewpoints were identified:

1. Family involvement – decisions should be made by, and with, the family, and the wishes of people with dementia should be documented in advance to help families with this process. Family carers do not see caring for their relative as a burden: it is more important to keep the person with dementia in their own home and have the family with them at the EOL.
2. Living in the present – people with dementia live life day by day, and carers are more concerned with ensuring the comfort and safety of the person with dementia at that moment in time rather than planning ahead.
3. Pragmatic expectations – carers acknowledge their limits as carers for their relative with dementia and give high priority to having processes in place to provide the best possible care. This may include moving the person with dementia to a care home.
4. Autonomy and individuality – people with dementia want a significant level of autonomy and individuality, with their opinions and choices respected and integrated into their EOLC plans.

These findings reveal several different views on what is important about EOLC for people with dementia; therefore, a one-size-fits-all approach to care is unlikely to be the most appropriate. However, areas of consensus across all views did emerge, including the provision of compassionate care and ensuring that relevant information was available to people with dementia and their families when making decisions.

Workstream 1 conclusions

Existing guidelines recommend that people with dementia be cared for as long as possible in the community. These guidelines include key aspects of care, such as access to key services, ACP and optimal symptom management. Examples of sustainable national good practice are dependent on reliable funding streams, and local clinical leadership, hospice and charity sectors play a key role in the development and sustainability of such services.

No guidelines provided any quality improvement indicators specific to the palliative care phase of dementia. Current palliative care quality indicators may not be entirely suitable for use as they do not include key aspects of dementia care, such as behaviours that challenge and person-centred care. In the design of future services for EOLC, the Q-methodology study highlighted that there is no single way of providing care that will suit everyone. Outcomes for measuring EOLC that are important to people with dementia and their families include the provision of compassionate care and facilitating informed, shared decision-making.

Reflections on workstream 1

There persists a lack of empirical data to inform policy and clinical guidelines in this area of dementia care. Although a consensus framework has been developed, which identifies 11 domains for optimal palliative care for people with dementia, further research is needed to develop appropriate outcome measures or quality indicators to better assess both the quality of EOLC in dementia and outcomes that are important to people with dementia and their families. Q-methodology has the potential to identify person-centred outcomes; unfortunately, this study was limited to a small, selective sample of people with mild dementia and carers who were recruited from a dementia research network. To be generalisable, the study should be replicated with a larger and broader sample to capture additional viewpoints.

Workstream 2: defining and delivering good practice for care towards, and at, end of life in dementia

This work has been published as Bamford *et al.*,[93] Lee *et al.*[94,95] (see *Acknowledgements*, *Publications*) and Poole *et al.*[96] (see *Appendix 2*).

Overview

We used the MRC guidance on the development and evaluation of complex interventions[72–74] to inform intervention development. The evidence synthesis (WS1) was followed by a qualitative exploration of current care delivery (WS2). This provided new insights into the key components that are essential for good-quality EOLC in dementia by using qualitative methods (i.e. interviews, focus groups and observation) to explore and compare the perspectives of different stakeholder groups. Three published papers from this workstream separately describe the views of key groups: national experts,[94] service managers and front-line staff,[95] (see *Acknowledgements*, *Publications*) and people with dementia and family carers[96] (see *Appendix 2*). These individual WS2 studies contributed to a final data set that comprised 119 interviews, 12 focus groups, 256 hours of observation and three case studies. The findings of the integrative analysis are summarised in this section, with full details available in the published paper[93] (see *Acknowledgements*, *Publications*), which drew together the findings of the three studies to identify seven key components of good EOLC:

1. timely planning discussions
2. recognising EOL and providing supportive care
3. co-ordinating care
4. working effectively with primary care
5. managing hospitalisation
6. continuing care after death
7. valuing staff and ongoing learning.

These key components then informed intervention development (described in *Workstream 3: development of the SEED intervention*).

The integrative analysis highlighted discrepancies between the data, policy objectives and existing literature. Although policy, national experts and service managers often emphasised ACP as crucial to delivering good EOLC,[35,44,45] whereas many people with dementia and their families preferred to focus on the present or considered future planning only in relation to wills and funeral arrangements.[96] Providing timely opportunities to discuss future care preferences is challenging in a context in which people with dementia generally receive little support during the mid-stage of the illness trajectory.[97,98] The uncertainty of the dying trajectory in dementia has been identified as a key barrier to good EOLC.[20,21,31,99] However, care home staff did not necessarily view uncertainty as problematic, partly because they were comfortable with the lack of a clear trajectory and partly because they felt that they were often able to identify when individuals were approaching the EOL, but also because following the principles of person-centred care would ensure that needs were recognised and met at all stages of the illness.

Patient and public involvement

Members contributed to WS2 by advising on recruitment approaches and materials, discussing sampling for services to be included in focus groups and the comparative case studies, and reviewing emerging themes from the qualitative analyses.

Research aim

The aim of WS2 was to develop a detailed understanding of good practice in EOLC in dementia to inform development of an intervention (WS3), which would subsequently be tested (WS4). This was achieved through a series of qualitative substudies, with the objectives of:

- defining good practice from the perspectives of key stakeholders, including national experts, service managers, front-line staff and people with dementia and their family carers
- understanding existing approaches to EOLC in dementia
- exploring challenges and unmet need in EOLC in dementia
- exploring the value and relevance of current tools for EOLC in dementia.

Methods

Qualitative methods were used throughout WS2, including semistructured interviews (face to face and telephone), focus groups, informal discussions and non-participant observation. Data were collected between October 2013 and January 2016 for four substudies that explored:

1. the range of approaches to EOLC in dementia with national experts (WS2.1)
2. service manager approaches to providing EOLC in dementia (WS2.2)
3. the views and experiences of EOLC from the perspectives of people with dementia, family carers and front-line staff (WS2.3)
4. day-to-day practice in EOLC in dementia (WS2.4).

Topic guides are available in *Report Supplementary Material 1*. The principles of purposive sampling were used in all substudies.[100] Interviews and focus groups were transcribed verbatim and analysed thematically.[101] Episodes of observation were recorded in anonymised field notes. Analysis was iterative and interspersed with data collection. To avoid imposing ideas from one group of stakeholders onto subsequent groups, data sets from individual studies were initially analysed independently. Further details of methods and participants are available in the publications of this work.[93–96] The subsequent integrative analysis involved reconceptualising and developing themes to reflect the nuances in the data from different stakeholders.[93]

Key findings

The integrative analysis led to the identification of seven key components of good EOLC for people with dementia. These were central to the development of the intervention in WS3. *Table 1* illustrates how themes from different data sets were combined and reconceptualised to produce the seven key components. The original themes from individual data sets often contributed to more than one of the seven components. For example, the theme 'planning for EOL' from the comparative case studies was relevant to both timely planning discussion and managing hospitalisation. The mapping was sometimes less intuitive, reflecting nuances within themes that were not necessarily reflected in the overall theme title.

TABLE 1 Mapping themes from individual data sets to the seven key components

	Interviews and focus groups with			
Seven key components	**National experts**	**Service managers and front-line staff**	**People with dementia and family carers**	**Comparative case studies**
Timely planning discussions	Leadership and management	Communicating with families Continuity of care Recognising EOL and providing appropriate care	Uncertainty about planning ahead/difficulties planning ahead Expectations about decisions and decision-makers	Planning for EOL
Recognising EOL and providing supportive care	Use of guidelines Integrating clinical expertise Continuity of care Leadership and management	Supporting families Ensuring comfort at the EOL Communicating with families Recognising EOL and providing appropriate care Continuity of care	The value of practical support Emotional support towards and after EOL Reliance on family at EOL Confidence in standards of future care	Recognising EOL and providing physical care Planning for EOL Access to clinical care Emotional work at EOL
Co-ordinating care	Integrating clinical expertise Continuity of care	Collaborative working Continuity of care Recognising EOL and providing appropriate care Ensuring comfort at the EOL	Reliance on family at EOL Challenges in accessing and co-ordinating care	Access to clinical support Planning for EOL Equipping staff with appropriate skills and knowledge
Working effectively with primary care	Integrating clinical expertise	Collaborative working Continuity of care Recognising EOL and providing appropriate care Ensuring comfort at the EOL Developing and supporting staff	Challenges in accessing and co-ordinating care	Access to clinical support Planning for EOL Equipping staff with appropriate skills and knowledge
Managing hospitalisation	Continuity of care	Recognising EOL and providing appropriate care Collaborative working Continuity of care Communication with families	The value of practical support Reliance on family at EOL	Access to clinical support Planning for EOL
Continuing care after death		Supporting families Ensuring comfort at EOL Developing and supporting staff	The value of practical support Emotional support towards and after EOL	Emotional work at the EOL Recognising EOL and providing physical care

continued

TABLE 1 Mapping themes from individual data sets to the seven key components (*continued*)

Seven key components	Interviews and focus groups with National experts	Service managers and front-line staff	People with dementia and family carers	Comparative case studies
Valuing staff and ongoing learning	Leadership and management	Developing and supporting staff	Confidence in standards of future care	Equipping staff with appropriate skills and knowledge
	Continuity of care	Recognising EOL and providing appropriate care	Skilled and empathic staff	Emotional work at the EOL
	Use of guidelines	Continuity of care		Access to clinical support
		Communicating with families		
		Ensuring comfort at EOL		

Although there were differences in emphasis between data sets, the relevance of the seven components to all stakeholder groups is largely demonstrated in *Table 1*. The integrative analysis was also helpful in refining minor themes within data sets. For example, the emotional work in providing EOLC for front-line staff was a strong theme in the comparative case studies, but was not identified as an explicit theme in other data sets. The integrative analysis drew attention to the presence of this theme in other data sets and helped to ensure that it was embedded in the theme of valuing staff and ongoing learning.

Workstream 2 conclusions

There were some important discrepancies between the findings, policy objectives and existing literature. Although planning for EOL is promoted as best practice,[33,35,45] the findings confirmed that people with dementia often prefer to live in the moment, and some had strong reservations about planning for the future.[47,49,62] In terms of practical implications, this suggests the need for planning discussions to be conducted with a professional who has time to get to know the individuals, understands the barriers to planning and is able to approach topics over a period of time (while recognising that it may never be appropriate for some families). Although national experts emphasised skills and training, they paid less attention to the relational context needed to support discussions about future care.[94] The integrative analysis promoted a more detailed understanding and provided insights into how to translate the components into practice. Seven key components were identified as being core to the provision of good-quality EOLC in dementia: (1) timely planning discussions, (2) recognising EOL and providing supportive care, (3) co-ordinating care, (4) working effectively with primary care, (5) managing hospitalisation, (6) continuing care after death, and (7) valuing staff and ongoing learning.

The uncertainty of the dementia trajectory is often cited as a key barrier to good EOLC in dementia.[20,21,31,99,102] However, data from front-line staff, particularly care home staff, suggested that uncertainty may be less relevant than was previously thought. Many staff anticipated and were accepting of fluctuations in people with dementia, and were able to explain these to family carers. Experienced staff often used a combination of their personal experience and knowledge of the individual, subjective changes (e.g. seeming more withdrawn) and objective measures (e.g. weight loss and decreased appetite) to identify people potentially approaching the EOL.[95]

Reflections on workstream 2

The integrative analysis promoted a more detailed understanding of key components of EOLC in dementia than would have been achieved through individual data sets. Observation provided valuable insights into how to translate these components into practice. The findings, therefore, highlight the value of including multiple stakeholder groups and different methods to inform complex interventions. A key limitation was the relatively small numbers of people with dementia involved in interviews. It proved difficult to recruit participants through the services taking part in the focus groups; this may have been because of workload, desire to 'protect' people with dementia or a lack of confidence in the research team. These difficulties were offset, to some extent, by the involvement of a considerable number of people with dementia in the observations, which often included informal conversations about the care they received and their views on the components of good care.

Workstream 3: development of the SEED intervention

This work has been published as Macdonald *et al.*[103] (see *Acknowledgements*, *Publications*). A detailed description of the SEED intervention is provided in *Appendix 3*.

Overview

In WS3, we developed an intervention that is grounded in the key findings of WS1 and WS2, and that builds on the results of the MCDP. Using a co-design approach, the seven key components identified in WS2 as underpinning good-quality EOLC in dementia were operationalised into a primary care-based intervention to be piloted in WS4. The primary care-based intervention, delivered by a DNS, targets two key groups of people: (1) those in the earlier stages of the dementia trajectory, with mental capacity to address future care planning; and (2) those in the more advanced stages of dementia, who would benefit from a palliative approach to their care. Findings also suggested the need for a care resource kit, containing current and possibly new resources, targeting the seven key components. As an integral part of the SEED intervention, the resource kit supports intervention delivery, enables effective working with people with dementia and their families, and improves the knowledge and skill set of community-based health and social care professionals. WS3 used an inclusive design-led approach[103–105] to co-develop blueprints for a number of new EOL resources that could be included in the care resource kit.

Patient and public involvement

This was integrated throughout WS3. Specific PPI contributions included discussing and advising on the emerging intervention, testing workshop-based activities to inform future stakeholder involvement methods, advising on acceptability of existing resources for the care resource kit, providing detailed feedback on the draft care plan guide and advising on the concept of developing a MOOC.

Research aims

The research aims were to:

- develop an evidence-based intervention to support professionals to provide good-quality EOLC in dementia
- co-develop new resources to support implementation of the intervention
- identify key determinants of costs and outcome to inform WS5 (to prevent duplication, this element is described in *Workstream 5: economic modelling study*, *Valuing the consequences of the SEED intervention*).

Developing an evidence-based intervention (see *Appendix 3*)

The MRC guidance on developing complex interventions includes three key activities relating to intervention development: (1) identifying the evidence base, (2) identifying/developing theory and (3) modelling process and outcome.[74] In the SEED programme, the first activity took place in a series of workshops with the full SEED programme team to review the evidence from WSs 1 and 2 and to generate and prioritise ideas for possible intervention. The broad concept of the intervention was then operationalised through small group co-design workshops, which included modelling process and outcome using the theory of change.[106] Although we had intended to develop the intervention within the team and then conduct task groups with stakeholders, this process was adopted to ensure more integrated involvement of stakeholders (i.e. PPI members, clinical specialists and service providers) throughout the second phase of intervention development.

Phase 1: generating and prioritising ideas

A series of five workshops with the full SEED programme team was undertaken (November 2014 – December 2015). The initial five workshops involved early and ongoing discussions of the existing evidence base (WS1 reviews) and qualitative findings (WS2). The focus was to identify possible frameworks for the intervention, and appropriate methods and processes to inform its development. A brief summary of each workshop is provided in *Appendix 3*, *Developing an evidence-based intervention*. Following this series of workshops, the co-design process then continued in a smaller group to develop the intervention in more detail and facilitate translation into practice.

Phase 2: prototype development

The smaller group met every few weeks over a 12-month period, with a 5-month gap between months 4 and 9 (when Sandra Neves was on maternity leave). Members included the design team, PPI members, key researchers, clinical experts and service providers. The main focus of the smaller group was to consider how the ideas identified in the workshops linked to existing theoretical frameworks and could be operationalised in terms of what the intervention would comprise, who it would be targeted at, where it would be based, who would deliver it and how intervention delivery could best be supported. A summary of each of these areas is provided in the following sections.

What theoretical approaches could inform the SEED intervention?

We did not have an explicit theoretical framework to inform the intervention at the outset. Relevant theoretical frameworks to inform the intervention were identified from the literature reviews, qualitative interviews and case studies. These included extending the ideas of person-centred care[107,108] to person-centred death and to other key individuals (family members and professionals) involved in EOLC.[109,110] We also drew on ethnomethodological ideas about the social organisation of death.[111] Other aspects of the intervention were informed by complexity theory,[112,113] recognising the need for the intervention not only to address individual needs but to enhance systems to support EOLC. The SEED intervention was, therefore, informed by a range of blended theories. With the exception of the social organisation of death, each of the remaining theories informed all of the seven components comprising the intervention.

We subsequently used the framework of normalisation process theory (NPT)[114,115] to understand whether or not and how the intervention was implemented (see *Workstream 4: pilot trial of the SEED intervention, with process evaluation, to ascertain feasibility and acceptability*).

What components would comprise the SEED intervention?

It was agreed that the SEED intervention would focus on the seven key components of care identified in WS2 and would consist of:

- direct work to support people with dementia and carers towards, and at, the EOL
- developing a supportive context for EOLC in dementia by –
    - mapping and co-ordinating local services
    - developing the workforce through co-working, training and development
    - improving systems to enhance EOLC, for example improving use of the general practice palliative care register, or improving links between general practices and local care homes
    - a care resource kit.

Who would the SEED intervention focus on?

As the aim of the programme was on improving care towards, and at, the EOL in dementia, the consensus of the small co-design group was that the intervention would focus on two groups of people with dementia and their families: (1) those in the earlier stages of the dementia trajectory with mental capacity, to address future care planning; and (2) those in the more advanced stages of dementia, who would benefit from a palliative approach to their care. The ambition was that the intervention would also focus on improving the delivery of EOLC to people with dementia through more strategic work. Although this would be tailored to the local context, we anticipated that this systems-level work might include building capacity of existing staff or enhancing use of the general practice palliative care register for people with dementia.

Where would the SEED intervention be based?

Alzheimer's Disease International has urged implementation of a task-shifted model of dementia care whereby the majority of post-diagnostic care is delivered in community settings by a generalist workforce such as primary care teams.[116,117] In England, this approach has been widely implemented for a range of long-term conditions, usually with a specialist nurse co-ordinating care and facilitating links and knowledge exchange between the general practice and secondary care.[118] To date, dementia has generally been excluded from this model. The findings of WS2 suggested that an intervention based in primary care could address a number of existing shortcomings in EOLC in dementia. For example, better community support was needed to facilitate care in place and obtaining timely support from primary care was a recurrent issue for some care homes. Although the MCDP tested a care home-based intervention,[119] this excluded those people with dementia living in their own homes. Basing the intervention in primary care was therefore supported both by the empirical data and the increasing policy emphasis on a primary care-led model of dementia care.

Who would deliver the SEED intervention?

As the seven key components of care largely involved clinically related duties such as future care planning, care co-ordination, working effectively with primary care and supporting/training generalist staff, it was agreed that the SEED intervention should be delivered by a professional with clinical knowledge and expertise. The recently completed MCDP intervention study had tested a non-clinical care co-ordinator role.[119] However, as the SEED intervention would comprise independent working in the community, it was considered that it should be delivered by an experienced nurse, particularly as this was consistent with the role of specialist/nurse practitioners in delivering most chronic care in the community. The post was termed a DNS.

Further discussion led to the development of a job description and person specification outlining the prior knowledge and expertise required and responsibilities of the role (see *Appendix 3*, *Job description provided to NHS trusts and person specification*). Existing job specifications for similar community-based, specialist nurse roles (e.g. Macmillan nurse for cancer and Admiral nurse for care of people with dementia and their families) were used to inform the job description.

What support will be needed to deliver the SEED intervention?

To enable the DNS to deliver the SEED intervention, a range of support needs were identified:

- training and supervision
- practical support in negotiating the new role
- an accessible manual describing the SEED intervention [see *Report Supplementary Material 2* and *Appendix 3*, *Example of SEED activities and outcomes for one key component (timely planning discussions)*, and *Example of SEED activity checklists for one key component (timely planning discussions)*]
- care resource kit [see *Appendix 3*, *Example of resources for one key component (timely planning discussions)*].

Practical issues included secondment arrangements, equipment required, induction and training, and anticipated caseload. Training needs were identified and prioritised using an educational needs assessment (see *Appendix 3*, *Educational needs assessment for dementia nurse specialist*). An induction period of 4–6 weeks was agreed to enable the DNSs to meet key professionals in the locality and to build relationships with their general practice. A bespoke SEED manual was developed to introduce the DNSs to the research programme and the intervention, and to help guide them through the role (see *Report Supplementary Material 2*). This included a description of the intervention using the Template for Intervention Description and Replication (TIDieR) checklist.[120]

The SEED intervention

The SEED intervention comprised a DNS to focus on the seven key components of good EOLC, identified in WS2, through working with individual people with dementia and family carers and working at a more strategic level to build capacity. A conceptual model of the SEED intervention is provided in *Figure 2*.

Using the theory of change to translate theory into practice

The next stage of intervention development involved translating the conceptual model into practical activities. For each of the seven components, we began by identifying objectives for working (1) with individual people with dementia and their families and (2) at a strategic level (*Box 1*). The activities were also presented as checklists that could be used by the DNSs to document activities and plan their work. These documents were included in an appendix to the SEED manual [see examples in *Appendix 3*, *Example of SEED activities and outcomes for one key component (timely planning discussions)*, and *Example of SEED activity checklists for one key component (timely planning discussions)*].

We then summarised the intervention using the theory of change.[106,121] This was used because it focuses on desired outcomes, adopts a collaborative approach and explicitly explores the rationale underlying interventions. Developing a theory of change for the SEED intervention involved an iterative and collaborative process between the research team and key local stakeholders, including a palliative care clinical lead, who would support the DNSs, and a specialist dementia nurse (who was subsequently seconded to the role of DNS for the pilot trial).

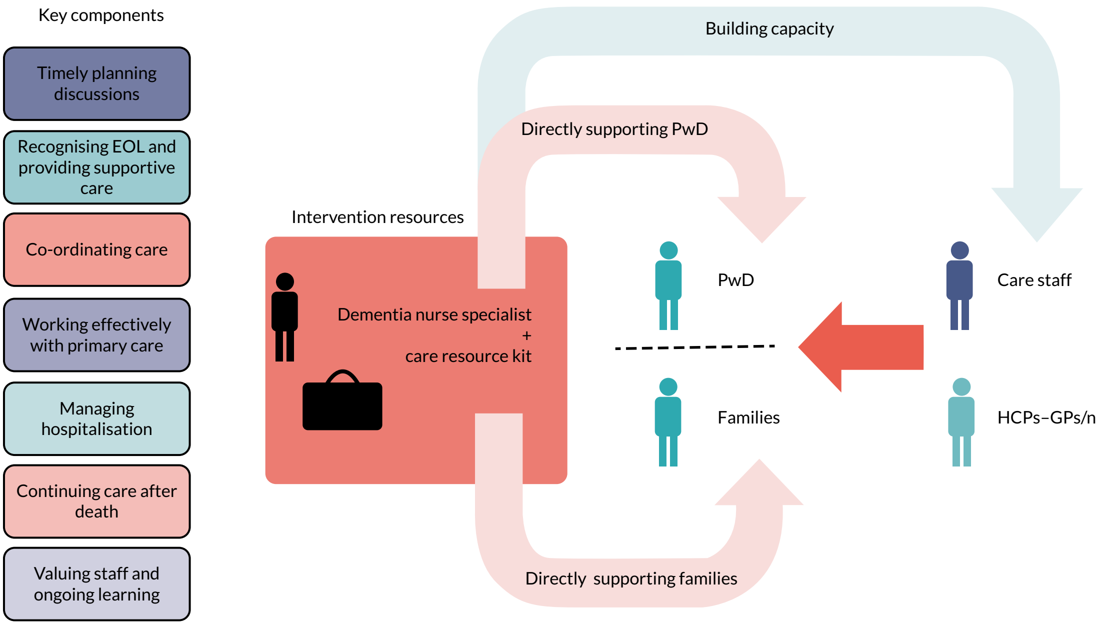


FIGURE 2 The SEED intervention. HCP, health-care professional; PwD, people with dementia. Reproduced from Macdonald *et al.*[103] with permission from *The Journal of Dementia Care*.

BOX 1 Translating the seven key components into objectives for the DNS

Timely planning discussions

- To provide opportunities for discussions about EOLC with patients and families.
- To provide opportunities for documenting preferences for EOLC.
- To ensure appropriate dissemination of completed documents.
- To ensure the timely review of completed documents.

Recognising end of life and providing supportive care

- To identify people with dementia approaching the EOL and add them to the palliative care register.
- To share prognosis with families and prepare them for EOL.
- To ensure the timely recognition and management of pain and discomfort at EOL.
- To review EOL planning documents.
- To ensure that all staff are aware of, and follow, relevant documentation.

Co-ordinating care

- To improve co-ordination between multiple services and agencies.
- To improve communication within and between services.
- To improve access to continuing health-care funding.
- To refer appropriately to specialist services.

Working effectively with primary care

- To provide a conducive environment in care homes for GP visits.
- To have a named GP and alternate identified.
- To ensure regular (e.g. 3-monthly) proactive clinical review of people with dementia.
- To review medications towards EOL.

Managing hospitalisation

- To ensure that a clear rationale is provided for hospital admissions.
- To ensure that preferences regarding hospitalisation are reviewed and documented.
- To identify a range of options to support families and care home staff in the event of unanticipated changes.
- To ensure that professionals who do not know the patient have access to key information.

Continuing care after death

- To prepare families for what will happen following the death of the person with dementia.
- To support families in the immediate post-death period.
- To assess the need for ongoing bereavement support.

Valuing staff and ongoing learning

- To value the emotional work involved in EOLC.
- To recognise the personal strengths of staff.
- To establish routine post-death reviews.

The stages involved in developing the theory of change included:

- identifying a realistic and definite goal for the SEED intervention (*Figure 3* presents the ultimate goal)
- working backwards from the goal to identify outcomes that would contribute to achieving the goal
- summarising activities needed to achieve these outcomes and the intended changes through which the outcomes would be achieved
- identifying resources required for the intervention.

In addition, we explored the assumptions underlying the links between activities and the overall goal. The theory of change aimed to provide an overview of the intervention. Individual activities included in *Figure 3* are, therefore, not specifically linked to individual components of the SEED intervention (e.g. planning for changing needs at the EOL is clearly linked to timely planning discussions, but is also likely to affect other components, such as providing supportive care, working effectively with primary care and managing hospitalisation). Similarly, the intended changes may result from one or more of the activities (e.g. increased acceptance of, and ability to manage, the uncertainty of EOL in dementia may result from developing and supporting the workforce and/or from planning for changing needs at the EOL). The outcomes and ultimate goal are, therefore, achieved through a combination of activities, rather than being directly linked to a specific activity.

Co-development of the care resource kit

A key role of the DNSs was to provide appropriate information to the right people at the right time. Therefore, we developed a care resource kit containing examples of existing resources to facilitate intervention delivery, and identified potential new resources to address any gaps.

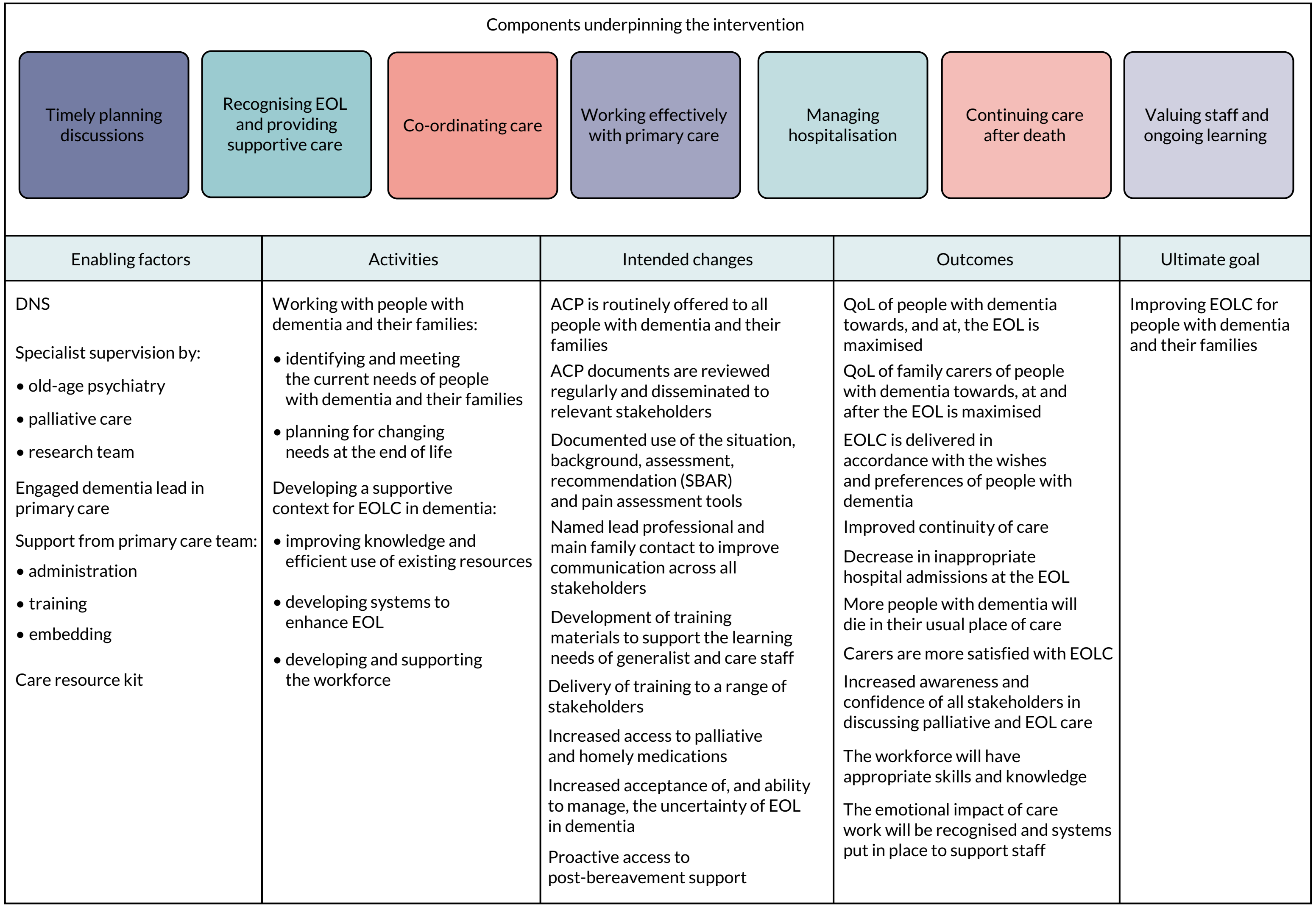
Existing resources

Existing resources were identified through online searches, targeting key websites (e.g. Alzheimer's Society, Alzheimer's Association and the National Council for Palliative Care) and using the keywords 'end-of-life care' and 'dementia'. A small group of SEED programme team members with personal and professional experience of EOLC in dementia reviewed the suitability of resources for (1) people with dementia and their families and (2) professional carers. Selected resources were grouped according to:

- relevance to one or more of the seven key components
- whether the resource focused on EOLC in general or was specific to dementia
- target audience (people with dementia, family carers and professionals)
- country of origin.

The accessibility of the resources was also considered in terms of format and availability (e.g. downloadable, free or paid for). The quality of the identified resources was then reviewed by considering whether and how research evidence had informed their development. In view of the large number of resources identified, many of which covered similar areas, we then selected the most appropriate existing resources for inclusion in the care resource kit, based on the following criteria: dementia-specific, freely available, UK based and evidence based. International resources for professionals were selected if they were of high quality with a strong evidence base. International resources for people with dementia and their families were included if they were accurate, of high quality and judged acceptable by the PPI member of the SEED team.

This process resulted in a detailed table of resources, which was included in the appendices to the SEED manual [see *Appendix 3, Example of resources for one key component (timely planning discussions)*, for an example]. Different ways of enabling the DNSs to quickly identify and access the resources were considered. One suggestion was to develop a web portal to facilitate searching and retrieval of documents, which could be used by people with dementia and their families, as well as professionals. A preliminary structure for the web portal was agreed, in which resources would be organised by their



Components underpinning the intervention

- Timely planning discussions
- Recognising EOL and providing supportive care
- Co-ordinating care
- Working effectively with primary care
- Managing hospitalisation
- Continuing care after death
- Valuing staff and ongoing learning

Enabling factors	Activities	Intended changes	Outcomes	Ultimate goal
DNS Specialist supervision by: • old-age psychiatry • palliative care • research team Engaged dementia lead in primary care Support from primary care team: • administration • training • embedding Care resource kit	Working with people with dementia and their families: • identifying and meeting the current needs of people with dementia and their families • planning for changing needs at the end of life Developing a supportive context for EOLC in dementia: • improving knowledge and efficient use of existing resources • developing systems to enhance EOL • developing and supporting the workforce	ACP is routinely offered to all people with dementia and their families ACP documents are reviewed regularly and disseminated to relevant stakeholders Documented use of the situation, background, assessment, recommendation (SBAR) and pain assessment tools Named lead professional and main family contact to improve communication across all stakeholders Development of training materials to support the learning needs of generalist and care staff Delivery of training to a range of stakeholders Increased access to palliative and homely medications Increased acceptance of, and ability to manage, the uncertainty of EOL in dementia Proactive access to post-bereavement support	QoL of people with dementia towards, and at, the EOL is maximised QoL of family carers of people with dementia towards, at and after the EOL is maximised EOLC is delivered in accordance with the wishes and preferences of people with dementia Improved continuity of care Decrease in inappropriate hospital admissions at the EOL More people with dementia will die in their usual place of care Carers are more satisfied with EOLC Increased awareness and confidence of all stakeholders in discussing palliative and EOL care The workforce will have appropriate skills and knowledge The emotional impact of care work will be recognised and systems put in place to support staff	Improving EOLC for people with dementia and their families

FIGURE 3 Theory of change for the SEED intervention.

intended audience, the seven components and format (e.g. booklet or video). Although a blueprint for the portal was developed, there were insufficient resources to develop it further.

New resources

The review of existing resources highlighted gaps in three key areas:

1. a simple introductory guide to planning for the future
2. clinical scenarios illustrating common issues in EOLC in dementia and strategies to address these
3. online training for both family carers and professional carers focused on advanced dementia and EOLC.

The rationale for selecting these areas and description of the progress made in developing new resources are described in detail in *Appendix 3*, *Development of new SEED resources*. Only one of these new resources, a MOOC on advanced dementia, was successfully completed and marketed.

Massive open online course

This work has been published in Poole *et al.*[122,123] (see *Acknowledgements*, *Publications* and *Appendix 2*).

The major gap identified by the review of existing resources was the absence of educational resources for both family and professional carers on advanced dementia and the provision of care as the illness progresses. A MOOC was seen as the most appropriate way of addressing this gap. A MOOC is an online course aimed at unlimited participation and open access via the web. In addition to traditional course materials, such as filmed lectures, many MOOCs provide an interactive forum for users.

The SEED-based MOOC, *Dementia Care: Living Well as Dementia Progresses*, aims to help family carers of people with advancing dementia to feel prepared and supported towards, and at, the EOL. Although primarily designed for family carers, the MOOC was a useful resource for professional carers, particularly care home staff. The content is underpinned by the seven key components that informed the SEED intervention, and addresses three main areas:

1. understanding the progression of dementia and planning for the future
2. working together to ensure the care and comfort of the person with dementia
3. looking after yourself as a carer.

Participants involved in the MOOC included members of the SEED project team (Marie Poole and Louise Robinson), DNSs, family carers, a range of health-care professionals who participated in SEED and additional professionals to ensure that key organisations were represented. The resources included in the MOOC aim to be engaging and informative, and comprise short videos, articles, images, quizzes, animations and interactive forums. *Dementia Care: Living Well as Dementia Progresses* was launched in March 2019; the 3-week course is now delivered twice-yearly and has been completed by > 3000 participants from 130 countries. To date, the MOOC has been promoted at a range of national and international conferences and with organisations including Dementia UK, Health Education England, local NHS foundation trusts and local dementia services.

Workstream 3 conclusions

Following an extensive co-design process involving all key stakeholders, the seven key components identified in WS2 as underpinning good-quality EOLC in dementia were operationalised as a primary care-based, nurse-led intervention. From a theoretical perspective, we utilised the theory of change[106,121] as it allows a collaborative and iterative process and focuses on desired outcomes. A training and supervision programme was developed along with an intervention manual. Findings also indicated the need for a care resource kit to help the DNSs deliver the intervention, work more effectively with people with dementia and their families, and improve the knowledge and skills of family carers and community-based care professionals. An extensive review was undertaken of existing resources, information and tools focused on supporting the delivery of good-quality dementia care towards, and at, the EOL. This indicated a number of gaps, in particular the absence of educational resources for both family carers and professional carers on advanced dementia and the provision of care as the illness progresses. Using the empirical data from earlier WSs, we developed a MOOC to address this gap. The MOOC, *Dementia Care: Living Well as Dementia Progresses*, was launched in March 2019.

Reflections on workstream 3

Development of the intervention required considerable time and effort that, in hindsight, we underestimated. In addition, the length of the process was increased because of (1) the design researcher undertaking maternity leave mid-way through WS3 and (2) a recommendation from our ESC to extend intervention development time to ensure that key aspects that were essential for operationalisation in practice were completed. Developing new, relevant and innovative educational resources was another key challenge during WS3. Considerable effort was put into searching for and retrieving existing resources, tools and information on EOLC in dementia. However, even once we had identified potential areas for the development of new resources, it was difficult to determine if there were any resources already under development that would address these gaps. Consequently, considerable time and effort were spent creating potential new resources and tools, only for updated review searches, which also required considerable time and human power, to identify new resources that had just been published.

Workstream 4: pilot trial of the SEED intervention, with process evaluation, to ascertain feasibility and acceptability

Further details on WS4 are provided in *Appendix 4*.

Overview

Workstream 4 comprised a pilot trial to assess the feasibility and acceptability of recruitment and retention, the SEED intervention and outcome measures. Key success criteria for recruitment and retention were generally achieved, but operationalising the eligibility criteria was time-consuming. Many stakeholders thought that all people with dementia would benefit from the intervention and that this would offer a potential strategy for meeting the NICE recommendation for a named care co-ordinator for all people with dementia throughout the illness trajectory.[29] Despite the complexity of the SEED intervention and the requirement for the DNSs to adapt it to the local context, it proved both feasible and acceptable. The DNSs made significant changes at a strategic level (e.g. introducing a template for the annual dementia review in primary care), in addition to working with individuals and their families. None of the outcome measures was considered suitable as the primary outcome measure for a future trial. In the light of these uncertainties, we do not intend to proceed to a definitive trial of the SEED intervention at this stage.

Patient and public involvement

The views of PPI members were sought on progression to a future trial. In particular, we explored extending the intervention to all people with dementia, advantages and disadvantages of alternatives to the current model of one DNS for each general practice, and their views on appropriate outcome measures.

Research aim

The aim of WS4 was to investigate the feasibility of a definitive multicentre RCT of the SEED intervention. Specific objectives focused on three areas:

1. recruitment and retention of people with dementia, family carers and key informants, specifically to –
    - test the feasibility of recruiting 66 people with dementia (with at least 11 from each practice)
    - ascertain whether or not we could collect 12-month follow-up data from at least half ($n = 33$) of the people with dementia who were recruited
2. the implementation of the SEED intervention, specifically to –
    - explore the feasibility and acceptability of the SEED intervention and supporting educational resources
    - explore how and to what extent the intervention was implemented in practice
    - identify, describe and explain factors influencing the implementation of the SEED intervention

3. capturing outcome data, specifically to –
    - investigate the feasibility and acceptability of available outcome measures
    - assess the feasibility of collecting resource use data and health-related QoL for people with dementia and family carers
    - explore ways of capturing data on future care planning.

Methods

The MRC guidance on developing and evaluating complex interventions emphasises the importance of pilot work to address key uncertainties before progressing to a full trial.[74] Key functions of feasibility/pilot studies are estimating recruitment/retention, testing procedures and estimating sample size.[74] In the present study, there was a high level of uncertainty over each of these areas, in particular over whether or not the intervention could be delivered in practice and whether or not available outcome measures would prove feasible and acceptable in a UK community context. These uncertainties indicated that a pilot trial with an embedded process evaluation was required to inform whether or not progression to a full trial was appropriate.

The strategic focus of the intervention could potentially lead to changes in general practices, local care homes and joint working arrangements with other professionals. Because these changes would affect all participants regardless of their allocation, randomising individual participants was not appropriate. Therefore, we used a cluster design, with clusters comprising individual general practices. Each cluster contained two general practices from North East England, one of which was allocated to receive the intervention, whereas the other acted as a control, providing usual care. The trial methods are described in full in *Appendix 4*, *Pilot trial methods*, including key areas from the relevant reporting guidelines.[124–127] Details of approvals and trial management by the Newcastle Clinical Trials Unit are provided in *Appendix 4*, *Trial management*. Data collection tools (e.g. activity logs and topic guides) are available in *Report Supplementary Material 1*.

Recruitment

Allowing for 10% attrition, we aimed to recruit a total of 66 people with dementia, to meet the recommended minimum sample size of 30 participants per trial arm.[128] To test the feasibility of recruitment, we aimed to recruit at least 11 people with dementia from each practice. People with dementia were initially identified from the practice dementia register and were screened by a GP to ascertain whether or not:

- they had been diagnosed within 2 years (hereafter termed ‘recently diagnosed’)
- they were on the palliative care register
- they were thought to be approaching EOL, as judged by the question ‘Would you be surprised if this patient were to die in the next 12 months?’[129] (hereafter termed ‘potentially approaching EOL’).

Those on the palliative care register were assumed to be approaching EOL and were, therefore, combined with the third group. We anticipated that the intervention would focus on future care preferences with the recently diagnosed group and on the co-ordination of care and supporting non-specialists caring for those potentially approaching EOL. Full eligibility criteria are provided in *Appendix 4*, *Pilot trial methods*.

Following screening, selected eligible participants were sent a participant information sheet (PIS) giving them the opportunity to opt out of further contact. The remainder were contacted by a member of the practice team to seek verbal consent to pass their contact details to the research team. The researchers then telephoned potential participants to discuss the study further, and, if appropriate, arranged a home visit to take formal consent and complete the baseline outcome measures. We followed the provisions of the Mental Capacity Act 2005[130] for those people with dementia thought to be unable to give informed consent; in such cases, we approached either a personal or a nominated consultee.

Although not essential to participation, for each person with dementia we sought to recruit a family carer and, for those living in care homes, a key informant. They were identified by the person with dementia, the general practice or the care home managers. Family carers and key informants were provided with a PIS, then followed up by the research team, as described previously. We analysed the numbers of eligible participants seen over the recruitment period, and the resulting rates of recruitment, and retention, both by intervention arm and by practice.

Process evaluation

Although the primary focus of the process evaluation was on the implementation, feasibility and acceptability of the intervention, it also provided insights into recruitment and outcome measures. The consent form for people with dementia, family carers and key informants asked if they were also willing to participate in the process evaluation. Additional health and social care professionals for the process evaluation were identified through the DNSs, lead GP and/or practice manager and non-participant observation. The principles of purposive sampling[100] were used to obtain a maximum variation sample of people with dementia and family carers in terms of demographic factors, social arrangements, stage of dementia and types of engagement with the DNS. Health and social care professionals (e.g. social workers, members of community palliative care and mental health teams, home care and care home staff) were sampled in terms of level and type of involvement with the DNS. We also interviewed both DNSs at different time points during the study and members of the supervisory team.

All potential process evaluation participants were sent a PIS and followed up by the researcher, and consent was sought prior to data collection. People with dementia who lacked mental capacity to consent, as judged by the researcher and in line with guidance,[130] were eligible to participate in observation.

Interviews with professionals were informed by NPT,[114] for example by asking about whether or not and how the SEED intervention was distinct from existing services, whether or not and how host general practices supported the DNSs, skills displayed and required by the DNSs, and ways in which the intervention evolved over time. All interviews and informal discussions covered selected areas from the following list, tailored for different types of participant:

- recruitment processes
- views on outcome measures and perceived impacts
- feasibility and acceptability of the SEED intervention
- fit with existing services
- factors influencing implementation.

For the process evaluation, we continued data collection until data saturation was reached; we estimated that this would be achieved with up to 10 people with dementia, 15 family carers and 30 professionals.

We also captured intervention delivery through intervention supervision and activity logs (see *Appendix 4, Delivery of the SEED intervention*). Initially, the DNSs kept weekly activity logs using a predefined list of categories. As the role evolved, additional activity logs were introduced to capture, in more detail, interactions with people with dementia and family carers, care home staff and other professionals.

Details of data management for the process evaluation are provided in *Appendix 4*, *Pilot trial methods*. Data were analysed thematically.[101] The team discussed emerging issues and themes in data workshops and drafted a coding frame; this was then applied to new transcripts and modified until a final version was agreed. All qualitative data were coded in NVivo version 10 (QSR International, Warrington, UK). Team members wrote narrative summaries for each code for discussion in further data workshops. Data relating to implementation of the SEED intervention were subsequently mapped to the key constructs of NPT. This framework has been used extensively in exploring the implementation of complex health-care interventions,[115] and focuses on the individual and collective work of implementation.[114]

We iteratively developed and piloted a coding frame with each type of activity log (weekly, individual, care home, professional), until a final coding frame was agreed. All logs were then coded in a bespoke Microsoft Access® database (Microsoft Corporation, Redmond, WA, USA). Data from different logs were cross-referenced to ensure that data were as complete as possible and to avoid double counting. Data were transferred to IBM SPSS Statistics version 22 (IBM Corporation, Armonk, NY, USA) for simple descriptive analysis.

We also developed a series of vignettes to provide insight into the SEED intervention and the ways in which the seven components were enacted in practice. We purposefully sampled four people with dementia (and their family carers and/or key informants) to showcase the range of activities, settings and ways in which the intervention was tailored to the needs of individuals and services. The individuals varied in terms of their eligibility criteria (recently diagnosed or potentially approaching EOL), informal support and living arrangements. Data from interviews, observation and activity logs were cross-referenced to develop a comprehensive account of the content and delivery of the SEED intervention for each selected participant. To capture the more strategic components of the intervention, we used similar methods to develop a vignette from a care home perspective. A care home was selected where the DNS had worked with individual study participants and at a more strategic level to improve EOLC.

Collection of outcome data

A detailed description of all outcome measures and their interpretation is provided in *Appendix 4*, *Table 12*. In brief, measures relating to the person with dementia explored neuropsychiatric symptoms, physical health, pain and QoL. Family carer measures included anxiety and depression, views on care provided and QoL. Key informants completed measures relating to the care provided. Data on resource use by people with dementia and carers were collected using a bespoke questionnaire. Family carers and/or key informants completed a proxy version of the EuroQol-5 Dimensions, five level version (EQ-5D-5L),[131] for all people with dementia at all time points to ensure that full data were available in case the person with dementia was unable or unwilling to complete this measure. When data were provided by both a family carer and a key informant, the latter was given precedence because key informants usually had more consistent daily contact with the person with dementia.

Most outcome measures were completed at baseline and at 4, 8 and 12 months (*Table 2*). Demographic data were collected during baseline study visits. A post-death study visit was completed at either 2 months (family carers) or 2 weeks (key informants) after the death of the person with dementia. These time periods were selected to avoid the interview request clashing with the NHS survey typically sent out 3 months after death (for family carers) and to maximise recall (for key informants). Data on comorbidities, ACP and, when appropriate, cause of death were collected from general practice and/or care home records at baseline and either at 12 months or post death (see *Table 2*).

The feasibility and acceptability of outcome measures were assessed by examining:

- the proportion of outcome measures completed within data collection windows
- the proportion of people with dementia for whom outcome data were collected
- data completion rates for each outcome measure
- the views of people with dementia, family carers, key informants and the researchers administering the outcome measures.

TABLE 2 Assessment of outcome measures at each time point

		Completed at				
Outcome measure	**Completed by**	**Baseline**	**4 months**	**8 months**	**12 months**	**Follow-up after death**
HADS[132]	Family carer	✓	✓	✓	✓	✓
NPI-NH[133]	Key informant	✓	✓	✓	✓	
NPI[134]	Family carer	✓	✓	✓	✓	
QUALID[135]	Key informant/ family carer	✓	✓	✓	✓	
BANS-S[136]	Key informant	✓	✓	✓	✓	
PAINAD[137]	Researchers (observation)	✓	✓	✓	✓	
SWC-EOLD[138]	Key informant/ family carer	✓	✓	✓	✓	✓
SM-EOLD[138]	Key informant/ family carer	✓	✓	✓	✓	
CAD-EOLD[138]	Key informant/ family carer					✓
EQ-5D-5L[131]	Person with dementia	✓	✓	✓	✓	
	Family carer	✓	✓	✓	✓	✓
EQ-5D-5L Proxy[131]	Key informant/ family carer	✓	✓	✓	✓	
Resource utilisation questionnaire (person with dementia)[a]	Key informant/ family carer/ care home records		✓	✓	✓	✓
Resource utilisation questionnaire (family carer)[a,b]	Family carer (about own service use)				✓	✓
Advance care plan	Researchers	✓	N/A	N/A	✓	✓
DNACPR	Researchers	✓	N/A	N/A	✓	✓
Emergency Healthcare Plan	Researchers	✓	N/A	N/A	✓	✓
Prescription of anticipatory medications	Researchers	✓	N/A	N/A	✓	✓
Views on hospitalisation	Researchers	✓	N/A	N/A	✓	✓
Demographics	Researchers	✓	N/A	N/A	N/A	N/A
CCI[140,141]	Researchers	✓	N/A	N/A	✓	✓
Cause of death	Researchers	N/A	N/A	N/A	N/A	✓

BANS-S, Bedford Alzheimer Nursing Severity Scale; CAD-EOLD, Comfort Assessment in Dying with Dementia; CCI, Charlson Comorbidity Index; DNACPR; do not attempt cardiopulmonary resuscitation; HADS, Hospital Anxiety and Depression Scale; N/A, not applicable; NPI, Neuropsychiatric Inventory; NPI-NH, Neuropsychiatric Inventory-Nursing Home; PAINAD, Pain Assessment in Advanced Dementia; QUALID, Quality of Life in Late-stage Dementia; SM-EOLD, Symptom Management at the End Of Life in Dementia; SWC-EOLD, Satisfaction with Care at the End of Life in Dementia.

a Based on the Client Services Receipt Inventory.[139]

b Piloted on five family carers at either the 12-month follow-up or the post-death visit.

Statistical analyses of outcome measures focused on data completeness of outcome measures and any potential bias in the completion of follow-up data (see *Appendix 4*, *Pilot trial methods*). When statistical analysis indicated larger numbers of missing data, or when findings were inconsistent with data from other studies [e.g. Pain Assessment in Advanced Dementia (PAINAD)], we drew on data from reflective field notes by the researchers and interviews with people with dementia, family carers and key informants to explore reasons for missing data.

Integrating data from different methods, data sources and respondents

We designed the pilot trial to provide both methodological and data triangulation[142] for each of the broad research objectives (*Table 3*). With the exception of the planned development of vignettes, because of the large number of data available and limited time, we adopted a pragmatic, problem-solving approach, using triangulation to explore emerging issues.

Recruitment and retention of people with dementia, family carers and key informants

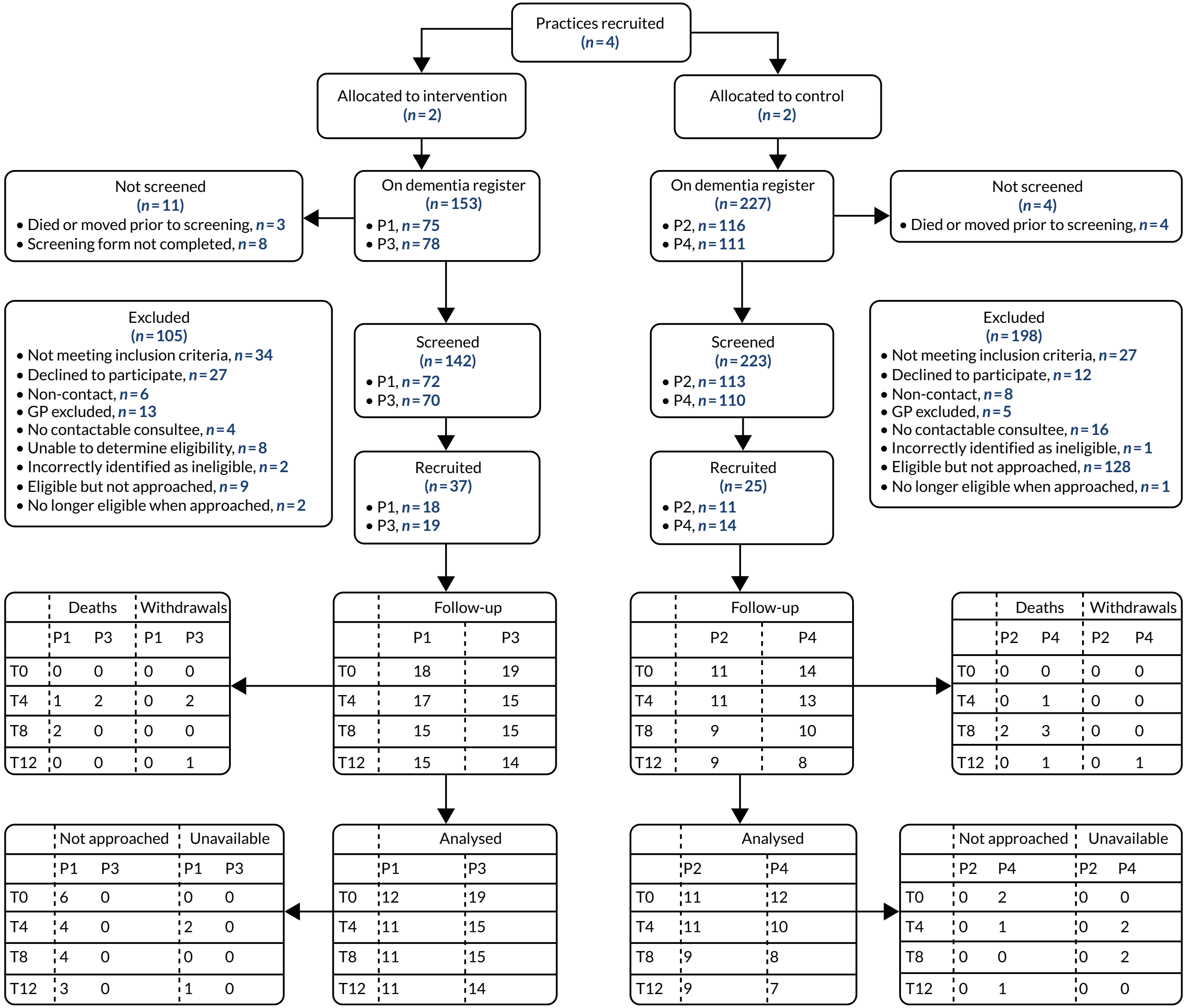
Recruitment

We achieved the minimum target of 11 people with dementia per practice, but fell marginally short of the overall target (62/66). Recruitment and retention of people with dementia are summarised in a Consolidated Standards of Reporting Trials (CONSORT) flow diagram (*Figure 4*). CONSORT diagrams for family carers and key informants are provided in *Appendix 4*, *Figures 5* and *6*. Overall, 82% of patients who were screened met the eligibility criteria. Either a family carer or a key informant was recruited for at least part of the study for all but three people with dementia.

There was some variation in screening and recruitment processes between practices (see *Figure 4*). The proportion of people on the dementia register who were screened ranged from 89.3% to 91.1%, and the proportion of those screened who were eligible ranged from 73.1% to 91.2%. Lack of resources in control practices meant that almost three-quarters (74%) of people with dementia who were eligible and potentially contactable (i.e. had not been excluded by the GP and, if appropriate, had a contactable consultee) were not approached, compared with only 11% in intervention practices. This explains the better recruitment rates observed in intervention practices (where 36.7% and 38.8% of eligible patients were recruited, compared with 10.7% and 14.3% of those eligible in control practices).

TABLE 3 Methodological and data triangulation for each broad objective

Objective	Data collection techniques	Data sources and/or respondent groups
Recruitment and retention	• Database logging participants at each time point • Qualitative interviews • Reflective field notes by research assistants responsible for recruitment and follow-up	• Practice staff and DNS involved in recruitment • Patients and carers • Key informants • Research team
Intervention delivery	• Activity logs • Qualitative interviews • Observation of intervention delivery • Intervention supervision	• DNSs • Patients and carers • Key informants • Practice staff • Wider health-care and social care professionals • Clinical supervisors • Research team
Outcome measures	• Completion of outcome measures • Reflective field notes by research assistants responsible for recruitment and follow-up • Qualitative interviews	• Patients and carers • Key informants • Research team



	Deaths		Withdrawals	
	P1	P3	P1	P3
T0	0	0	0	0
T4	1	2	0	2
T8	2	0	0	0
T12	0	0	0	1

	Follow-up	
	P1	P3
T0	18	19
T4	17	15
T8	15	15
T12	15	14

	Follow-up	
	P2	P4
T0	11	14
T4	11	13
T8	9	10
T12	9	8

	Deaths		Withdrawals	
	P2	P4	P2	P4
T0	0	0	0	0
T4	0	1	0	0
T8	2	3	0	0
T12	0	1	0	1

	Not approached		Unavailable	
	P1	P3	P1	P3
T0	6	0	0	0
T4	4	0	2	0
T8	4	0	0	0
T12	3	0	1	0

	Analysed	
	P1	P3
T0	12	19
T4	11	15
T8	11	15
T12	11	14

	Analysed	
	P2	P4
T0	11	12
T4	11	10
T8	9	8
T12	9	7

	Not approached		Unavailable	
	P2	P4	P2	P4
T0	0	2	0	0
T4	0	1	0	2
T8	0	0	0	2
T12	0	1	0	0

FIGURE 4 The CONSORT flow diagram for people with dementia. P, practice.

Three-quarters (75%) of the 56 family carers identified were recruited; only one person with dementia requested that we did not approach a family carer. Key informants were identified, and agreed to take part, for 26 of the 33 (79%) people with dementia who lived in a care home at some point during the study. Although key informants were not recruited for the remaining seven people with dementia, this was at the request of either the person with dementia or their family carer, with the latter providing information instead.

Retention

Retention was better than expected: 12-month data were successfully collected for 41 (66%) people with dementia, exceeding the target of 33 people. Mortality was lower than expected: 12 people with dementia died during the study, five in the intervention and seven in the control arm. All of those who died had been identified as potentially approaching the EOL by a GP during screening. Post-death interviews were completed for 11 out of the 12 people with dementia who died; one family carer declined. Four people with dementia withdrew from the study: three moved to a care home and changed general practice, and one was withdrawn because of the ill health of his spouse.

No family carers died during the study. Four family carers withdrew: two when the person with dementia moved care home and changed general practice, one because of ill health and one did not give a reason. Post-death information was provided by five of the six family carers who were the main informants for people with dementia who died.

Three key informants were withdrawn when the person with dementia moved care home. There was considerable continuity of key informant, with 18 key informants providing information at all time points; two key informants were involved for seven people with dementia, and information on one person with dementia was provided by three different key informants. An additional 10 key informants were recruited during the study: eight replaced key informants who were unavailable at follow-up and another two provided data for people with dementia who moved into a care home or moved between care homes. Post-death interviews were completed with key informants for six of the eight people with dementia who died while in a care home (the family carer provided post-death information for the remaining two people).

We collected data at the end of the study to examine the accuracy of the ‘surprise’ question by reviewing the status of all patients who had been on the dementia register at the time of screening. Patients for whom the surprise question was not answered ($n = 28$) and those whose status was not known at the end of the study (e.g. because they had moved practice; $n = 35$) were excluded (*Table 4*).

Only 9% of patients not thought to be potentially approaching the EOL had died by the end of the study, compared with 37% of those thought by the GP to be potentially approaching the EOL. These figures nevertheless confirm the difficulties of identifying people with dementia approaching the EOL, as > 60% of those thought to be potentially approaching the EOL were still alive at the end of the study.

TABLE 4 Status at study end by response to surprise question at screening

	Status at study end, *n* (%)		
‘Surprise’ question	**Dead**	**Alive**	**Total**
Would you be surprised if this patient were to die in next 12 months?			
Yes, surprised	8 (9.1)	80 (90.9)	88 (100)
No, not surprised	86 (36.8)	148 (63.2)	234 (100)

Participant characteristics

Participant characteristics were reasonably well balanced between intervention and control arms, given the relatively small study. Full details are provided in *Appendix 4*, *Tables 19–22*.

As previously described, we aimed to recruit two distinct groups of patients: those recently diagnosed and those potentially approaching the EOL. Patients who met both criteria have been classed as potentially approaching EOL in *Table 5*. This shows that the majority of patients screened (85%) were considered to be potentially approaching the EOL. Those not considered to be potentially approaching EOL were almost four times as likely to be recruited as those potentially approaching EOL (42% vs. 11%). Despite the unequal recruitment of patients from the two eligible groups, the majority of those recruited (69.4%) were nevertheless thought to be potentially approaching the EOL. We are, therefore, confident that the intervention was provided to both groups of eligible patients.

Data from the qualitative interviews suggest that reservations over approaching patients and their families thought to be approaching the EOL and concerns over what the intervention would involve or could offer this patient group contributed to the under-recruitment of people with dementia potentially approaching the EOL. Similar issues with access to patients approaching the EOL and their carers were experienced in the process evaluation, whereby the DNSs could be protective towards potential participants thought to be at the EOL.

Recruitment to the process evaluation

We completed a total of 55 interviews with 59 interviewees in the process evaluation. Interviewees included people with dementia; family carers; DNSs; the intervention supervisory team; general practice staff (intervention and control sites), including GPs, practice managers, administrative staff and pharmacists; and a range of health-care and social care professionals who worked in care homes, community mental health teams, palliative care teams, primary care, sheltered housing and hospices. On average, interviews lasted 33 minutes.

Non-participant observation was conducted on 23 occasions (total time: 1243 minutes, mean 54 minutes, range 15–120 minutes). Observations were predominantly of intervention delivery, including training, working with other practitioners and working with people with dementia and their families. Observation settings included care homes, hospitals, GP surgeries and participants' homes. DNS training and intervention supervision sessions provided by the research team were also observed and audio-recorded with the consent of all participants.

Views on screening and recruitment

Key findings from the qualitative data are summarised in this section; full details with illustrative quotations are provided in *Appendix 4*, *Feasibility and acceptability of recruitment and retention*. Feedback from practice staff and the DNSs indicated that the process of screening patients and recruitment was more challenging than anticipated. This was partly because of difficulties in answering the screening questions, with some GPs questioning the validity of the 'surprise' question. Recruitment of family carers was hindered by poor documentation of next of kin in GP records. Relatively few potential participants opted out of further contact from the research team, suggesting that this approach was

TABLE 5 Characteristics of screened and recruited patients

	Screened as potentially approaching EOL		
Recruited to trial	**No, *n* (%)**	**Yes, *n* (%)**	**Total, *n***
No	26 (57.8)	208 (88.9)	235
Yes	19 (42.2)	43 (11.1)	62
Total	45 (100)	251 (100)	296

acceptable to this group of patients and carers. Few comments were made by people with dementia and carers about recruitment processes. Some people with dementia and their carers who had been recently diagnosed did not see the SEED intervention as relevant to their situation. However, some of those who initially thought that the intervention had little to offer were subsequently surprised by how much they gained from the intervention. Key issues relating to recruitment and potential strategies to maximise recruitment to a future trial are summarised in *Appendix 4*, *Table 23*.

Feasibility and acceptability of the SEED intervention

An overview of DNS activity, including new resources developed and implemented during the study, is summarised in *Table 6*. This shows that interventions relating to all seven components of the SEED intervention were delivered to participants living at home and in care homes, at both individual and systems levels. Although all activity logs, except for the weekly log, provided space to map activities to

TABLE 6 Examples of work with individuals, strategic work and new resources related to the seven components underpinning the SEED intervention

Component	Individual work	Systems-level work	Resources
Timely planning discussions	• Raising awareness of illness trajectory in dementia • Providing resources to facilitate ACP (see *Appendix 4*, *Box 5*)	• Reviewing EOL documentation in care homes • Including section on ACP in annual dementia review template • Training GPs on EHCPs	• Annual dementia review template
Recognising EOL and providing supportive care	• Developing comfort care plans (see *Appendix 4*, *Box 2*)	• Training on dementia, pain and symptom management, and comfort care planning for care homes	• List of EOL indicators • Comfort care plan
Co-ordinating care	• Liaising between services (see *Appendix 4*, *Box 4*)	• Providing general practice with details of local services	• Mapping local services
Working effectively with primary care	• Facilitating GP review for person with dementia and carer (see *Appendix 4*, *Boxes 3* and *4*)	• Establishing meetings between consultant old-age psychiatrist and dementia lead GPs • Introducing the SBAR technique to facilitate communication between care homes and GPs	• Annual dementia review template • Flow chart for EHCP
Managing hospitalisation	• Liaising with families, primary and secondary care about EOLC during hospital admission (see *Appendix 4*, *Box 3*)	• Training paramedics • Training GPs on EHCP • Introducing the SBAR technique to facilitate communication between care homes and GPs	• Flow chart for EHCP
Continuing care after death	• Providing ongoing support to a family carer (see *Appendix 4*, *Box 3*)	• Facilitating a post-death review meeting in a care home • Developing ways of remembering people with dementia who have died in care homes	• Checklist for reflective meetings with care home staff
Valuing staff and ongoing learning		• Training care home staff, practice staff, GPs and paramedics (see *Appendix 4*, *Box 6*) • Mentoring individual members of staff	• Training materials on dementia, EOLC, pain recognition and management, comfort care planning

EHCP, Emergency Healthcare Plan; SBAR, situation, background, assessment, recommendation.

the seven key components of the SEED intervention, this aspect of the logs was inconsistently completed and there was a significant number of missing data. We could not, therefore, analyse the extent to which different components were covered by the intervention. Instead, we focused on the activities listed in the theory of change and considered:

- the proportion of days on which specific activities were recorded
- the focus of work with participating dyads
- collaborative working.

Findings from the activity analysis showed that the intervention focused on the current needs of people with dementia and family carers, networking and service mapping (see *Appendix 4*, *Figure 7* and *Table 26*). The vignettes (see *Appendix 4*, *Boxes 2–6*) illustrate how the seven components were operationalised. Four examples for individual dyads and one for a care home are provided in *Appendix 4*, *Boxes 2–6*. Bespoke training and supervision arrangements were provided for the DNSs by the research team, an old-age psychiatrist and a palliative care clinical lead (see *Appendix 4*, *Tables 24* and *25*). The DNSs also met regularly for peer support. Only one DNS received supervision from the dementia lead GP; without this, the role was potentially isolating. Administrative and information technology (IT) support from the host general practices were necessary to navigate primary care systems effectively. The different backgrounds of the DNSs (in palliative care and mental health) proved useful in joint working and mutual support. Although we did not succeed in establishing a multidisciplinary team (MDT) to support the DNSs, they did not feel that their case load was complex enough to merit this.

Stakeholder views on the SEED intervention

Key issues relating to the feasibility and acceptability of the SEED intervention concerned the location of the SEED intervention in primary care, relevance of the seven components to real-world practice, appropriateness of working with individuals and at a more strategic level, qualifications and training needed to fulfil the DNS role, and the fit of the SEED intervention with existing services. These issues are summarised in this section, with further elaboration and illustrative quotations provided in *Appendix 4*, *Feasibility and acceptability of the SEED intervention*.

Basing the intervention in primary care was valued because this facilitated access for people with dementia and family carers, face-to-face contact with GPs, access to patient records and links with other services.

Each of the seven components was thought to be relevant, and no additional components were identified. Although the DNSs were initially more comfortable working with individuals, through intervention supervision and the growing familiarity with their role, they became enthusiastic about working at a systems level (see examples in *Table 6*). The DNS role in co-ordinating care (across primary and secondary care) was valued by family carers and enhanced continuity of care. From a GP perspective, a proactive approach was thought to avoid crises, and reduce hospitalisation and demands on their time. The emphasis on timely planning discussions was valued by health-care professionals, as no existing professionals had a clear responsibility for these. Some of the barriers to planning ahead that were identified in our earlier work,[96] for example reluctance to talk about the future and a preference to focus on the present, were encountered by the DNSs. The opportunity to invest time in relationship-building and to embed such discussions in a broader context of talking about changes in circumstances were key to facilitating ACP.

The nursing background of the DNSs was valued by both family carers and care home staff. Others considered professional background less important, but emphasised personal attributes, such as inspiring confidence and being reliable and approachable. Most stakeholders viewed the SEED intervention as complementary to existing services and tensions over role boundaries were rare.

We drew on the framework of NPT[114] to identify factors influencing the implementation of the SEED intervention (see *Appendix 4*, *Feasibility and acceptability of the SEED intervention*). The NPT analysis suggested that the individual and collective work required for successful implementation of a new intervention was largely achieved. In terms of coherence (whether or not the intervention was easy to grasp and made sense), the DNSs and practice staff contested the focus on EOLC and were keen to extend the intervention to all people with dementia. Although the perceived lack of clarity over the focus and content of the SEED intervention was initially a barrier to implementation, as the DNSs became more confident with the components underpinning the intervention they valued the opportunity to develop the intervention autonomously.

Cognitive participation or investment in the SEED intervention was high for the DNSs, but varied between the two host general practices; this affected the extent to which the DNSs were successfully embedded and limited the scope for improving systems in one practice. The temporary nature of the intervention influenced buy-in of all stakeholders and required a strong focus on relationship-building by the DNSs to successfully engage people with dementia, family carers and care homes.

The work involved in delivering the SEED intervention (collective action) required experienced staff who were used to working autonomously. Supervision arrangements ensured access to specialist knowledge and support relating to different aspects of their role. Intervention supervision was particularly important because of the initial uncertainties of the DNSs over the scope of the intervention, and to encourage working at a more strategic level.

Although the SEED intervention was piloted for only 12 months, there was evidence of reflexive monitoring: the process of reflecting on, and adapting, the intervention. Access to different perspectives through supervision facilitated reflection on the intervention. A number of pieces of work were undertaken iteratively with care home managers, GPs and other local professionals to maximise likelihood of integration into practice. System-level changes likely to be sustained after the study included the annual dementia review template in one general practice, comfort care planning and revised EOL documentation in some care homes.

Feasibility and acceptability of outcome measures

Completion of outcome measures

All data were collected within the target window with one exception, confirming that the time parameters set for data collection were achievable. Aggregating data across all time points for current study participants (i.e. excluding those who had died or withdrawn), data were collected from 86% of people with dementia, 97% of family carers and 100% of key informants. The main reason for missing data was that some people with dementia were not approached for data collection at the request of their family carer or key informant, because the family carer or key informant either thought that the person would not be able to provide data and/or thought that data collection would have a negative impact (e.g. creating anxiety). Data were occasionally missing because of ill health or holidays. Data for family carers were missing because of unavailability, typically because of holidays, their own ill health or difficult circumstances.

The proportion of fully completed measures (i.e. those with no missing items) at each time point by type of respondent ranged from 9.1% to 100%. All but three measures were fully completed on > 80% of occasions. The three measures with poor completion rates were as follows:

- the PAINAD during movement, with a full completion rate of 53.5% across all time points and respondents (range 43.8–68.4%; see *Appendix 4*, *Tables 30–33*)
- the EQ-5D-5L completed by people with dementia, with a full completion rate of 65.1% across all time points (range 54.2–86.7%; see *Appendix 4*, *Table 36*)
- the Satisfaction with Care at the End of Life in Dementia (SWC-EOLD), with full completion rates of 40.7% for family carers (range 11.8–100%) and 35.4% for key informants (range 9.1–66.7%; see *Appendix 4*, *Tables 30–33* and *Table 35*).

Qualitative data and further analyses suggested that the reasons for missing data were specific to individual measures. Missing data on the PAINAD were because of the inability of researchers to rate pain during movement when people with dementia remained seated (or asleep). Difficulties on the EQ-5D-5L appeared to reflect the difficulties experienced by some people with dementia in understanding and grasping the task. Given the large number of missing data on the SWC-EOLD, completion rates for individual items were reviewed. This suggested particular difficulties with two items (questions 4 and 10; see *Appendix 4*, *Table 34*, for details). The finding that completion of this measure improved at the post-death interview (see *Appendix 4*, *Table 35*) may suggest that the items are more relevant at the EOL, although interpretation is difficult because numbers are small. The validity of the SWC-EOLD was disputed by key informants who commented that they were unlikely to criticise their own care; this may contribute to the large numbers of missing data.

Detailed scores for numeric outcome measures are tabulated by time point and intervention arm in *Appendix 4*, *Tables 40–61*.

Capturing data on advance care planning

Although the intention had been to collect data from both general practice and care home records at baseline, 12 months and post death to ascertain whether or not plans were filed in both places, only one set of records was routinely checked. Data were available for all people with dementia at baseline and for all but four individuals at follow-up, most commonly because they had withdrawn (see *Appendix 4*, *Table 38*). Further analyses indicated wide variation between practices in the proportion of people with dementia for whom plans were available in either general practice or care home records (see *Appendix 4*, *Table 39*).

Stakeholder view on outcome measures

A detailed analysis of the qualitative data relating to outcome measures, including quotations from participants, is provided in *Appendix 4*, *Feasibility and acceptability of outcome measures*. In summary, all participants thought that the set of measures was acceptable. The relevance of some measures was questioned, for example whether or not the End of Life in Dementia (EOLD) measures were appropriate for recently diagnosed people with dementia, and whether or not rating satisfaction with care was appropriate for care home staff. Concerns were raised over the reliability of some measures; in particular, some family carers and key informants queried the responses of the person with dementia to the EQ-5D-5L. Some measures [e.g. Neuropsychiatric Inventory (NPI), Comfort Assessment in Dying with Dementia (CAD-EOLD)] were potentially distressing for family carers, either because they raised awareness of the range of symptoms that might occur in the future or because they highlighted discrepancies between desired and actual care. A number of potential modifications to the resource use questionnaire were identified to reduce respondent burden.

Key implications for a future trial of the SEED intervention

Recruitment to a future trial

Given the high proportion (82%) of patients on the dementia register who were eligible, the rationale for excluding the remainder was questioned. Broadening the eligibility criteria would ensure equitable provision to all people with dementia. It would also streamline recruitment processes. A range of practical barriers to recruitment were identified. One successful strategy used in the pilot trial was to pay for a locum to free up GP time for screening; although the screening process may be less onerous in a future trial (if the eligibility criteria change), this strategy should still be considered. The acceptability of an opt-out approach was demonstrated for this patient group. Training other practice staff to make the follow-up telephone calls could also reduce the burden on GPs. The lack of information routinely recorded on next of kin created additional work and caused delays in recruitment. Working with practices prior to recruitment to improve recording of next of kin is recommended in a future trial. The pilot trial demonstrated the importance of close, formal monitoring of recruitment processes, and this should be planned from the outset. Detailed recommendations for maximising recruitment to a future trial are provided in *Appendix 4*, *Table 23*.

Changing the eligibility criteria would, however, have implications for the intervention that was developed rigorously using extensive data from WS2 and the previous experience of the MCDP to improve EOLC. Additional components are likely to be relevant at other stages of the illness trajectory and further work would be needed to identify these and to consider how best to address them if the intervention were to be extended to cover the entire dementia trajectory.

Implementation of the SEED intervention in a future trial

Basing the intervention in general practices was successful, but more explicit negotiation about the required level of engagement from GPs and practice staff is needed. Intervention supervision facilitated an ongoing dialogue about the boundaries of the intervention, how to operationalise the seven key components and opportunities for making strategic changes. It is, therefore, recommended that similar arrangements are made in a future trial. Although we did not succeed in establishing a MDT to support the DNSs, the clinical supervision from old-age psychiatry and palliative care met their needs.

Data from the pilot trial could be used to further refine the intervention manual and resources (e.g. by providing examples of the range of activities). This should enable DNSs in a future trial to feel clearer and more confident about their new role. Assessing the fidelity of a complex, tailored intervention was inevitably challenging. Involving the DNSs in the development of activity analysis tools and iteratively monitoring and refining their use is recommended in a future trial. Despite clear areas of overlap with existing services, particularly Admiral nurses, most stakeholders saw this as a benefit, rather than a problem. Each intervention practice was allocated a full-time DNS in the pilot trial; alternative, less costly, ways of providing the intervention should be explored.

Outcomes for a future trial

Many of the outcome measures appeared to work well in the pilot trial in terms of acceptability to participants and completion rates. However, we did not clearly identify an appropriate primary outcome measure for a future trial, particularly if the intervention was extended to include the full illness trajectory. Despite the previous validation and successful use of the SWC-EOLD in the USA[138] and the UK,[64,119,143] it was poorly completed and criticised by respondents and researchers in this study. Identifying measures that focus on well-being, not just deficits, is also recommended because the intervention may foster a positive sense of well-being.

We demonstrated the feasibility of collecting data on resource use and health-related QoL. Given the relatively large numbers of missing data on the EQ-5D-5L for people with dementia, collecting proxy data at all times is recommended in a future trial. People with dementia may also find the EuroQol-5 Dimensions, three-level version (EQ-5D-3L), easier to complete. Further investigation of how to prioritise or combine data from proxy respondents is needed. A number of recommendations for modifying the resource use questionnaire were made to reduce respondent burden. Data on ACP were successfully captured and suggest that the percentage change in documentation in practices may be a more appropriate way of analysing data in a future study. Although we focused on whether a range of plans was present or absent from the notes, content analysis of such plans may provide a more nuanced approach. Given the emphasis on staff training, the inclusion of measures of staff knowledge, skill and confidence could be considered in a future trial.

Workstream 4 conclusions

The pilot trial achieved the key success criteria of recruiting at least 11 people with dementia per practice, collecting outcome data for at least 33 people with dementia at 12 months, and demonstrating the feasibility and acceptability of the SEED intervention. The data and insights from the pilot trial will enable us to revise intervention materials and provide more practical guidance on future implementation. Extending the intervention to all people with dementia was widely recommended by stakeholders and could offer one model for providing the named care co-ordinator recommended by NICE.[29] The feasibility of collecting outcome data on ACP and resource use was demonstrated, although further adaptations to data collection are recommended. None of the outcome measures used, however, was found to be suitable as the primary outcome measure for a future trial.

Reflections on workstream 4

In the pilot trial, we allocated one DNS to each intervention practice; this is unlikely to be sustainable. Alternative ways of delivering the intervention by using teams with a range of qualifications and experience (including dementia advisors) across a number of practices may be more cost-effective. However, this would need to be managed in a way that facilitates relationship-building in the host general practice, with individual people with dementia and family carers, and with local care homes.

Key limitations related to recruitment processes and the difficulties in identifying a primary outcome measure. Lack of support for recruitment meant that only a small proportion of eligible people with dementia were approached in control practices, highlighting the need to adequately resource recruitment in a future trial. Further work is needed to identify appropriate outcome measures to capture the impacts of the intervention on people with dementia and family carers, with consideration also given to evaluating the impact of the SEED intervention on care home staff. In the light of the remaining uncertainties over eligibility and outcome measures, we do not intend to proceed to a definitive trial of the SEED intervention at this stage.

Workstream 5: economic modelling study

Further details on the economic modelling study are provided in *Appendices 5* and *6*.

Overview

As health and social care resources are limited, decision-makers need information about whether or not the benefits an intervention provides are worth its costs.[144] This information can be provided by an economic evaluation. An economic evaluation involves the comparative analysis of alternative courses of action in terms of both costs and effects.[145] In this section, we compare the SEED intervention, in which a DNS based in a general practice focuses their efforts on seven key components of EOLC, with alternative ways of providing care, including an example of current practice. The potential value of the SEED intervention was assessed using a contingent valuation survey of 1002 members of the general public. These data were used in an economic decision model. The economic model describes what happens to a person who has been diagnosed with dementia over time and how the SEED intervention might change this. Findings are presented in terms of costs and consequences (e.g. hospitalisations) and, using the contingent valuation data, a cost–benefit analysis. We found that the general population perceived the SEED intervention as having real value in economic terms. This was particularly the case for individuals with some experience of dementia in their close family members, colleagues or relatives, and by those with higher income levels.

Research aim

The aim of WS5 was to estimate the relative efficiency of the SEED intervention. WS5 was conducted between October 2013 and May 2018. The specific objectives were to:

- value the consequences of the SEED intervention using contingent valuation methods
- develop an economic model of the usual care pathway and new alternative pathways, including the SEED intervention developed in WS3
- conduct a cost–consequence analysis of the SEED intervention compared with usual care
- conduct a cost–benefit analysis of the SEED intervention compared with usual care by incorporating the results of the contingent valuation into the economic model.

Work relating to the first objective is described in the following section; the remaining objectives are addressed collectively in *Economic evaluation of the SEED intervention*. The economic evaluation was conducted following best-practice guidelines conforming to the Consolidated Health Economic Evaluation Reporting Standards (CHEERS).[146]

Valuing the consequences of the SEED intervention

See *Appendix 5*, *Valuing the consequences of the SEED intervention*, for supplementary data. This work has been published as Bhattarai *et al.*[147] (see *Acknowledgements*, *Publications*).

Measures typically used in economic evaluations to quantify the benefits of interventions, such as quality-adjusted life-years (QALYs), may not adequately capture individual preferences for how services are organised and their associated outcomes. An alternative approach to determine the benefits that an individual derives from an intervention is to determine their maximum WTP for it using a contingent valuation study. Maximum WTP represents the maximum amount, expressed in monetary terms or in terms of other goods, an individual is willing to give up (or sacrifice) to gain the benefits of the intervention.[148]

Methods

Five scenarios were developed that described different combinations of the seven key components to support good EOLC identified from WS2. These five scenarios mirrored the comparators used in the economic model. The contingent valuation survey took a community perspective, with respondents asked to give their WTP for the SEED intervention to be available in the NHS, even though they would not (necessarily) benefit from it themselves. Given this perspective, respondents were asked their WTP in the form of an additional tax per month that they would pay for the next 10 years. The survey comprised three sections: background information on current provision of dementia care towards the EOL and on the SEED intervention, the WTP questions and the participant demographics (see *Report Supplementary Material 1*). The survey was pre-piloted with Newcastle University staff using the 'think-aloud' technique.[149] Piloting of the full web survey was conducted in a subsample of the target general population. For the pilot and final surveys, the sample of the general population was recruited from the online panel managed by a marketing company (ResearchNow, London, UK). For the main survey, a sample of 1000 respondents was targeted, with quotas on age, gender and employment status to be representative of the UK general population.

Key findings

Data were collected from 1002 members of the general public (see *Appendix 5*, *Valuing the consequences of the SEED intervention* for details of the sample). *Table 7* reports the mean and median WTP values across the scenarios for both the untrimmed and the trimmed data sets. The trimmed data set excluded the top 1% of responses. The mean WTP computed from the untrimmed data set for the alternative scenarios was much higher than the mean WTP value for the main scenario, and the very wide 95% confidence intervals (CIs) indicate the presence of very high outlier values. When the top 1% of WTP values were trimmed,[150] the mean WTP for the main scenario was higher than for the alternatives and the CIs were narrower. The medians for both the trimmed and the untrimmed data sets generally remained the same. The number of zero responses per scenario ranged from 19% to 35% of the total sample, of which 10–13% could be classified as protest zeros, that is respondents indicated that they were not willing to pay because they believe that should not have to pay for health care. The protest zero responses were removed from the analysis of mean/median WTP.

Compared with individuals with no experience of dementia, individuals who have seen their close family members, friends or relatives with dementia placed a higher value on the tailored support provided by the DNS and the provision of high-quality EOLC to people with dementia (see *Appendix 5*, *Table 65*). Respondent characteristics, such as age, gender, household size or health utility score, did not influence the WTP value (see *Appendix 5*, *Table 66*). However, some higher-income groups had

TABLE 7 Mean and median WTP (Great British pounds, 2018 values)

		Alternative			
WTP	**Main**	**1**	**2**	**3**	**4**
Mean (95% CI)	40.13 (26.25 to 54.01)	2357.20 (23 to 14,006)	257.47 (28 to 1391)	810.22 (27 to 4700)	2313.69 (22 to 13,750)
Mean (95% CI)[a]	24.19 (21.85 to 26.52)	18.38 (15.95 to 20.82)	16.18 (13.59 to 18.76)	18.36 (15.72 to 21.00)	16.99 (14.15 to 19.83)
Median (95% CI)	10.0 (10.0 to 15.0)	10.0 (7.5 to 10.0)	7.5 (5.0 to 8.0)	9.25 (7.5 to 10.0)	6.0 (5.0 to 9.0)
Median (95% CI)[a]	10.0 (10.0 to 12.5)	10.0 (7.5 to 10.0)	7.5 (5.0 to 8.0)	8.0 (7.5 to 10.0)	6.0 (5.0 to 8.0)

CI, confidence interval.
a Top 1% of WTP values removed; figures expressed are additional monthly taxation over a 10-year period.

WTP values that were significantly higher than the WTP values of those on the lowest income level, which is consistent with economic theory. These findings suggest that members of the general public do value the care provided by the SEED intervention. Moreover, a higher WTP value for the main scenario indicated that it was valued more than packages with selected features only.

Economic evaluation of the SEED intervention

See *Appendix 5*, *Economic evaluation of the SEED intervention*, and *Appendix 6*, *Economic modelling study (workstream 5): additional explanatory text*, for supplementary data.

The economic evaluation aimed to estimate the potential relative efficiency of the SEED intervention. As the way in which this intervention will be implemented is not, as yet, precisely known, an early economic model was developed.[151] In such models, plausible ranges for model parameters are specified and the impact on cost–benefit outcomes of varying these model parameters over these plausible ranges is estimated. A cost–consequences analysis was designed in which multiple health and non-health consequences were estimated separately.[152,153] A cost–benefit analysis was then conducted, incorporating the results of the contingent valuation into the economic model, and valuing the benefits of the intervention collectively in commensurate units (money).[145]

Methods

A decision-analytic model was developed to estimate the impact of the SEED intervention activities on relevant service outputs and related outcomes for people with dementia (see *Appendix 5*, *Economic evaluation of the SEED intervention*), as well as health and societal costs. We modelled the main elements of a patient's journey through care, as well as how dementia may progress over time. The literature was reviewed for economic evaluations to inform the model structure (see *Appendix 5*, *Economic evaluation of the SEED intervention*). In the model, care and health events occur based on probabilities derived from different sources. Following the diagnosis, dementia progresses in three severity domains (see *Appendix 5*, *Event probabilities*, and *Appendix 6*, *Dementia progression*). The setting of care for an individual may change between home, care home and hospital (see *Appendix 5*, *Event probabilities*, and *Appendix 6*, *Transition probabilities between care settings*). An individual eventually requires palliative care, and there is a risk of death at any stage of the model (see *Appendix 6*, *Mortality and palliative care*). The likelihood of care and health events were influenced by patient characteristics (see *Appendix 6*, *Baseline population*) and by the prevalence of specific dementia care services (see *Appendix 6*, *Care services and their effects*). Finally, costs were assigned to the SEED intervention, the care settings and the care services (see *Appendix 6*, *People with dementia: care-setting costs*).

The cost–consequence analysis compared the presence of the SEED intervention with usual care. The effect of the SEED intervention on service outputs and related outcomes for people with dementia is unknown. Therefore, a set of scenarios was designed to estimate the relative impact of all activities combined and each activity individually:

- the maximum and minimum expected provision of all activities are set in a favourable and conservative SEED scenario, respectively
- the minimum and maximum expected provision of each activity was set, while the remaining four activities were set at the average level of provision.

In the cost–benefit analysis, the net monetary benefit of providing a SEED intervention over an illustrative 5-year period was estimated for each of the scenarios described in *Appendix 5*, *Valuing the consequences of the SEED intervention*, compared with a scenario in which these services are absent. The net monetary benefit is the difference between the WTP for the services and the additional costs associated with the services.

Key findings

Cost–consequence analysis

The SEED intervention had, on average, the following effects: reduced rates of hospitalisation; reduced length of hospital stay; increased number discharged from hospital to usual place of care; and increased access to, and duration of, palliative care (*Table 8*). However, the health-care and social care costs increased. The 95% CIs indicate some uncertainty in the direction of the effect for all outcomes, except for duration of palliative care and number of hospitalisations avoided.

The SEED conservative scenario is, on average, less costly than the SEED favourable scenario because the expected provision of the SEED intervention activities is not as great in the conservative scenario.

Cost–benefit analysis

The cost–benefit analysis compared the different variants of the SEED intervention, described in *Appendix 5*, *Valuing the consequences of the SEED intervention* (main scenario and alternative scenarios 1–4; see *Boxes 7–11*). Every WTP scenario is associated with a positive net benefit (column D in *Table 9*). Scenarios in *Table 9* are ordered from lowest to highest net benefits. The main scenario, which incorporates all of the activities of the SEED intervention, has the greatest net benefit; alternative 4 has the lowest net benefit. These net benefits are all relative to the provision of usual care, showing that it would be efficient to provide the SEED intervention. Column F in *Table 9* shows the probability that each scenario provides the greatest net benefit. The main scenario has the highest probability of being the most cost-effective (30%). However, no scenario clearly stands out because of the considerable uncertainty in the cost and WTP estimates.

The results of the cost–consequence analysis suggest that the SEED intervention is likely to increase costs, overall, related to changes in the care services. These services are expected to benefit people with dementia and family carers. These findings are reinforced by the cost–benefit analysis, which suggests that the value of the benefits of the SEED intervention is likely to be greater than the increased cost of care services. The results are imprecise (the CIs are wide) because they are based on an early economic model; further research is needed to obtain more evidence for the model inputs, particularly of the effects of SEED intervention activities.

Workstream 5 conclusions

This WS describes several innovative economic evaluations, namely the first contingent valuation of a specialist dementia service, the first detailed economic model for a non-pharmacological intervention in dementia from diagnosis to EOL and the first economic evaluation model that incorporates the results of a contingent valuation into a probabilistic economic model. Its methodology, as a minimum, meets internationally accepted best-practice recommendations for contingent valuation, economic evaluation and economic modelling.[154]

A key finding is that the SEED intervention is perceived by the general population as having real value in economic terms, in particular by individuals with some experience of dementia in their close family members, colleagues or relatives and by those with higher income levels.

Despite being highly valued by the general public, the SEED intervention is unlikely to reduce costs, but it may change service use in ways that benefit people with dementia and their families. These changes may relieve pressure on some NHS services (e.g. hospital beds), but may increase demand on other NHS services that are overstretched (e.g. palliative care services).

TABLE 8 Mean estimates and 95% CIs of the difference between the favourable and conservative interventions, compared with usual practice

		Mean estimate[a] (95% CI)				
Scenario	**Estimate**	**Cost (£)**	**Length of stay (days)**	**Time in palliative care (months)**	**Discharge to usual place of care (per 1000 discharges)**	**Avoided hospitalisations (per 1000 possible hospitalisations)**
Favourable SEED scenario		9930 (–3174 to 23,553)	–1.4 (–2.8 to 0)	1.91 (1.07 to 2.86)	25 (–31 to 75)	161 (119 to 201)
Conservative SEED scenario		2007 (–10,701 to 14,189)	–1.3 (–2.8 to 0.1)	0.46 (0.09 to 0.9)	0 (–50 to 44)	81 (57 to 109)
Reviews	Minimum	5833 (–7946 to 18,342)	–1.35 (–2.8 to –0.1)	1.17 (0.52 to 1.91)	13 (–38 to 61)	120 (82 to 164)
	Maximum	6669 (–6512 to 19,907)	–1.36 (–2.7 to 0)	1.87 (0.99 to 2.94)	13 (–40 to 63)	121 (84 to 165)
ACP	Minimum	4590 (–8362 to 17,295)	–1.32 (–2.8 to 0)	1.83 (0.96 to 2.95)	3 (–47 to 51)	103 (73 to 136)
	Maximum	8481 (–4339 to 21,854)	–1.33 (–2.8 to 0)	1.84 (1.01 to 2.97)	22 (–30 to 73)	138 (99 to 180)
SBAR technique	Minimum	6067 (–6552 to 19,160)	–1.3 (–2.8 to 0)	1.85 (1.01 to 2.96)	13 (–39 to 61)	106 (72 to 142)
	Maximum	7202 (–6176 to 19,945)	–1.32 (–2.8 to 0)	1.89 (1.04 to 3)	13 (–39 to 64)	135 (96 to 177)
Transfer sheets	Minimum	6553 (–6392 to 19,493)	–1.35 (–2.8 to 0)	1.85 (0.99 to 2.93)	13 (–42 to 65)	121 (84 to 164)
	Maximum	6586 (–6222 to 19,496)	–1.43 (–3.1 to 0)	1.87 (0.98 to 2.97)	13 (–42 to 65)	121 (84 to 164)
Discharge planning	Minimum	6475 (–6102 to 19,756)	–1.32 (–2.9 to 0)	1.87 (0.96 to 2.98)	7 (–48 to 57)	121 (84 to 164)
	Maximum	6788 (–5321 to 20,159)	–1.32 (–2.9 to 0)	1.87 (1.01 to 2.94)	13 (–42 to 66)	121 (84 to 166)

SBAR, situation, background, assessment, recommendation.

[a] Mean incremental outcome compared with usual care.

TABLE 9 The WTP scenario net benefit results (values in £000,000)

Scenario	(A) Mean cost (95% CI)	(B) Mean incremental cost compared with usual care (95% CI)	(C) Mean incremental monetary benefit (95% CI)	(D) Net benefit (95% CI) (C – B)	(E) Incremental net benefit	(F) Probability of being the optimal strategy (%)
Alternative 4	58,999 (53,295 to 63,153)	–30 (–1048 to 968)	8263 (280 to 31,629)	8293 (–63 to 31,602)	8293	10
Alternative 1	58,587 (53,408 to 62,750)	–443 (–1675 to 466)	8372 (732 to 27,407)	8815 (960 to 28,164)	522	16
Alternative 2	54,455 (49,578 to 58,434)	–4574 (–10,556 to 1332)	7221 (432 to 28,743)	11,795 (1458 to 33,186)	2980	19
Alternative 3	54,593 (50,090 to 58,446)	–4437 (–10,622 to 2267)	8832 (426 to 34,220)	13,269 (976 to 38,614)	1474	24
Main scenario	53,841 (49,931 to 57,118)	–5188 (–10,471 to 931)	11,313 (491 to 43,849)	16,501 (2994 to 49,612)	3232	30

Reflections on workstream 5

The results of the contingent valuation study are based on a large sample thought to represent the UK general population, but the validity of the responses could have been affected by biases arising out of the construction of the WTP survey or by the interpretation and understanding of the scenarios by the respondents. Using the internet survey panels could have introduced bias by failing to include major consumers of health-care services who are not internet users.

The economic analyses are based on an early economic model; therefore, there is considerable uncertainty surrounding both the model inputs and the underlying structure of the model. The effects of this uncertainty are that estimates for model outputs may be imprecise (i.e. CIs are wide) and important costs and benefits may not be accurately captured. Nevertheless, rigorous approaches were taken to use the best evidence available to ensure that the model captured key aspects.

The economic evaluation allowed us to explore the contribution of each component of the SEED intervention to relative efficiency. The reliability of these estimates is directly related to the trustworthiness of the structural assumptions of the model. The individual components of the SEED intervention do not change outcomes in an additive way; rather there appear to be diminishing returns from adding each component. This phenomenon has been observed in many studies investigating complex multicomponent interventions.[155,156] However, the precise nature of correlation between components is unclear. Should new data and understanding become available, consideration should be given to refining the model and the data inputs. Further details of data reported here are presented in *Appendices 5* and *6*.

Workstream 6: commissioning good-quality, community-based end-of-life care in dementia

Overview

Specific evidence-based guidance to inform the commissioning of co-ordinated EOLC for people with dementia is limited;[51] WS6 aimed to develop and disseminate evidence-based guidance for the commissioning of better-quality EOLC in dementia. Initially, a narrative review was undertaken to better understand the organisation of commissioning in dementia and EOLC; this found considerable gaps in the existing guidance.[157] The review was complemented by in-depth interviews with commissioners, which revealed an experiential picture different from the ideal commissioning scenario outlined in policy.[157] In 2015, NICE announced an update of national dementia care guidance. As this would include EOLC, specific SEED guidance development was postponed; instead, additional interviews and an updated review were performed while awaiting release of the revised guidance. Updated NICE guidance (2018) showed little new evidence underlying EOLC, but recommended the provision of a 'single named health or social care co-ordinator' [reproduced with permission from NICE.[158] © NICE 2018 *Resource Impact Report: Dementia: Assessment, Management and Support for People Living with Dementia and their Carers (NG97)*. Available from www.nice.org.uk/guidance/ng97/resources/resource-impact-report-pdf-4897901485. All rights reserved. Subject to Notice of rights] from point of diagnosis to death.[158] The SEED intervention has been proposed to commissioners as a potential method for implementing the nationally recommended care co-ordinator role.

Patient and public involvement

Contributors advised the team whether to pause or amend planned work owing to the revision of the NICE guidelines. They also contributed ideas for the dissemination event.

Research aims

- To summarise how EOLC for people with dementia was commissioned and organised.
- To produce guidance that summarises the evidence, and case for change, to commission good-quality, community-based EOLC in dementia.
- To facilitate national dissemination of this guidance.

Workstream 6 was conducted between October 2014 and September 2018.

Commissioning end-of-life care in dementia: mapping the status quo

This study has been published as Gotts *et al.*[157] (see *Acknowledgements*, *Publications*).

Methods

A mixed-methods approach was used, combining a narrative review and qualitative interviews with commissioners of EOLC for people with dementia. The former examined current guidance and policy (national and international) and academic literature with initial web-based searches in January 2014, repeated in January 2016. Academic papers were included if they focused on commissioners' experiences of the commissioning process, service providers' experiences of the commissioning process or factors that enable or inhibit the commissioning process, or if they compared commissioning arrangements. Using review findings, a semistructured topic guide was developed (see *Report Supplementary Material 1*). Interviews with professionals responsible for commissioning EOLC for people living with dementia ($n = 20$) took place between October 2014 and January 2016. All interviews were audio-recorded and transcribed verbatim, then checked and anonymised prior to analysis.

Policy and guidance documents included in the narrative review were categorised as follows:

- guidance (a guide to commissioning or clinical practice)
- policy (documents concerned with aspirations and aims issued by the Department of Health and Social Care, NHS England and other government agencies)
- strategy (e.g. national EOLC strategy)
- non-governmental organisation position papers (e.g. Alzheimer's Society, Nuffield Trust and The King's Fund).

Findings from the academic literature were summarised and grouped thematically. Interview transcripts were analysed using a thematic approach.[101]

Key findings

The review found major gaps in commissioning guidance for EOLC, specifically for people with dementia. Findings from the academic literature mainly focused on commissioning at a general level, with little on condition-specific commissioning for EOLC. Three key themes emerged from the triangulated findings of the narrative review and first round of commissioner interviews:[157]

1. the importance of joint commissioning
2. a lack of clarity in commissioning processes
3. facilitators of and barriers to commissioning.

Commissioners faced several challenges, not least a constantly changing policy landscape. Broader policy change, for example the introduction of sustainability and transformation plans and constantly changing commissioning structures, led to commissioners working in a context of persistent uncertainty. In exploring health professionals' perceptions of the commissioning process, uncertainty emerged as an overarching theme. In terms of expertise, commissioners need succinct evidence summaries, knowledge of local resources and an understanding of how health-care organisations function at a national level. New guidance could focus on assisting commissioners to address day-to-day practical problems and contain concise evidence to inform activities such as contract specification (a structured description of what the commissioning organisation requires from a provider).

The narrative review was updated with new searches conducted between February and June 2017 using the same search strategy and search terms as the original review. Only studies published since 2015 were considered for inclusion. Fifteen potentially relevant articles were retrieved, of which eight met the inclusion criteria. Three studies explored dementia and EOLC,[159–161] with the other five focused on general commissioning of health services.[30,162–165] A summary of the studies included in the updated narrative review is provided in *Appendix 7*, *Table 95*. Key findings revealed increasing complexity and persistent lack of clarity in processes, particularly in three areas: the role of the GP, contracting models and the commissioning of palliative care and EOLC in general.

Clinical Commissioning Groups and the role of the general practitioner

Clinical Commissioning Groups are very complex, varying both in size (population coverage ranges from 90,000 to 855,000) and organisation.[166] There was a lack of clarity as to how other health-care organisations and governance structures related to CCGs and whether or not any formal relationships had been established. In this new commissioning environment, the role of the GP was complicated; GPs held various and diverse roles (e.g. account officers and CCG lead) in addition to their clinical provider role.

Contracting models and care integration

The contracting models used by CCGs varied, for example (1) a prime provider model whereby one prime provider undertakes responsibility for parts, or all, of care agreed, (2) a prime contractor model whereby an organisation manages other providers that directly provide care services and (3) an alliance contracts model whereby separate providers share responsibility. The main aim of the contractual frameworks was, ultimately, to attain greater care integration, but it was unclear how the different models were successfully operationalised in practice.

Commissioning of palliative and end-of-life care in general

Often service provision was not consistent with population need, with great variability in the funding provided from local authorities; this was particularly so for palliative care services. In terms of dementia, there was an imbalance in service commissioning, with the main focus of resource allocation dedicated to early diagnosis and intervention (i.e. memory clinics) and early disease management (i.e. day care services), rather than care at the EOL.[160,161] Moreover, some commissioners do not have an in-depth understanding of the needs of people with advanced dementia, expressing uncertainty as to whether or not people with dementia need EOLC provision that is different from that for other patients.[161]

Follow-up interviews

Further commissioner interviews ($n = 7$) were conducted between January and August 2017, to explore any subsequent changes to commissioning processes and information needs. There were a number of parallels with the thematic analysis conducted for the first round of interviews. A theme of continuous organisational change with persistent lack of clarity in processes prevailed.

Organisation of commissioning

Participants commented on the continued re-organisation of commissioning services alongside complex top-heavy commissioning structures and new initiatives (such as sustainability and transformation plans), which created additional upheaval. There was also a lack of clarity around commissioning processes and where responsibility lay for commissioning. Notwithstanding a new proposed local organisational structure, an Accountable Care Organisation was considered an opportunity for more efficient, integrated working.

End-of-life care and dementia: lack of integrated guidance

Some progress has occurred regarding integrated EOLC in dementia, but, generally, systems remained separate. For example, it was highlighted that the EOL guidelines do not include dementia, and dementia commissioning guidelines do not include the EOL.

Specification as an emerging art form

Participants still considered specification, a structured description of what the commissioning organisation requires from the service provider, a useful tool. However, this too was a constantly changing process to adapt to a shifting political and organisational landscape. It did, however, provide an opportunity to clearly define the detail of service provision, and its evidence base, and to incorporate performance measurement.

Evidence-based guidance for commissioners: comparison of the updated National Institute for Health and Care Excellence guideline with the SEED intervention findings

Further details are provided in *Appendix 7*.

Methods

Following a decision to suspend the development of SEED specific guidance in view of the updated NICE guidance in dementia care, the new 2018 guidance, once published, was scrutinised to identify new recommendations and/or changes in guidance specific to EOLC in dementia, for example care planning, review and co-ordination, and involving people with dementia in decisions about their care. Sections of the original[32] and updated[29] clinical guideline were extracted and entered into a structured data table. The content along with the strength and quality of the evidence underpinning the recommendations was compared.

Key findings

Although very similar in terms of the recommendations for practice, the evidence base underpinning the 2018 NICE recommendations had strengthened considerably, owing to an increase in both the quantity and the quality of available research. The one exception to this was for palliative care and EOLC, for which there was still limited empirical research. Three key components were relevant to improving EOLC in dementia; these are outlined below.

Involving people with dementia in decisions about their care

In terms of involving people with dementia in decisions about their care, 13 recommendations are made, which are grouped into three themes: providing information, ACP and involving people in decision-making. There is a clear emphasis on providing ongoing opportunities throughout the illness trajectory to discuss and make advance decisions. Both the person with dementia and the staff should be supported to engage in discussions about future care preferences.

Care planning

In terms of care planning, six recommendations are made, with a core emphasis on the provision of a single named health-care or social care professional who is responsible for co-ordinating the care of a person with dementia from diagnosis to the EOL. Guidance is also provided about the roles and responsibilities of the care co-ordinator role in practice, and the involvement of the person with dementia in care planning.

Palliative care

For the delivery of palliative care, the 2018 dementia recommendations[29] refer the user to the NICE guidelines on (1) palliative care[15] and (2) care of adults in their last days of life.[14] The emphasis is on a person-centred approach that includes the use of anticipatory health-care planning, ACP and structured observational tools.

Comparison with the SEED intervention findings

Table 10 shows how the seven SEED components, identified as essential to the delivery of good EOLC for people with dementia, closely align with several elements of the NICE recommendations[29] (e.g. providing ongoing opportunities throughout the illness trajectory, use of a person-centred approach, co-ordination of care). To '[p]rovide people living with dementia with a single named health or social care professional who is responsible for co-ordinating their care' [reproduced with permission from NICE.[158] © NICE 2018 *Resource Impact Report: Dementia: Assessment, Management and Support for People Living with Dementia and their Carers (NG97)*. Available from www.nice.org.uk/guidance/ng97/resources/resource-impact-report-pdf-4897901485. All rights reserved. Subject to Notice of rights] was one of three original (clinical guideline 42[32]) NICE recommendations that was identified as not having been fully implemented, and for which there was evidence of wide variation in practice.[158] The SEED intervention, developed with the seven factors at its core, provides a potential solution to the uptake of this recommendation.

Dissemination and refinement of guidance on end-of-life care in dementia

A series of local and national dissemination activities for commissioners and service providers was undertaken to publicise both the NICE 2018 dementia guidance specific to EOLC and the SEED intervention.

TABLE 10 Mapping of the SEED intervention components to updated NICE guidance[29]

SEED intervention component	NICE recommendation
Timely planning discussions	1.1 Involving people living with dementia in decisions about their care
Co-ordinating care	1.3 Care co-ordination
Working effectively with primary care	1.3 Care co-ordination
Managing hospitalisations	1.1 Involving people living with dementia in decisions about their care
	1.3 Care co-ordination
	1.10 Palliative care
Recognising EOL and providing supportive care	1.10 Palliative care
Continuing care after death	1.11 Supporting carers
Valuing staff and ongoing learning	1.13 Staff training and education

Local dissemination: North East Dementia Alliance presentation

Twelve members were in attendance at the North East Dementia Alliance presentation, representing a range of regional organisations, including hospice and care homes, charities, the NHS, local authorities and research. A further presentation was made to regional dementia leads in October 2019.

National workshop: commissioning for excellence in end-of-life care in dementia

A half-day interactive event was held in London (in December 2018), attended by 52 delegates (commissioners and providers of dementia services). The majority of delegates indicated that they were familiar with the 2018 NICE dementia guidance.[29] Commissioning care co-ordination through the dementia trajectory was very difficult. Dementia and EOLC are not joined up: there is no 'connectivity' between guidance for each area of care and there is 'not enough cross-talk' between the two specialties. No one has ultimate responsibility (accountability and authority) for the total dementia care pathway or for the joining up or integration of services. Rather than being a strategic process, commissioning appeared to be guided by personal interests and 'who knows who'. The DNS who was included in the SEED intervention as a named care co-ordinator would require expertise in palliative care and dementia. Concerns were raised that such a specialist role could lead to increased silo-working and duplication, and about whether or not such a new role (or person) was necessary. It would be important to look at the current system and existing resources to see whether or not a new role is needed. Delegates considered whether or not the SEED intervention should be a care pathway (from diagnosis to EOL), rather than a person. Generally, delegates concluded that there is an abundance of good, evidence-based guidance for both commissioners of dementia and EOLC, but what is missing is guidance that joins/integrates the two.

Workstream 6 conclusions

Service commissioners work in a context of persistent uncertainty, because a constantly changing policy landscape, with little national guidance or training regarding their role. Currently, dementia and EOLC are commissioned separately; a more integrated, joined-up commissioning approach is required. Updated 2018 NICE guidance[29] showed little new empirical evidence underlying EOLC recommendations; however, it recommends the provision of a 'single named health or social care professional' [reproduced with permission from NICE.[158] © NICE 2018 *Dementia: Assessment, Management and Support for People Living with Dementia and their Carers*. Available from www.nice.org.uk/guidance/ng97 All rights reserved. Subject to Notice of rights] responsible for co-ordinating care from diagnosis to EOL. The SEED intervention is a potential method for implementing this new role.

Reflections on workstream 6

The approach to participant sampling for the commissioner interviews was a mixture of purposive and convenience. We sought diversity in geographical area, urban/rural setting and between clinical organisations and adult services. However, the introduction of both new commissioning structures during the programme and new national service models for older people's care (e.g. vanguard sites[167]) led to difficulty in undertaking repeat interviews with first-round participants. Thus, the second-round participants included a mixture of repeat interviewees and new participants who were part of newly formed structures, such as vanguard site representatives.

Programme grants offer a unique opportunity to undertake health service research over a 5-year period. However, the biggest challenge to undertaking and completing such research was the constantly changing health-care and social care landscape at both local and national levels.

Overall conclusions

Updated national guidelines on dementia care[29] revealed that, although there has been a considerable increase in dementia research, there has been little UK-based empirical research to inform evidence-based practice in EOLC. Extending existing evidence and using new empirical data, we followed the MRC framework for complex interventions[73] to co-design and pilot a primary care-led DNS intervention to enable community-based professionals deliver co-ordinated, proactive EOLC to people with dementia and their families. The intervention was acceptable, feasible and shown to integrate well with existing care. The DNS role was highly valued by all stakeholders, both in real life and hypothetically in the contingent valuation study. Seven components of care were key to the DNS role: timely planning discussions, recognising EOL and providing supportive care, co-ordinating care, working effectively with primary care, managing hospitalisation, continuing care after death, and valuing staff and ongoing learning. The economic evaluation, cost–consequence analysis and cost–benefits analysis showed that the DNS intervention is unlikely to reduce costs; however, it was highly valued by all stakeholders.

National policy recommends that older people be cared for in their usual place of care. In addition, there has been a sustained shift of chronic illness management to primary care. Notwithstanding, nearly 40% of people with dementia in England still die in acute hospitals and very few die in their own homes.[61,62] In addition, a recent UK cohort study found that > 50% of participants with severe dementia in care homes had persistent pain and distressing agitation over a 9-month follow-up period,[63] that family stress increased as the dementia advanced[64,65] and that large numbers of people with dementia attended emergency departments in the last year of life.[66] This evidence suggests the need for an enhanced care model as dementia progresses that targets comfort and QoL for people with dementia,[43] proactive care planning, care co-ordination and carer support, to address these findings and ensure the provision of person-centred care throughout the illness from diagnosis to death.[29]

These findings and the proposed intervention are timely from multiple perspectives. First, the persistent lack of specific, integrated commissioning guidance for people living with dementia as they approach EOL.[15] Nationally, examples of local good practice were limited and usually reliant on enthusiastic service providers and short-term funding, thus leading to unacceptable inequalities in care. This is surprising considering the persistent evidence of suboptimal care, compared with the care provided to people with cancer.[12,31,44,48,54,63,168–170] Caring for people with advanced dementia is especially challenging, for both families and professional carers, because of a loss of both communication skills and mental capacity, which makes needs assessment and decision-making complex. Second, updated national dementia guidance recommends that all people with dementia have a named health-care/social care co-ordinator from the point of diagnosis to the time of death.[29] Finally, and perhaps most importantly, there is a rapidly increasing service demand: dementia is now the most common cause of death in women aged > 65 years[4,5,171] and the number of people with the illness is predicted to double in the next two decades.[172,173]

Comparison with national and international models of care

A recent national cohort study of people with advanced dementia showed that symptom management was still suboptimal, with high levels of pain and agitation.[63] However, even in European countries where national quality improvement policies for palliative care have been introduced, there is still a need for added intervention(s) to improve EOLC for people with dementia and older people in care homes.[174] National and international studies have demonstrated care deficiencies in many of the seven components of good practice that underpin our intervention, namely timely planning discussions,[175,176] co-ordinating care,[177] effective working with primary care,[178,179] recognising EOL and providing supportive care,[63,174,175,180] and educating and supporting families in areas of conflict and decision-making.[175,180–182] Recent reviews have also highlighted the need for studies that explore (1) how to best implement ACP in practice, via an ongoing process of communication with a trusted professional, and (2) the use of more informal proactive planning processes, rather than formal written documentation.[183,184] The DNS role has considerable potential in both of these areas. In addition, this is the first primary care-based intervention to specifically target both people with dementia living in their own homes and those living in care homes; most studies have focused only on care/nursing home settings.

Strengths and key challenges/limitations

In a complex and highly sensitive area of care for which there is very limited research to date, we have undertaken and successfully completed a number of innovative research 'firsts'. These are as follows:

- the development of an evidence-based primary care intervention, addressing key areas of need identified via new empirical research, and aimed at improving the quality of EOLC in dementia
- a successful pilot trial achieving predicted recruitment rates
- the completion of novel health economic evaluations, for example the first economic model for a non-pharmacological intervention that attempts to model disease progression from diagnosis to EOL in detail and that incorporates a contingent valuation study.[146,154]

Key methodological limitations have already been outlined and discussed in the individual WS sections. Ultimately, the biggest challenge to the successful delivery and completion of this programme was the translation of the theoretically co-developed intervention to real-world practice in a constantly changing policy and service organisational landscape at both national and local levels. Early in the programme, a well-established, but non-evidence-based, palliative care intervention, the LCP, was removed from practice as a consequence of a national investigation.[75] This led to confusion and greater variation in the definition of usual care. The introduction of new commissioning structures, especially in primary and community care, with a considerable and continuous period of change and reorganisation, led to difficulty identifying and recruiting participants (WSs 2 and 6) and delays in securing governance approvals. However, the most significant change that we could not have foreseen was an unplanned shift in the provision of post-diagnostic dementia services to primary care. Local memory clinics moved to a 'one-stop shop' diagnostic service, with loss of any specialist post-diagnostic follow-up for the majority of newly diagnosed patients. If such a shift is happening on a national basis, there is considerable potential for the DNS role to be available throughout the entire post-diagnostic dementia care pathway and/or fulfil the recent NICE-recommended care co-ordinator role.[29]

A further major limitation, especially for a future trial, is the lack of a valid and relevant primary outcome measure to evaluate the effectiveness of such complex interventions to improve care at EOL in dementia, which targets both patient- and system-level outcomes. Two of the potential future primary outcome measures performed well [Symptom Management at the End of Life in Dementia (SM-EOLD) and CAD-EOLD]; however, the SWC-EOLD measure, which was the proposed primary outcome measure for a future trial, was criticised by participants. A 2018 systematic review[177] confirmed the need for further research in this area. It evaluated the applicability and psychometric properties of 67 tools to measure (1) quality of care at the EOL and (2) quality of dying and death. No single tool was found to be adequate across all the properties assessed. However, for quality of care, two measures, the Care of the Dying Evaluation (CODE)[185] and the SWC-EOLD,[138] performed very well psychometrically, and, for quality of dying, two measures, Quality of Dying and Death[186] and Staff Perception of their patient's End of Life Experience (SPELE),[187] performed moderately well. Despite the SWC-EOLD performing well in their systematic review, the authors[177] concluded that it required further testing in different settings as its use to date had been limited to research studies in care home settings. The review noted that some of the newer and promising outcome measures, such as CODE and SPELE, included a comprehensive range of assessment criteria, for example environment, symptom management, communication and decision-making.[177] It may be that, for dementia care in general, new measures need to be developed that better reflect outcomes that are important to people with dementia and their families, in terms of evaluating the success of new interventions[188] or more accurately reflecting the symptom burden of dying with, or from, dementia, by incorporating both the symptoms of advanced dementia and general EOL symptoms and outcomes.[189,190] In addition, emerging research on effective quality indicators that measure practice performance and/or changes in the processes, outcomes and structure of community care systems may be more relevant.[191,192]

Future research recommendations and implications for practice

Based on these key findings, we do not plan to progress to a full randomised trial of the SEED intervention in its current form. In view of the introduction of updated NICE dementia guidance, and a steady and unplanned shift of post-diagnostic dementia care to primary care, the priorities for future research are to:

- Determine the feasibility of providing the SEED intervention throughout the illness trajectory, that is to all people with dementia from point of diagnosis to death, and if, and how, it would need to be adapted.
- Identify appropriate, and/or develop new, outcomes to evaluate the effectiveness of such a complex intervention in real-world settings, including (1) patient- and carer-relevant outcome measures and (2) quality indicators to assess/measure quality of care. When possible, the latter should focus on processes, outcomes and structure of care.

In addition, we also think that there is a need for further health economics-related research to:

- Refine estimates for the cost of the SEED intervention and of its consequences based on actual data from its implementation. Ideally, as its relative impact is not known, these data should come from a study with a strong study design.
- Cross-validate estimates of WTP from the public with those obtained from a sample of patients and carers to understand whether or not views and preferences for care differ substantially between these different groups.
- Revise WTP estimates based on the data obtained from any future rigorous evaluation (WTP for an intervention will depend on what respondents understand that intervention provides, and this should come from a more rigorous prospective evaluation).

Notwithstanding, in the absence of the proposed future research above, it would be worth exploring whether or not, from a commissioning and service provider perspective, specialist micro- and macro-simulation economic modelling techniques, as used in the Modelling Outcome and cost impacts of interventions for DEMentia (MODEM) programme,[193] could help inform translation of the SEED intervention into an efficient model for future practice. MODEM is using a suite of techniques to model the costs and outcomes of care from the point of diagnosis and how these can be influenced by particular interventions. It has already produced an online dementia guidance toolkit and is developing a legacy model for commissioners to use to inform service provision at a local level.[190] Such an approach may facilitate how the SEED intervention may be more efficiently implemented while containing costs but improving quality.

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Workstream 1

Amador S, Goodman C, Robinson L, Sampson EL. UK end-of-life care services in dementia, initiatives and sustainability: results of a national online survey. *BMJ Support Palliat Care* 2016;**8**:424–7.

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Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to available anonymised data may be granted following review.

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Appendix 1 Supplementary data relating to workstream 1: evidence synthesis

Existing end-of-life care guidance and models of care in dementia

Key WS1 deliverables were to provide a summary of existing recommendations in EOLC in dementia, and of the quality of the evidence base underpinning them, and to identify resource implications of existing pathways to inform subsequent modelling. This work builds on a 2015 systematic review,[77] which employed a methodology identical to that described in the SEED protocol to provide (1) a systematic review of current guidelines/pathways in dementia and (2) an assessment of the quality of guidelines/pathways using the AGREE instrument.[194]

Five dementia practice guidelines that scored ≥ 4 on the AGREE-II instrument address issues related to palliative care:

1. *Clinical Practice Guidelines and Care Pathways for People with Dementia Living in the Community*[79] (Queensland University of Technology, 2008)
2. guideline on supporting people with dementia and their carers in health and social care[80] [NICE–Social Care Institute for Excellence (SCIE), 2007]
3. *Guideline for Alzheimer's Disease Management*[81] (California Workgroup on Guidelines for Alzheimer's Disease Management, 2008)
4. Ministry of Health's *Dementia: MOH Clinical Practice Guidelines*[82] (Singapore, 2013)
5. Ministry of Health's *Clinical Practice Guidelines, Management of Dementia*, 2nd edition[83] (Malaysia, 2009).

To identify resource implications of existing pathways, we assessed the key components and content of guidelines/care pathways (i.e. setting, timing and content of each pathway, care model or guideline, who 'leads' it, staff/resource implications and how adherence and variance are documented), to begin cost estimation for WS5, in collaboration with WS5 lead Luke Vale.

Setting

Overall, guidelines recommend that people with dementia be managed, as far as possible, in the community. UK guidelines[80] do, however, recognise that admission to acute or general inpatient services/psychiatric admission may sometimes be required. Only Malaysian guidelines[83] recommend assessment and treatment in outpatient and inpatient, as well as community, settings.

Timing

Recommendations vary as to when palliative care for people with dementia should be introduced (*Table 11*). Only one set of guidelines (UK) does not make a clear recommendation as to the timing of palliative care. Both Australian[79] and Singaporean[82] guidelines tie the introduction of palliative care to the severity of dementia as assessed by the Functional Assessment Staging Tool (FAST),[195] in addition to specified dementia-related comorbidities. Californian[81] guidelines also recommend the introduction of palliative care when the person with dementia becomes eligible for hospice care (mortality predicted within 6 months). Finally, Malaysian[83] guidelines suggest that palliative care begins from the time of diagnosis to death.

Content

Guidelines are a mix of evidence- and consensus-based recommendations (note that Asian guideline recommendations are graded according to the strength of the evidence underpinning them, which may

TABLE 11 Summary of key recommendations from national guidance on EOLC in dementia

Clinical area	Queensland, Australia[79]	UK[80]	California, USA[81]	Singapore[82]	Malaysia[83]
Timing of palliative care	Prognosis of ≤ 6 months	Not specified	Not specified, although notes that hospice care requires a prognosis of mortality within 6 months	Provides severity indicators, which indicate that palliative approach should be considered	Palliative care begins at diagnosis and ends at death
Assessment of palliative stage and review	• Assessment of palliative care needs by primary care team • FAST can be used for staging in advanced dementia[195]	Primary care teams should ensure that the palliative care needs of people with dementia are assessed and communicated	• Assess, document and monitor changes in the need for palliative and/or EOLC • Reassessment should occur at least every 6 months and sudden changes in behaviour or increase in the rate of decline should trigger an urgent review by the PCP		
Palliative care approaches in dementia		Health and social care professionals should adopt a palliative approach			
Access to palliative care services		People with dementia who are dying should have the same access to palliative care services as people without dementia	Provide appropriate EOLC, including palliative care as needed		

Clinical area	Queensland, Australia[79]	UK[80]	California, USA[81]	Singapore[82]	Malaysia[83]
Hydration and nutrition	Artificial (tube-) feeding is not recommended	Health and social care staff should encourage people with dementia to eat and drink by mouth for as long as possible. Specialist assessment and advice concerning swallowing and feeding should be available. Nutritional support, including artificial (tube-) feeding should be considered if dysphagia is thought to be a transient phenomenon, but should not generally be used in people with severe dementia for whom dysphagia or disinclination to eat is a manifestation of disease severity		Decisions on tube-feeding should be individualised given the lack of evidence for its efficacy in advanced dementia	• It is important to individualise and balance the risk–benefit ratio of artificial nutrition and hydration • Alternative conservative measures, such as posturing, feeding technique and food thickener, should be considered
Management of fever and infection	Antibiotics for fever management	Following a clinical assessment, simple analgesics, antipyretics and mechanical means of cooling the person may suffice. Antibiotics may be considered as a palliative measure		Decisions on the use of antibiotics in advanced dementia should be individualised to the patient by weighing the risk and benefit of antibiotic treatment	The use of antibiotics for treatment of infections and pneumonia in severe and late-stage dementia should be individualised, taking into consideration the severity of dementia, comorbidity, nutritional status, mobility status and virility of the organism

continued

TABLE 11 Summary of key recommendations from national guidance on EOLC in dementia *(continued)*

Clinical area	**Queensland, Australia**[79]	**UK**[80]	**California, USA**[81]	**Singapore**[82]	**Malaysia**[83]
Pain management	• Health-care professionals need to be knowledgeable about pain assessment and management • The Abbey pain scale can be used for measuring pain[196]	• Unexplained changes in behaviour and/or signs of distress should prompt health and social care professionals to assess whether or not the person is in pain, using an observational pain-assessment tool • The treatment of pain in people with severe dementia should involve both pharmacological and non-pharmacological measures		• Patients with advanced dementia should be assessed for pain and treated accordingly • A stepped protocol is recommended for pharmacological management of pain in dementia (the WHO analgesic ladder[197] or the American Geriatric Society's pain guidelines[198] may be used)	• A high index of suspicion of the presence of pain and the use of pain assessment scales will be helpful to improve pain • Pain in dementia should be treated, the cause of pain determined and managed along the WHO analgesic ladder[197]
ACP, including decisions to resuscitate	• Advance care options should be discussed with carers • Where care outside the home is needed, staff should be aware of the wishes of the person with dementia	• Policies in hospitals and long-stay residential, nursing or continuing care units should reflect the fact that CPR is unlikely to succeed in people with severe dementia • If there is no advance decision to refuse resuscitation, the decision to resuscitate should take into account any expressed wishes or beliefs of the person with dementia, together with the views of the carers and the MDT	• Discuss a patient's need to make care choices at all stages of the disease through the use of advance directives and identification of surrogates for medical and legal decision-making • Discuss the intensity of care and other EOLC decisions with the patient and involved family members, while respecting their cultural preferences	ACP with regard to CPR should be encouraged, given the poor outcomes of CPR in advanced dementia	• Early consideration of advance statements and advance directives to refuse treatment should be planned while the person with dementia still has capacity • Health-care professionals should have more discussion about CPR and make individualised decisions after taking consideration of all factors
Assessment of carer needs (including support system, grief and loss)	• Family conferences with GP to discuss EOL issues • Assess carer need for psychological support with grief and loss	The right of carers to receive an assessment of their needs should be upheld by health and social care managers	Identify the primary caregiver and assess the adequacy of family and other health support systems, paying particular attention to the caregiver's own mental and physical health		

CPR, cardiopulmonary resuscitation; WHO, World Health Organization.

include workgroup consensus only). Guidelines outline anywhere between 5 and 11 recommendations, covering the following issues (see *Table 11*):

- assessment (including staging) and review
- palliative care approaches in dementia
- access to palliative care services and communication within and across services
- hydration and nutrition (including tube-feeding)
- management of fever and infection
- pain management
- ACP (including decisions to resuscitate)
- assessment of carers needs (including support system, grief and loss).

Two topics are not included in *Table 11*, as each appears in only a single guideline. Australian guidelines[79] include two recommendations on admission to residential care (when care outside the home is needed, staff should be aware of the wishes of the person with dementia; a carer may benefit from the help of health professionals in planning for residential care). Malaysian guidelines[83] cover the use of restraints (physical restraint should be used sparingly and should be individualised).

In addition, Australian[79] and Singaporean[82] guidelines provide context-specific contact information for local programmes, helplines and services termed 'practice tips' and 'community resources', respectively. Californian,[81] Malaysian[83] and Singaporean[82] guidelines provide copies of some of the assessment tools (e.g. functional and nutrition assessment), which are cited in the text. Finally, Australian[79] guidelines include three advanced phase pathways for care workers, allied health professionals and GPs.

Care lead/model

The model of care outlined by each set of recommendations has been identified and categorised using Luckett *et al.*'s[199] definitions of models of palliative care.

Both Singaporean[82] and Malaysian[83] guidelines appear to recommend a 'consultation model' approach to care, in as much as neither outlines mechanisms for collaboration between the health-care professionals involved. Luckett *et al.*[199] define a consultation model as:

> *An approach to care by which specialist advice is provided on assessment and treatment of symptoms, communication about goals of care and support for complex medical decision-making, provision of practical and psychosocial support, care coordination and continuity, and bereavement services when appropriate. Advice is provided without necessarily assuming primary responsibility for care, although there is negotiation of the level of palliative care involvement.*
>
> Luckett et al.[199] *This article is published under license to BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/2.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly credited. The Creative Commons Public Domain Dedication waiver (https://creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated*

UK[80] and Californian[81] guidelines recommend a 'case management model', led by care managers/co-ordinators and primary care practitioners. Luckett *et al.*[199] define a case management model as:

> *. . . a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's holistic needs through communication and available resources to promote quality cost effective outcomes. The definition of case management notes the focus upon the meeting of a client's health needs. Case management can be placed within a social model of health, within which improvement*

> *in health and well-being are achieved by directing efforts towards addressing the social and environmental determinants of health, in tandem with biological and medical factors.*
>
> Luckett et al.[199] *This article is published under license to BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/2.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly credited. The Creative Commons Public Domain Dedication waiver (https://creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated*

Finally, Australian[79] guidelines recommend a 'shared-care model' approach to palliative care involving GPs, allied health professionals/care managers and care workers. Luckett *et al.*[199] provide one definition of shared care as:

> *. . . an approach to care which uses the skills and knowledge of a range of health professionals who share joint responsibility in relation to an individual's care. This also implies monitoring and exchanging patient data and sharing skills and knowledge between disciplines.*
>
> Luckett et al.[199] *This article is published under license to BioMed Central Ltd. This is an Open Access article distributed under the terms of the Creative Commons Attribution License (https://creativecommons.org/licenses/by/2.0), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly credited. The Creative Commons Public Domain Dedication waiver (https://creativecommons.org/publicdomain/zero/1.0/) applies to the data made available in this article, unless otherwise stated*

Staffing/resourcing

Overall, guidelines outline the type of resourcing required, rather than the quantity of the resource use that is needed, for example how much of a care worker's time is required.

Clinical audit parameters/indicators for quality improvement

Only Singaporean[82] and Malaysian[83] guidelines have a set of indicators for quality improvement, although neither provides a set of indicators that is specific to the palliative care phase. Remaining guidelines either do not address clinical audit and/or quality improvement, or recommend that inspection standards be developed separately within a more broadly based implementation strategy (i.e. UK[80] guidance).

Appendix 2 Full texts of publications that are not open access

Amador *et al.*[84]

Reproduced from UK end-of-life care services in dementia, initiatives and sustainability: results of a national online survey. Amador S, Goodman C, Robinson L, Sampson EL. Vol. 8, pp. 424–7, 2016, with permission from BMJ Publishing Group Ltd.

Short report

UK end-of-life care services in dementia, initiatives and sustainability: results of a national online survey

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ABSTRACT

Background People living and dying with non-cancer diagnoses, including dementia, have poorer access to generalist and specialist palliative care than people with cancer, and experience worse outcomes in terms of pain and symptom control, and quality and experience of care. In the UK, the National Council for Palliative Care (NCPC) ran a national survey of services for end-of-life care for people with dementia (2008) in which 16 services were identified, and reported on case studies and examples of good practice. We updated the NCPC survey to review progress in previously identified services, identify factors that lead to sustainable services and identify new initiatives in this area of care.

Methods An online survey was developed and piloted before use. Initiatives were contacted via targeted (N=63) and open call invitations. The survey was made up of 5 sections. Quantitative data were analysed using descriptive statistics.

Results 15 services responded. They engaged in a wide range of activities predominately providing direct care (80%) and workforce development/advisory or educational activities (87%). Results suggest that sustainability of services is reliant on clinicians with a leadership role and wider system support through funding mechanisms and a minimum level of integration within normal service provision.

Conclusions Recent initiatives are largely built on the expertise of the nursing profession (with or without input from medical consultants), and driven mainly by the charity and hospice sector. This has generated a potential new model of care provision in end of life dementia care, 'Hospice-enabled Dementia Care'.

INTRODUCTION

People living and dying with non-cancer diagnoses, including dementia, have poorer access to generalist and specialist palliative care than people with cancer, and experience worse outcomes in terms of pain and symptom control, and quality and experience of care.[1] Barriers to providing end-of-life care for people with dementia include healthcare professionals' and families' awareness of the terminal nature of dementia and associated attitudes towards end-of-life treatment (eg, hospitalisation, tube feeding, resuscitation) and an uncertain illness trajectory[2 3] which makes it difficult to meet needs and plan care, potentially leading to inappropriate or reactive care. This is compounded by the negative impact of hospital admissions tied to lack of skills and resources in acute settings; lack of dementia-specific expertise among health and social care staff; lack of communication and coordination between care agencies, primary and secondary services, including out-of-hours services.[4 5]

Prior to the implementation of the English national dementia strategy in 2009 which made little mention of end-of-life care,[6] the National Council for Palliative Care (NCPC) ran a national survey of local practice in end-of-life care for people living and dying with dementia. Sixteen services were identified and reported on in a compendium of case studies and good practice examples.[7] The recent Prime Minister's challenge on dementia sets a strategic framework to deliver major quality improvements to dementia services, pledging that people with dementia and their carers receive co-ordinated, compassionate and person-centred care towards the end of life, including access to high-quality palliative

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care from health and social care staff trained in dementia and end of life.[8] As part of the Supporting Excellence in End of life care in Dementia (SEED) research programme (https://research.ncl.ac.uk/seed/) and in association with the NCPC, we updated the 2008 survey to review progress in previously identified services, identify factors affecting sustainability of services and identify new initiatives in this area of care.

METHODS

An online survey was developed using OPINIO (V.6.9), a web-based tool which provides a framework for authoring and distributing surveys. The survey was piloted with members of the SEED research group and ran from beginning of October 2014 to end of February 2015. The survey consisted of five sections covering (1) general information regarding the service (ie, title, contact information and location), (2) service activities and referral criteria, (3) team size and composition, (4) situation, funding mechanisms, sectors of operation and (5) dissemination and evaluation activities.

Over 60 services which were set up specifically to provide end-of-life care to people with dementia (N=63) were purposively sampled, via targeted email invitation. This included respondents to the NCPC 2008 survey; services identified via professional networks of the SEED research group (ie, the NCPC Working Group and the Health and Care Champion Group for the PM's Dementia Challenge); Gold Standard Framework accredited care homes registered to provide dementia care and awarded Beacon status; Integrated Care Pioneer Sites and other services identified via web-based searching using search terms, including 'dementia', 'end of life', 'palliative', 'service' and 'innovation'. Open call invitations were posted in the NCPC News Roundup, the National Care Forum newsletter and Practice Forum, the UK edition of ehospice, the January 2015 issue of the Old Age Psychiatrist Magazine, the Admiral Nursing Network and via social media (ie, Twitter). We distributed flyers advertising the survey at the NCPC's 9th Annual Conference on Dementia and End of Life. Targeted email and open call invitations, and flyers contained a brief description of the SEED programme and link to the survey.

ETHICS

The study did not involve human subjects and ethics committee approval was not required.

RESULTS

Fifteen respondents representing discrete service initiatives responded (see table 1 for summary of their main characteristics). Two-thirds of returns were received in response to the 63 targeted email invitations (16%), and one-third in response to open calls. Only one initiative is located outside of England, in Wales. Remaining initiatives are concentrated in the South East and North of England.

The funding and organisation of services are mixed with no clear pattern of funding or provision identifiable. Forty per cent (n=6) of initiatives are run by the National Health Service (NHS). The same proportion (ie, 40%) is hospice-based, and remaining initiatives are charity-led by organisations including Dementia UK. Respondents reported engaging in a wide range of activities (see table 1). These include (1) direct care for people with dementia and/or their families/carers (80% of initiatives identified), (2) informational and educational support for families/carers of people with dementia at the end of life (66.6%), (3) workforce development including advisory and educational activities (86.6%), (4) tool, framework and/or pathway implementation and/or development (60%) and (5) development of mechanisms for care coordination, for example, training and provision of care coordinators or development of strategies and/or policies for joint working across palliative and dementia care (60%). Eighty per cent of initiatives engage in either (1) virtually all types of activity described above (2) or all activities described above except direct care services. In other words, since 2008, current initiatives have either forgone or are extending the clinical delivery model, in favour of practice and/or workforce development approaches.

Over 85% of initiatives relied on nursing professionals, from nurses and mental health nurses; clinical nurse specialists (ie, palliative care, Macmillan and Admiral); advanced nurse practitioners and nurse consultants. Medical consultants (ie, old age psychiatry, psychological medicine, palliative care and geriatrics) and allied health professionals (ie, occupational therapists and physiotherapists) were also involved to a lesser extent, each group providing expertise in 33.3% of services identified. The majority of services (73.3%) were multidisciplinary, with remaining services mainly relying on nursing input only.

The majority of services (73.3%) receive funding from just one source; remaining services receiving funding from two or more sources. The majority of services receive public funding via a Trust (40%) or are partially or fully commissioned (33.3%). Forty per cent of initiatives are either totally or partially funded by the hospice sector. Over 65% of services evaluate their activity. Outcomes evaluated include patient and service outcomes such as completion of ACP documents, place of death and number of unscheduled admissions to hospital (40% of services), service user satisfaction (40%), educational outcomes, that is, numbers trained and staff confidence measures (26.6%) and economic evaluation (20%). Most services publicise their practice either at conferences (53.3% of services), through publications (13.3%), or via inclusion as case studies or in surveys (13.3%).

Table 1 Main characteristics of identified initiatives (N=15)

Situation	
National Health Service	40.0%
Hospice sector	40.0%
Charity sector	20.0%
Funding	
Trust (Mental Health, Acute, Health and Care)	40.0%
Clinical Commissioning Group/Regional Innovation Funding	33.3%
Hospice sector	40.0%
Community/voluntary/charity sector	26.6%
Independent care sector	13.3%
Staffing	
Direct care	
Nursing incl. registered nurse (palliative care, mental health); clinical nurse specialist (MacMillan, Admiral, palliative care); advanced nurse practitioner, nurse consultant	86.6%
Medical consultant incl. old age psychiatry, psychological medicine, palliative care, geriatrics	33.3%
Allied health professional (occupational therapist, physiotherapist) and complementary therapists	33.3%
Social worker	26.6%
Care worker and care assistant	20.0%
Counsellor	6.6%
Educational	
Educationist	20.0%
Service management/development/commissioner roles	
Strategic (chief executive) and administrative (incl. project manager) support	20.0%
Commissioner	6.6%
Activities	
Direct care (eg, care planning and review)	80.0%
Informational and educational support for families/carers of people with dementia at the end of life (eg, educational resources and/or training)	66.6%
Workforce development (eg, educational resources, programmes and/or training	86.6%
Tool, framework and/or pathway development and implementation	60.0%
Development of mechanisms for care coordination (eg, training and/or provision of care coordinators; development of strategies and/or policies for joint working across palliative and dementia care)	60.0%

Five out of eight direct care services identified in 2008 were still existed in 2015 (four out of eight responded to the present survey). Those services running 7 years later are either part of statutory services (ie, part of normal service trust provision) or are commissioned (ie, reported receiving CCG funding), and benefit from leaders from within the UK end-of-life in dementia practice community, who have been recognised for their contribution to the field in theory and practice through either awards or selection as demonstrator sites in major research, or who are heavily involved in advancing end-of-life care practice in dementia at a strategic level.

DISCUSSION

Despite the increased policy attention and funding accorded to people living and dying with dementia since the 2008 survey, the present survey did not identify an equivalent expansion of activity or reach in dementia-focused end-of-life care services. Initiatives surveyed appear to concentrate on practice-level issues in end-of-life care in dementia through the development of tools, frameworks for assessment and management and care pathways which may address the uncertainty of the illness trajectory. There is also ongoing investment in educational and advisory activities to remedy the lack of skills and expertise in the workforce. These results suggest that many of the barriers to delivering excellent end-of-life care in dementia remain. The initiatives we identified are largely built and rely on the expertise of nursing professions (with or without input from medical consultants) and supported via hospice and charitable organisations. These may indicate a new model of care provision in end of life in dementia care, referred to as 'Hospice-enabled Dementia Care'.[9]

Our results are similar to those obtained in 2008 (ie, 15 examples of local practice vs 16). This survey provides a snapshot of how services are supporting people dying with dementia since the 2008 survey, but the relatively small sample size and our purposive sampling frame limits the extent to which findings can be generalised. New services and models of care are constantly developing and it would be useful to repeat this survey, with a wider sampling frame of all generic

palliative care services, collecting data on the numbers of people with dementia that they care for. Sustainability of initiatives appears to be attributable to funding mechanisms and integration of the service as part of normal service provision. Continuity of leadership at a more individual level[10] is also important, as has been highlighted elsewhere.[11] We identified pockets of service provision supported by piecemeal funding, but the challenge remains how to ensure this is achieved for all people who would benefit from such care.

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Contributors SA, CG, LR and ELS made substantial contributions to the conception or design of the work. SA and ELS acquired, analysed and interpreted the data. SA, CG, LR and ELS drafted the work and revised it critically for important intellectual content. SA, CG, LR and ELS gave final approval of the version to be published and agree to be accountable for all aspects of the work.

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RESEARCH ARTICLE

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What is important at the end of life for people with dementia? The views of people with dementia and their carers

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Background: Approaching end of life is often a time of vulnerability; this is particularly so for people with dementia and their families where loss of capacity and the ability to communicate, make assessment and shared decision-making difficult. Research has consistently shown that improvements in care and services are required to support better quality and more person-centred care for people with dementia towards and at end of life. However, the views of people with dementia about what factors contribute to high-quality care at this time are a neglected area.

Aim: The aim of this study was to identify the aspects of end-of-life care for people with dementia that are most important to them and their carers.

Design: Q-methodology, a mixed method combining qualitative and quantitative techniques to study subjectivity, was used to identify the views of people with mild dementia, their family carers and bereaved carers on end-of-life care for people with dementia. Fifty-seven participants were included in the study.

Results: Four distinct views were identified: family involvement, living in the present, pragmatic expectations and autonomy and individuality. Some areas of consensus across all views included compassionate care, decisions being made by healthcare professionals and information availability when making decisions.

Conclusion: Our findings reveal several different views on what is important about end-of-life care for people with dementia; therefore, a 'one-size-fits-all' approach to care is unlikely to be most appropriate. Notwithstanding the differing viewpoints could provide a framework for service providers and commissioners for future care. Copyright © 2016 John Wiley & Sons, Ltd.

Key words: dementia; end-of-life care; Q-methodology; Q-sort; decision-making
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Introduction

The need for high-quality, compassionate care for people and their families, especially at their most vulnerable moments, such as towards and at the end of life (EoL), is well-recognised internationally (World Health Organization, 2011; Department of Health, 2012; van der Steen *et al.*, 2014). Delivering EoL care is particularly challenging in dementia where issues such as impaired mental capacity and communication skills can make it difficult to provide high quality, person centred care (Robinson *et al.*, 2005; van der Steen *et al.*, 2014). Difficulties in prognostication, failure to recognise dementia as a terminal illness and failure to initiate future care planning discussions, whilst the person with dementia has capacity that also contribute to these difficulties (Mitchell *et al.*, 2004; Thuné-Boyle *et al.*, 2010; Dickinson *et al.*, 2013; Robinson *et al.*, 2013). Research has shown specific areas in need of

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improvement include symptom control (Hendriks *et al.*, 2014); the need for better services to enable dying at home or hospice care (Treloar *et al.*, 2009); and the provision of compassionate care (Crowther *et al.*, 2013).

Exploring the views and preferences of all stakeholders involved in EoL care in dementia is necessary to evaluate current provision and inform how care can be improved. Often, the perspectives, experiences and opinions sought are those of family carers (Treloar *et al.*, 2009; Hennings *et al.*, 2010; Davies *et al.*, 2014a), healthcare professionals (Livingston *et al.*, 2012; Davies *et al.*, 2014b; Lee *et al.*, 2015) or sometimes both (Thuné-Boyle *et al.*, 2010; Lawrence *et al.*, 2011; Raymond *et al.*, 2014), but it is also important to seek the views of those who are in receipt of EoL care. Some initial work has been undertaken with people with dementia and their carers to explore whether they were able to generate and prioritise preferences for EoL care (Dening *et al.*, 2013). The aim of this study was to further build upon these initial findings, using Q-methodology to identify and describe the views shared by people with dementia, current family carers and bereaved carers about the elements of care considered important towards and at EoL.

Methods

Q-methodology is an approach that combines qualitative and quantitative techniques to study subjective areas (Baker *et al.*, 2006; Watts and Stenner, 2012) and thus was applied to obtain the subjective views of the people with dementia and carers. This method provides a way to understand participant views on what is important to them about the care services they receive and enabled the team to elicit features, which are important to certain groups of participants and not others or alternatively what is important (or unimportant) in consensus.

The stages of a Q-study are described in detail elsewhere (Watts and Stenner, 2012); therefore, only a summary is provided here. The first stage of a Q-study is to develop the concourse that represents all of the possible views on the topic in question (Brown, 1980). As this concourse can be very large, it is necessary to sample from this to derive a smaller (but still representative) set of statements (Q-set). The second stage is the Q-sort; here, each individual respondent provides their point of view by rank ordering the statements (usually according to agreement). Following the Q-sorting exercise, a form of 'by-person' factor analysis is conducted. This analysis groups together similar Q-sorts to reveal a small number of underlying perspectives, which are referred to as factors. Through interpretation of the factors, rich descriptions of different points of view are generated (Mason *et al.*, 2011).

Details of the stages of this Q-study can be found in Table 1.

Study sample and setting

Sampling in Q-methodology is purposive, seeking to recruit respondents that may hold different views on the topic to identify the different, shared views that exist (Brown, 1980). Three key groups of respondents were recruited to obtain a diverse range of perspectives and experiences: people with early-stage dementia, family carers and bereaved family carers. The inclusion criteria for family and bereaved carers was as follows: non-professional carers of a person with dementia who are either a member of family, spouse or a friend and family carers of a person with dementia who had died a minimum of 3 months prior to contact, respectively. Because of the nature of study topic and the cognitive demands of the Q-sort exercise, it was considered inappropriate to engage with people in more advanced stages of dementia. Therefore, the sample population was limited to individuals with mild dementia, for whom the Q-sort could be an appropriate and engaging tool to elicit their views (Forrest, 2010).

Participants were identified through the Dementias and Neurodegenerative Diseases Research Network,[1] Join Dementia Research [2] and VOICENorth.[3] A representative from the organisation used clinical records to ensure that the participants were in the earlier stages of dementia (determined by a dementia diagnosis in the past 3 years and/or, where available, a mini-mental state examination score >20) before they were approached about the study. Mental capacity to participate in the research was assessed by researchers and written consent obtained.

A separate set of statements was created for people with dementia. These were written in the first person (Table 2), whilst the statements for carers were written in the third person and referred specifically to their relation to the person with dementia (Table S1); the statements were piloted to ensure the terminology used and statement length was appropriate.

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[1] https://www.crn.nihr.ac.uk/dementia/

[2] https://www.joindementiaresearch.nihr.ac.uk/

[3] http://www.ncl.ac.uk/ageing/partners/voicenorth/#about

Table 1 Description of each stage of the Q-study in detail

Stages	Steps
Concourse generation (102 items)	• Conduct an in-depth search of academic literature relative to dementia care, palliative care and EoL care to identify a range of aspects of EoL care for people with dementia. • Search relevant guidance documents (National Collaborating Centre for Mental Health, 2007; Sampson *et al.*, 2009) • Conduct an online media search of news articles and dementia organisations' websites. • Examine transcripts from interviews with national experts in dementia care.
Q-set generation (24 statements)	• Condense the concourse using a framework based on the 'eight domains of palliative care' (NCP, 2009). • Categorise each concourse item according to the framework and merge similar statements. • Sample statements to ensure coverage of all of eight domains. • Pilot test 23 statements with a patient and public involvement group to further refine the statements and add anything that was considered missing. • Map the statements onto a 'conceptual framework' of outcomes and indicators of good-quality care (Amador *et al.*, 2015) resulting in a final set of 24 statements (Table 2).
Administering the Q-sort	• Present each statement to the participant on a separate, numbered card. • Ask the participant to think about what is important to them about EoL care for a person with 'memory problems'. • Instruct the participant to sort the statements into three piles: most important, quite important and least important; advise the participant to place any statements he or she disagrees with in the least important pile. • Invite the participant to rank order the cards onto a grid (Figure 1) starting with the 'most important' statements through to those that were 'least important'. • Conduct a short 'post-sort' interview with the participant to identify the reasoning behind their choices of most and least important statements and further explore their opinions. This also facilitated verification of their sorting and ranking choices.
Data analysis and interpretation	• Individual Q-sorts were entered into a specialist software package, PQ Method (Schmolck, 2002), and a 'by–person' factor analysis (Centroid factor analysis followed by Varimax rotation) was conducted. • The factor analysis identified clusters of respondents who completed the Q-sort in a similar way (Watts and Stenner, 2012), and these clusters define the different factors. • The decision on the number of factors to retain for interpretation was based on an examination of the Eigen values, the number of participants significantly correlated with each factor, the percentage explained variance and the post sort qualitative comments. • Each factor was interpreted by first examining the idealised Q-sort of each factor (which describes how a person who perfectly correlates with the factor would have laid out their 24 statements) with reference to the relative position of statements within and between factors. • Particular attention was given to the statements placed at the top and bottom rows of the Q-sort and distinguishing statements that have a significantly different ($p < 0.01$) position in the idealised Q-sort compared with the other factors. • The responses from the 'post-sort' qualitative interviews with respondents were used to help provide connections or explain the positioning of statements.

Ethics approval was granted by the NRES Committee North East on 19/12/2013, REC reference: 13/NE/0335.

Results

In total, 57 people participated in the Q-sort, 14 people with dementia, 21 carers and 22 bereaved carers.

Factor analysis revealed four factors comprising different shared viewpoints on what is important about EoL care for a person with dementia (Table 2). These factors were developed from 39 of the 57 Q-sorts, as 18 Q-sorts were not significantly correlated with any factor. The four factors altogether account for 49% of the total variance (F1 12%, F2 17%, F3 8%, F4 12%) between the 57 Q-sorts.

Factor 1: family involvement

The close relationship between family carers and their relative with dementia places carers in a good position to make decisions for their relative if he or she no longer can. This is viewed as being preferable to leaving important medical decisions to healthcare staff; to facilitate this, it was considered essential to have a plan in place for their care which documents their wishes 'it's really important to know that ahead of time so that we can plan for it and respect her wishes' (29C).

Family carers do not see caring for their relative as a burden but as a part of their relationship that they enjoy; therefore, carers do not see moving the person with dementia to a care home an important option. It is more important to keep the person with dementia in their own home, or usual place of care and have the family with them at the EoL. Most importantly, the

Table 2 The placement of each statement within the idealised Q-sorts for each factor where '3' = *most important* and '−3' = *least important*

No.	Statement	F1	F2	F3	F4
1	My opinions and choices for my care should be respected.	1	−1	0	2
2	I should be able to continue with my hobbies and interests in the last year of my life.	0	**−3**	1	1
3	Paid carers and family carers should take account of my spiritual or cultural beliefs in all caring duties.	1	**−3**	−1	−2
4	Paid carers should be trained to notice if I am in pain.	2	2	1	0
5	I would like to have family/friends with me at the very end of life.	2	2	−2	**3**
6	I would like to have a plan in place for what care I would like to receive at the end of my life when I might not be able to clearly express myself.	**3**	−2	0	2
7	My care plans for end-of-life care should be regularly checked by paid and family carers in case I want to make any changes.	0	−2	−2	−1
8	I should be helped to take my medication even if I forget what it's for.	1	1	2	−1
9	Paid carers and family carers should help me eat only if I want to.	−1	−1	0	−2
10	Important medical decisions about my end-of-life care should be left to healthcare staff.	**−3**	0	**−3**	**−3**
11	My family should make decisions about my end-of-life care if I no longer can.	2	1	−2	2
12	I would move to a care home if it becomes too much for my family/friends to look after me.	−2	0	**3**	0
13	I would like to be able to receive the majority of the care I need at the same location (e.g. in my own home or care home).	0	2	2	1
14	I would like my family to be told about how my needs and care will change over time.	0	0	−1	0
15	Short stays in respite care should be available to give my family/friends a break from caring.	−2	0	0	0
16	Paid carers should be trained how to give me my medication.	−1	1	1	−1
17	My day to day care should be regularly discussed by family carers, paid carers and me.	−1	0	−1	0
18	I should have help to put my affairs in order and make preparations.	−2	−1	0	**−3**
19	Care should be taken to find the cause of any distress which may affect me.	1	**3**	2	1
20	Hospice care should be more available to me.	**−3**	−2	−1	0
21	I should be cared for with compassion.	**3**	**3**	**3**	**3**
22	Support should be available for my family after I pass away.	0	−1	**−3**	−2
23	Care homes should allow me to keep personal things in my room to make it homely.	−1	0	0	−1
24	When I or my family have to make decisions about my care, there should be someone who can provide us with information to help us.	0	1	1	1

The 'most important' and 'least important' statements in each idealised factor are highlighted in bold.

person with dementia should be cared for compassionately through understanding and acknowledgement of their needs and wishes.

One person with dementia, four current carers and three bereaved carers form this factor (Table 3).

Factor 2: living in the present

A day-to-day approach for the care of people with dementia is expressed in this factor, tackling challenges as they appear. Planning for EoL is not of high importance, people with dementia would prefer to focus on the present. It is more important that the correct processes are in place to ensure the comfort and safety of the person with dementia at the end of their life, for example, identifying any distress, having responsible carers trained to identify pain and, most importantly, compassionate care for the person with dementia. Carers wished to include a level of physical and tactile comfort for their relative with dementia, 'I think she could do with a little more feel and touch' (11C). It is also important that the person with dementia receives care in the same location, so that he or she is comfortable in familiar surroundings.

Family carers recognise the changes in the abilities and interests of their relative with dementia. Carers respect these changes, which are reflected in the view that enabling their relative to continue taking part in hobbies and interests in their last year of life is least important. Similarly, respecting spiritual/cultural beliefs is not considered important as there were perceptions that the person with dementia may no longer be able to engage in maintaining their spirituality and beliefs.

One person with dementia, six carers and eight bereaved carers form this factor

Factor 3: pragmatic expectations

This factor was characterised by two diametrically opposed viewpoints in that statements were placed in a similar pattern but at the opposite ends of the grid (Figure 1); the majority view is taken as the main viewpoint; however, the 'mirror-image' viewpoint, prescribed to by the two participants with dementia only, is also presented.

The main viewpoint

Family carers take a pragmatic approach to EoL care for people with dementia. They acknowledge their limitations as relatives, prioritising above all provision of the 'best care'. Ensuring the person with dementia's health and safety through compassionate care is of utmost importance even if this involves a move to a care home where trained staff can provide specific support. Wherever the person with dementia lives, it is important that he or she receives the majority of care in that location to minimise distress from being moved away from a place of familiarity.

Family involvement in making decisions is less important, but carers would still not feel comfortable leaving important care decisions entirely to healthcare professionals and would like relevant input. Family carers acknowledge that the person with dementia may not recognise the family at the very EoL; therefore, being present at this time is not very important.

Table 3 Demographic details of participants in each factor

			Factor 1	Factor 2	Factor 3	Factor 4
People with dementia	*N*		1	1	2	4
	Mean age (median), years		78.0 (78.0)	74.0 (74.0)	74.0 (74.0)	65.5 (64.0)
	Mean time since dementia diagnosis (median), years		3 (3)	6 (6)	3.5 (3.5)	1.5 (1.5)
Carers	*N*		4	6	1	4
	Relationship to person with dementia	Wife	3	2	–	2
		Husband	–	1	–	–
		Son	–	1	–	1
		Daughter	1	2	1	–
		Other	–	–	–	1
Bereaved Carers	*N*		3	8	2	3
	Mean time since bereavement (median), months[a]		26.7 (34.0)	25.9 (28.5)	10.5 (10.5)	24.3 (18.0)
	Relationship to person with dementia	Wife	1	5	–	1
		Husband	–	2	1	1
		Son	1	–	1	–
		Daughter	1	1	–	–
		Other	–	–	–	1

[a]Rounded to the nearest 1d.p.

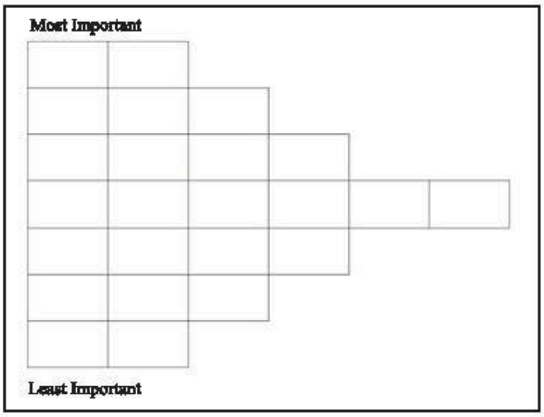

Figure 1 The Q-grid used with participants (scaled down).

Once the person with dementia has passed away, families do not feel support would be important; they see death as an inevitability and grief to be dealt with within the family circle; 'at the end of the day it's a death…families tend to know…the protocol' (14C).

The 'mirror-image' viewpoint

The statements placed at the extremes of the Q-grid, described in the following sections, highlight the contrast between the main and 'mirror-image' viewpoints.

Planning for future care is not important to people with dementia; they certainly do not want plans 'pushed in [their] face' (18D). It is least important that care is provided in the same location, and moving to a care home is not considered a priority.

This viewpoint regards healthcare professionals making medical decisions most important, whilst also considering important the family making decisions for the person with dementia. Another contrast to the main viewpoint is the opinion about support for families after the death of the person with dementia, which is regarded most important.

Finally, compassionate care, which is prioritised by the main viewpoint and all other factors, is considered less important by the 'mirror-image' view.

One carer, two bereaved carers and two people with dementia form this factor.

Factor 4: autonomy and individuality

People with dementia in this factor, value a significant level of autonomy and individuality for their EoL care, with their opinions and choices respected and the ability to put a plan in place for their care at the EoL; 'it's important the power and control are with the person [with dementia]' (13C). Should the person with dementia become unable to do this, they wish their family to make decisions on their behalf according to their wishes and not leave them to healthcare staff. Compassionate care is essential and incorporates respect for the person with dementia as an individual. Maintaining hobbies and interests at the EoL is also considered an important means of allowing the person with dementia to express their individuality.

Independence in self-care is important for the person with dementia; therefore, help with tasks such as taking medication and eating is not prioritised. In this factor, people with dementia do not feel that it is necessary to receive help putting their affairs in order as they are confident that this will be performed at a stage in their life where they are capable of managing this themselves. Whilst remaining independent for as long as possible is imperative to the person with dementia, having family and friends with them at the very EoL is still a comfort they rate highly.

Four people with dementia, four carers and two bereaved form this factor.

Consensus statements

Linking the four factors described previously, were three 'consensus statements' which appeared in the same position across all or most of the idealised Q-sorts of each factor. These common views suggest that there are areas of EoL care which are of key importance amongst a diverse range of views. These consensus statements included: #21 'I should be cared for with compassion'; #10 'Important medical decisions about my EoL care should be left to health care staff' and #24 'When I or my family have to make decisions about my care, there should be someone who can provide us with information to help us' (Table 2). In summary, participants felt compassion and supported shared decision-making were fundamental aspects of EoL care for people with dementia and their families.

Discussion

This is the first study to use a specific methodology, Q, to directly elicit the views of people with dementia, and their carers, about the sensitive subject of EoL care. Four different shared viewpoints on what is important to the participants about this aspect of care emerged. The most prominent conclusion to be drawn from the Q-sort is that, there are multiple perspectives of good EoL care for people with dementia; and thus, a 'one-size-fits-all' approach to planning is not appropriate to accommodate individual needs. This finding has implications for practitioners who in clinical care are often required to follow evidence-based guidance to ensure good-quality EoL care (NICE, 2015) which may detract from an individualised, person-centred approach. Whilst it is important that practitioners follow established guidelines, the results of this study suggest that this should not be at the expense of providing care to fit the specific needs and wishes of the individuals involved and practitioners should, therefore, be adaptable in their approach to EoL care for people with dementia.

Whilst the main finding of this study implies variation amongst views of the elements of EoL care that are important to people with dementia and their carers, the 'consensus' statements (#21, #10 and #24; Table 2) that are common to each factor do reflect some convergence of views about key aspects of EoL care. The first consensus statement, #21 'I should be cared for with compassion', was placed as the most important in all factors. Our findings indicate that participants perceived compassion uniquely in each of the different factors. Whilst compassion may be considered fundamental to EoL care for people with dementia, the provision of compassionate care can be challenging (Department of Health, 2012; Crowther *et al.*, 2013). Previously identified barriers to providing compassionate care include: professionals who are desensitised to the needs of individuals often through working in target-driven environments (Crowther *et al.*, 2013), reflecting organisational pressures (Davies and Iliffe, 2014) and more deeply rooted cultural factors (Kellehear, 2013). Whilst our findings cannot directly address these challenges, they do further highlight the importance of the provision of compassionate care through a person-centred approach with a focus on understanding and respecting the person's needs and wishes, good, safe care and a tactile and empathetic approach.

The second consensus statement, #10 'Important medical decisions about my end-of-life care should be left to health care staff', was considered least important for the majority of factors (with the exception of factor 2 which viewed it as 'quite important'). Participants who placed the statement 'least important' actively disagreed with it. The majority view is that family members should have some say in medical decisions about the person with dementia and not leave it solely in the hands of health care staff as they have intimate knowledge of the *person* with dementia's wishes. Enabling family involvement in decision-making is also underpinned by the third consensus statement, #24 (Table 2). Current UK guidance (Nuffield Council on Bioethics, 2009) recommends healthcare professionals engage with carers and family members to facilitate joint decision-making when the person with dementia experiences difficulties in expressing their wishes; previous research however reveals that relatives may feel ill-equipped or unable to do this on their relatives behalf (Raymond *et al.*, 2014).

The remaining factors each represent a viewpoint shared by a mix of carers and people with dementia. The main aspects of EoL care that differ between the factors are as follows: planning ahead, responsibility for decision-making and moving to a care home versus remaining at home. Another barrier to shared decision-making and the provision of high-quality EoL care is the ability of both the public and health professionals to have open and honest discussions about death and dying. In dementia, healthcare professionals struggle to initiate and undertake such sensitive discussions about future care planning at an early stage in the dementia trajectory, whilst the person is able to play an active role (Dickinson *et al.*, 2013; Robinson *et al.*, 2013). This makes involvement in shared decision-making particularly challenging (NHS - End of Life Care Programme, 2010). Shared decision-making is also a cornerstone of Advanced Care Planning which has been shown to prevent unnecessary hospital admissions for people with advanced dementia by facilitating better quality, person centred care for people with dementia (Robinson *et al.*, 2012; Ampe *et al.*, 2015).

Strengths and limitations

To date, the use of Q-methodology to establish the views of people with dementia is relatively novel (Forrest, 2010; Westbrook *et al.*, 2013). A Q-sort facilitates exploration of sensitive topics, such as EoL care, that may be difficult to discuss openly in society (Department of Health, 2008). Participants in a Q-study have to prioritise aspects; therefore, some level of relative preference can be identified using this method and the qualitative post-sort interviews strengthen interpretation of the viewpoints. However, one limitation is that due to our approach to sample selection, our findings may not be generalizable. The research databases we used to identify potential participants are established via an opt-in approach; therefore, our sample comprises people with dementia who are positive about engagement in research. Also, we excluded participants with advanced stage dementia thus, potentially missing views from the very group who would be in receipt of EoL care. However, this research does not claim to contain an exhaustive range of viewpoints.

In addition, interpretation of the factors was also influenced by the fact that the two participants with dementia prescribing to the 'mirror-image' view of factor 3 were unable to complete a post-sort interview. Limited qualitative data was therefore available to aid the interpretation of this viewpoint; the only available supplementary data were field notes taken by researchers during the card sorting process.

The post-sort interview provided a means of validating the Q-sorts by allowing participants to justify their choices. However, the validation method could be improved. A method used in a Q-sort study conducted with participants with severe intellectual disabilities was identified post data collection (Cramm *et al.*, 2009). This method, whilst not used with participants with dementia, could be a useful tool for validating Q-sorts administered with this population in future work.

Finally, our sample of participants with dementia was relatively small compared with the other groups which was a result of practical limitations in recruiting participants from this population. Of the 14 Q-sorts belonging to people with dementia, 6 (43%) did not load significantly onto a factor which potentially indicates that data saturation was not reached with this group. It is therefore possible that further study in this area, with a larger sample of participants with dementia, would identify additional viewpoints not captured here.

Conclusion

There is a plurality of views on what is considered important by people with dementia and their families with regard to end-of-life care. Four different viewpoints were identified by this study: family involvement, managing the present, pragmatic expectations and autonomy and independence. This variety in viewpoints indicates that there is no universal opinion on what is important about EoL care for people with dementia; therefore, when considering how best to improve care a 'one-size-fits-all' approach is unlikely to be most appropriate. This has implications for real world practice where clinicians are often required to follow national evidence-based guidelines which if applied to formulaically may interfere with providing individual person-centred care. In light of the findings from this study, practitioners should therefore be mindful of tailoring guidance to the needs of the individual. The Q-sort did however also identify several elements of consensus such as: prioritising compassionate care, family involvement in medical decision-making alongside healthcare staff and having someone help families make decisions. Whilst the views identified by this study may not be exhaustive, they are a good starting point for future research into this area and identify elements of care that should be focused on to improve EoL care for people with dementia.

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Conflict of interests

None declared.

Key points

- Four, distinct viewpoints (family involvement, living in the present, pragmatic expectations and autonomy and individuality) on ahwat is important about end-of-life care for a person with dementia are identified.
- A consensus of participants' views is found for specific aspects of care: compassionate care, shared medical decision-making between family members and healthcare staff and information availability when making decisions.
- A 'one-size-fits-all' approach to end-of-life care policy is unlikely to be most appropriate due to the plurality of viewpoints identified.

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Supporting information

Additional supporting information may be found in the online version of this article at the publisher's web-site.

Table S1: Statements written for a carer participant whose mother has dementia

Poole *et al.*[96]

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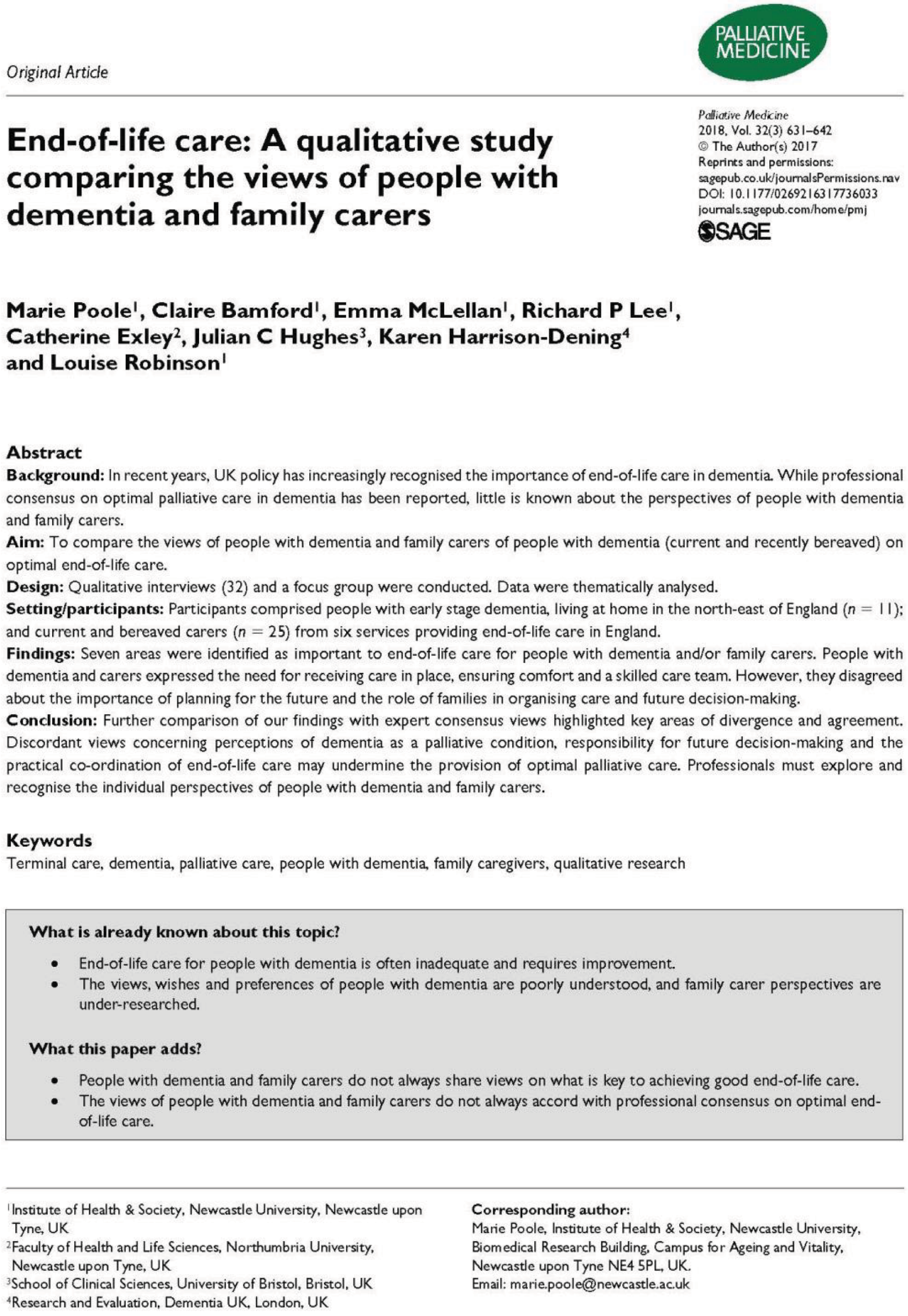

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End-of-life care: A qualitative study comparing the views of people with dementia and family carers

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Abstract

Background: In recent years, UK policy has increasingly recognised the importance of end-of-life care in dementia. While professional consensus on optimal palliative care in dementia has been reported, little is known about the perspectives of people with dementia and family carers.

Aim: To compare the views of people with dementia and family carers of people with dementia (current and recently bereaved) on optimal end-of-life care.

Design: Qualitative interviews (32) and a focus group were conducted. Data were thematically analysed.

Setting/participants: Participants comprised people with early stage dementia, living at home in the north-east of England ($n = 11$); and current and bereaved carers ($n = 25$) from six services providing end-of-life care in England.

Findings: Seven areas were identified as important to end-of-life care for people with dementia and/or family carers. People with dementia and carers expressed the need for receiving care in place, ensuring comfort and a skilled care team. However, they disagreed about the importance of planning for the future and the role of families in organising care and future decision-making.

Conclusion: Further comparison of our findings with expert consensus views highlighted key areas of divergence and agreement. Discordant views concerning perceptions of dementia as a palliative condition, responsibility for future decision-making and the practical co-ordination of end-of-life care may undermine the provision of optimal palliative care. Professionals must explore and recognise the individual perspectives of people with dementia and family carers.

Keywords

Terminal care, dementia, palliative care, people with dementia, family caregivers, qualitative research

What is already known about this topic?

- End-of-life care for people with dementia is often inadequate and requires improvement.
- The views, wishes and preferences of people with dementia are poorly understood, and family carer perspectives are under-researched.

What this paper adds?

- People with dementia and family carers do not always share views on what is key to achieving good end-of-life care.
- The views of people with dementia and family carers do not always accord with professional consensus on optimal end-of-life care.

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Implications for practice, theory or policy

- Practitioners need to find ways of improving understanding of dementia as a palliative condition. This will enhance the relevance of advance care planning for people with dementia and family carers.
- Practitioners should explore assumptions about decision-making towards the end of life to highlight and address any tensions between people with dementia and family carers and to increase carer confidence in decision-making and avoid additional burden and anxiety.

Introduction

Our rapidly ageing populations are leading to more people, globally, living with age-related illnesses like dementia, causing considerable concern for future health and social care provision.[1] Policy on dementia care has tended to focus on ensuring people maintain quality of life and 'live well' with the illness through earlier diagnosis and intervention. The importance of improving care towards and at end of life for older people in general,[2] and especially those with dementia, is increasingly recognised.[3–6] Research evaluating the organisation and provision of end-of-life care for people with dementia and their families gives cause for concern in terms of the quality and nature of such care.[7–10]

In principle, good end-of-life care is supported by individualised care planning which reflects the needs and wishes of the dying person and those important to them. However, people with dementia may not view future care planning as a priority[11] and may be excluded from decision-making and experience limited agency in securing good end-of-life care.[12] Currently, very few people with dementia die at home or with hospice care, with the majority dying in care homes and in acute hospitals.[13] This suggests that many people with dementia do not die in their preferred place of care and highlights the need to increase agency and act on, as well as elicit, preferences for end-of-life care.[12]

Increasing cognitive impairment and decreased ability to communicate as dementia becomes more severe, means it is important to ascertain a person's views about their future care in the earlier stages of the illness.[14] In practice, this rarely occurs, since health professionals struggle to find the 'right time' to initiate such discussions.[15] Discussing future care is further complicated by the fact that people with early stage dementia often prefer to concentrate on living in the present rather than planning ahead.[11] When discussions are delayed until the more advanced phase, professionals may place greater emphasis on physical and clinical issues, rather than individual values and preferences.[16]

A Delphi consensus of 64 expert professionals (health professionals and researchers) specialising in palliative and/or dementia care from 23 countries, identified essential domains for good-quality palliative care in dementia[5] (Figure 1). Subsequent research confirmed the importance of optimal treatment of symptoms to provide comfort; family involvement; and optimal communication and shared decision-making; to practitioners.[17]

11 Domains of palliative care for dementia

1. *Applicability of palliative care*
2. *Person-centred care, communication and shared decision making*
3. *Setting care goals and advance planning*
4. *Continuity of care*
5. *Prognostication and timely recognition of dying*
6. *Avoiding overly aggressive, burdensome or futile treatment*
7. *Optimal treatment of symptoms and providing comfort*
8. *Psychological and spiritual support*
9. *Family care and involvement*
10. *Education of the health care team*
11. *Societal and ethical issues*

Figure 1. European Association for Palliative Care (EAPC) 11 domains of palliative care for dementia.[5]

Little research to date has explored the views of people with dementia on end-of-life care.[18–20] There is also a limited understanding of family carer perspectives,[8,21,22] with their views often sought retrospectively in the post-bereavement period.[23] The 2016 World Alzheimer's Report recommended the urgent need to explore the perspectives of people with dementia to better inform care management and service delivery.[24] The aim of this study was to investigate the views of people with dementia and the views of family carers of people with dementia (both current and recently bereaved carers) on factors important to them regarding care towards and at end of life.

Methods

A qualitative approach was adopted to explore the views of people with dementia and family carers about end-of-life care. This was underpinned by a social constructivist epistemological stance.[25] The reporting of our research

11 people with dementia:

- *Early stage*
- *Convenience sample recruited via local Clinical Research Network and national register*
- *Participated in Q-sort exercise with additional open-ended interview questions (range of 4 – 45 minutes)*

25 family carers:

- *Convenience sample recruited from six participating services in England (Specialist dementia EMI; supported living; group living; standard nursing/residential care)*
- *Approached by service staff to participate*
- *Did not participate in Q-sort exercise*
- *21 took part in a semi-structured qualitative interview (range of 26 – 72 minutes)*
- *Four family carers requested to take part in a focus group (1 hour 17 minutes)*

Figure 2. Recruitment of participants.

is consistent with relevant guidance on reporting qualitative research.[26] All data were collected between January and December 2015. Figure 2 summarises the process of recruitment.

People with earlier stages of dementia (diagnosis in the past 3 years and/or, where available, a Mini Mental State Examination score of >20) were recruited via the local clinical research network and a national voluntary registry to participate using Q-sort methodology to seek their views on factors important to them in end-of-life care. The full methods and findings of this are published elsewhere.[27] However, to explore in-depth responses and better understand their views on a broader range of aspects of end-of-life care, additional face-to-face, qualitative interviews were conducted by M.P. immediately after completion of the Q-sort. Written consent was obtained from all participants.

The interviews and focus group with carers explored experience of services, care needs and components of good end-of-life care. Separate interview schedules were developed for current and bereaved carers. All participants were given the option to be interviewed either in their own home, at the care service, or at the university. The interviews with people with dementia and current carers explored mainly hypothetical views about end-of-life care, while those with bereaved carers considered personal experiences of palliative care. Interviews were conducted by C.B., R.P.L., E.M. and M.P.

Data were audio recorded, transcribed and anonymised before analysis. Each participant was assigned a unique numeric identifier, used to identify quotations. For current and bereaved carers, the type of service from which they were recruited is also indicated.

A thematic approach to analysis was adopted.[28] Initially, individual researchers (E.M. and M.P.) read and re-read a selection of transcripts to become familiar with the data. The researchers noted areas of interest and potential themes independently, compared ideas and discussed these in workshops (C.B., C.E., R.P.L., E.M., M.P. and L.R.). Following discussion of emergent themes, we applied the thematic framework to further transcripts and discussed collectively in a subsequent data workshop. Once the framework was agreed, this was applied to all transcripts. This inductive process enabled identification of the most salient points from the data. E.M. and M.P. wrote narrative summaries to explore emergent themes in more detail by considering the summaries alongside existing theory and literature. This enabled us to compare how these complemented existing ideas or were unique to our research. Data saturation was reached during analysis when no new themes emerged from the data.

Findings

In total, 11 people with dementia and 25 family carers participated in the study (see Figure 3). People with dementia and family carers were not family dyads.

Our findings highlight seven aspects core to the provision of good-quality care towards and at the end of life (see Table 1). Views and preferences varied both within and between people with dementia and family carers. In general, both groups emphasised the importance of remaining in their preferred place of care and ensuring comfort and minimising distress. In contrast, people with dementia and family carers disagreed on the importance of future care planning, who was responsible for decision-making, the co-ordination of end-of-life care and the core competencies and skills needed by care providers to deliver good end-of-life care.

Being cared for 'in place'

Most participants with dementia wished to stay at home for as long as possible. Some conceded that their declining health might require full-time institutional care; however, others did not consider this inevitable and hoped to remain in their own home for end-of-life care with appropriate support:

People with dementia (11)
- *All lived at home*
- *Female (4), male (7)*
- *Living with spouse (8), living alone with no support (2), living alone with support (1)*

- *Carers (25) - Current carers (11), Bereaved carers (14), Husbands (2), wives (8), siblings (2), adult children (12), other relatives (1).*

Interviews with 21 carers (9 bereaved and 12 current)
Focus group with 4 carers (2 current and 2 bereaved)

Figure 3. Summary of participants characteristics, *n* = 36.

Table 1. Comparison of views on core aspects of end-of-life care.

Theme	Pwd view	Carer view	EAPC domain – expert view	Agreement/tensions
Being cared for 'in place'	Essential	Essential	2. Person-centred care, communication and shared decision-making. 4. Continuity of care.	All in agreement (2 and 4)
Being comfortable at the end of life	Essential	Essential	7. Optimal treatment of symptoms and providing comfort. 8. Psychological and spiritual support.	All in agreement (7 and 8)
A skilled care team	Essential	Essential	2. Person-centred care, communication and shared decision-making. 10. Education of the healthcare team. 11. Societal and ethical issues.	All in agreement (2, 10 and 11)
Making future plans: importance and value	Importance unclear and little value attached	Some importance and value attached to making specific types of plans	3. Setting care goals and advance planning. 6. Avoiding overly aggressive, burdensome or futile treatment.	Tensions between views of people with dementia and carers (3). Additional tension with expert view concerning importance of making future plans (3 and 6)
Faith in family members	Expectation/ assumptions that family will do this	Family feel poorly equipped	2. Person-centred care, communication and shared decision-making.	Tensions between views of people with dementia and carers (2). Additional tension with expert view and the assumption that preferences are shared (2)
Trust in professionals	Prioritised ability to make medical decisions	Prioritised ability to make decisions about daily care	10. Education of the healthcare team.	Tensions between views of people with dementia and carers, but agreement with expert view (10)
Fitting care together: co-ordination and the role of families	Expectations/ assumptions that family will do this	Family feel poorly equipped	2. Person centred care, communication and shared decision-making. 9. Family care and involvement.	Tensions between views of people with dementia and carers (9). Additional tensions with expert view, contingent on families being adequately supported (2 and 9)

Pwd: people with dementia; EAPC: European Association for Palliative Care.

> I would like to have my end of life care at home, all of it if possible […] I think I'd like to stay at home if possible, I think my wife would like me to stay at home as well if I can. (Person with dementia, 8)

Regardless of whether the person with dementia lived at home or in a care home, all carers preferred their relative to remain in place rather than be admitted to hospital for end-of-life care. Hospitalisation was perceived to cause distress and upheaval for the person with dementia due to the unfamiliar environment and people. To facilitate continuity of care, many carers welcomed the opportunity to make appropriate plans to prevent unnecessary hospital admission:

> I sort of agreed with everybody here and the GP that if at all possible there would be no hospitalisation again 'cause I personally felt she got far better care here, than she would get in hospital. I mean I'm not criticising the hospital, I just think places like this are better set up for caring than a hospital ward is and it seemed to me she was far less disturbed by being here with the people around her that, she kind of recognised. (Bereaved carer 1, Supported living service 2)

When hospital admission was unavoidable, carers often emphasised the importance of the person with dementia returning to their usual place of care as soon as possible. This could be facilitated by communication between families, care home staff and hospital practitioners:

> I said 'my mother's 97, she can't recover, she's had a fantastic life full of love, she loved her children, she loved her family, I said and she's going back to where she belongs' […] 'my mother isn't going to live longer than three days, you've told me that, so she's not going in the ward' – so then they had consultation and they rang (care home) and the home backed me, they said, 'This is her home, she's coming home, to die'. (Bereaved carer 3, Supported living service 2)

Being comfortable at the end of life

Our findings indicate that people with dementia and carers considered being comfortable and pain-free as essential to good end-of-life care. They saw this as a basic requirement, readily achievable by carers attending to the 'little things':

> The key things for Mum is just for her to be kept clean, comfortable, pain free, and not distressed. And you know, I think that's quite easily achieved. (Current carer 1, Specialist EMI service 2)

> … I think the pain relief, pain management, one of the most important things when you're getting towards the end. In my own opinion, I'd rather have the pain decrease, even if it meant that I was going to live shorter. (Person with dementia, 8)

Although generally there were assumptions that ensuring comfort should be a standard competency in generalist staff providing end-of-life care, one carer recognised the role of specialist services in achieving this:

> I wouldn't like him to suffer that's one thing I wouldn't like, that's where the palliative nurses come in isn't it. (Current carer 4, Residential/nursing home 1)

In addition to physical comfort, both people with dementia and carers also took a holistic view of comfort and agreed on the importance of psychosocial elements such as emotional comfort, compassion and spirituality:

> There's more to it than just being a medical aspect being considered. Its welfare and compassion and all the factors like that. (Person with dementia, 3)

Whereas people with dementia often considered care staff to be responsible for practical aspects of comfort and care, family were commonly viewed as the main source of emotional support. The desire for family to be with them at the end of life was frequently expressed. Although family carers wished to be present at the end of life, they also valued the important role that care staff could play in providing emotional support to people with dementia. Bereaved carers drew comfort from knowing that staff attended to psychosocial as well as physical needs:

> I think to me as long as I've got [husband], as long as we're together that's all that matters to me. (Person with dementia, 5)

> ... she [staff carer] spent two or three hours every night reading the bible to my mother […] they were looking after her, they kept making sure she was comfortable, they kept moistening her face… and going in all the time and talking to her. (Bereaved carer 3, Supported living service 2)

A skilled care team

People with dementia and carers agreed that the delivery of good-quality end-of-life care required well-trained staff; however, they recognised the difficulties of achieving this in the context of limited resources and challenging conditions:

> … the salary that the carers get isn't enough, for the work they do, they're on minimum wage I think … and they're long hours … you're on the go all the time, I wouldn't like their job. (bereaved carer 2, Supported living service 2)

Being skilled in basic elements of care such as feeding and medication was seen as essential. People with dementia, in particular, assumed that staff would be sufficiently skilled to deliver these fundamental aspects of end-of-life care:

> I would expect that to happen [recognising pain and distress] as a matter of course. (Person with dementia, 7)

In addition, people with dementia and carers considered it necessary for staff to be trained and skilled in the delivery of individualised and person-centred care. While people with dementia often expected staff to be able to instinctively provide such care to all, family carers recognised the need to develop relationships in order to be able to provide individualised care:

> Compassion is automatic surely. (Person with dementia, 1)

> They liked him they loved him even, they were fond of him and they cared for him as somebody they were fond of. They responded to his needs. (Bereaved carer 3, Supported living service 1)

People with dementia and carers also recognised that staff providing end-of-life dementia care should have additional or specialist training to ensure a good standard of care. Such specialism was considered necessary to meet needs particular to dementia at end of life:

> So I think it's imperative that the training standards for people who work with Alzheimer's have extra input. (Person with dementia, 11)

Making future plans: importance and value

Discussing and planning future care was one area where considerable tensions existed between the views of people with dementia and family carers. However, current and bereaved carers also tended to have differing views on the value of planning ahead. People with dementia commonly reported they had already made adequate arrangements for their end-of-life care, often alluding to having their 'affairs in order'. However, further investigation revealed that people tended to focus on practical post-death arrangements such as wills, finance and funeral arrangements rather than specifics of their daily care towards end of life:

> Yeah, well everything is all sorted so it's everything is done, so if I pass away then everything is sorted. (Person with dementia, 10)

> Her only wishes were we weren't to make any fuss and that she was to be cremated not buried, […] obviously she was insistent that she made a will, […] she was a very practical lady really. So, she saw to the practical things […] but, no I can't say we did really talk about end of life care, no. (Bereaved carer 1, Supported living service 2)

Such plans were often regarded as complete, with no need to revisit or amend them in the future. Furthermore, people with dementia were often unaware of other plans, especially related to their health and future care, which they could put in place. One notable exception was a person with dementia who had previously worked in dementia care (person with dementia, 12) and was fully aware of the need to include these areas in their detailed care plan:

> We've got a will made out, for me and [Wife] like, but I don't know what, what we could do other than that like. (Person with dementia, 3)

> So I was thinking, well I've done all this, but I hadn't in a sense. The care plan, all I did for the care plan part- I did my end of life, but the care part is like my medication, injections, and how I like to drink water. (Person with dementia, 12)

As future plans primarily related to financial and funeral arrangements, some participants did not see the value of sharing this 'private' information with care providers. Instead, these plans were informally discussed with trusted family members, were frequently undocumented and ran the risk of not being legally recognised. Furthermore, misunderstanding around end-of-life care planning meant responsibility for planning was often considered personal. For those individuals, the involvement of care providers was not considered legitimate and potentially intrusive:

> IV: Well, I'll have a plan myself…But it might not involve any medical people or care people.
> I: Right, so it might not be a formal, written down one.
> IV: Formal – no but I'll have a good idea what I want to do.
> I: …And how will you let others know?
> IV: I'll discuss it with my wife. (Person with dementia, 8)
> I: And, how would you feel if staff at [service] asked you about, wishes about end of life and things like that?
> IV: Well they cannot it's not their job.
> I: You don't see that as their job, to be planning ahead?
> IV: It's what I said … I don't think it's got anything to do with them, because I mean it's something between you, the family. (Current carer 2, Residential/nursing home 1)

In addition, neither group seemed to understand dementia as a palliative condition. This included bereaved carers who attributed death to a general physical and mental decline, usually related to other co-morbidities, rather than recognising dementia as a terminal illness:

> … the GP had been and the carers told me that, you know, this was looking like the beginning of the end and then he steadied a bit, he didn't get better, but he levelled out a bit, so that prolonged things […] Just a general deterioration. (Bereaved carer 3, Supported living service 1)

This impacted on the perceived value of making future plans and the preparedness of people with dementia and families to have timely discussions concerning prognostication and planning. Predictions about death were not influenced by the diagnosis of dementia; therefore, a dementia diagnosis may not drive the need for planning end-of-life

care in the same way as other conditions which are commonly understood as terminal, for example, cancer:

> Well you can't plan – for something in place when you don't know when you're going to die. (Person with dementia, 3)

In addition, some people with dementia preferred to focus on their current situation and capabilities and not on future decisions which they found upsetting. Some carers also found looking towards the future challenging. In the quotes below, participants distance themselves from end of life, hinting at the desire to consider end of life as a future matter:

> … I can't relate to it [EoL]. […], I'm fit and well. (Person with dementia, 12)

> It's [EoLC], quite a difficult subject to talk about, isn't it? […] I suppose, the nearer you get to being in that situation more questions you, you could think of (Current carer 1, Residential/nursing home 1)

Although family carers similarly struggled to see the value of planning for the future in the abstract, they often responded positively to specific aspects of healthcare planning such as Do Not Attempt Cardiopulmonary Resuscitation (DNACPR). This suggests it may be easier for people to establish what they do not want when faced with clearly defined choices rather than trying to plan for a multitude of unknown potential eventualities. Carers often expressed strong feelings about resuscitation, fearing that this could have damaging short- and long-term consequences for the person with dementia:

> Obviously, if it's a chest infection, whatever, antibiotics, but other than that, you know, it's do not resuscitate. She's 92. She has, really, no quality of life. We don't want to lose her, but we don't want her to live in any worse situation than she's in. (Current carer 1, Specialist EMI service 2)

Faith in family members

In relation to the previous section on planning, our findings indicate that sharing wishes and preferences for end of life does not routinely happen in many families. In addition, people with dementia and family carers may place different values on the importance of sharing vital information to inform decisions at end of life. People with dementia may encounter a long phase in which their ability to express their wishes and preferences is compromised, in comparison with other palliative conditions. Therefore, dependency on others to fulfil their wishes may be particularly strong.

People with dementia often assumed that their families would already know their values and wishes and automatically fulfil an advocacy role for them if they became unable to communicate their preferences. This presumed knowledge was based on long-standing familial relationships, in which people with dementia often described putting their trust and faith in family. Such trust was often not formalised by people with dementia, although a small number had established Lasting Power of Attorney (LPA), thus legally devolving responsibilities to others:

> I would have faith in what they [family] are doing. It's as simple as that. I know my family very well, yeah. (Person with dementia, 7)

> I've done the things that I should do. You know, I've made a will and I've done the power of attorney, or it's well on the way. (Person with dementia, 12)

Despite expressions of confidence from people with dementia that families would uphold their wishes, carers often felt that they had not explicitly discussed wishes and preferences with their relative. Thus, carers frequently felt inadequately equipped to advocate care preferences, even in close- and long-established relationships. This was a source of distress to families who felt under pressure to make the right choices and generated concern around the amount of 'guess-work' families may be faced with when trying to make decisions on their relative's behalf:

> I mean I've known him since I was 18…and I'm 78 now. […] we never ever talked about dying … now I wish we had done … it's a funny thing you know, it is because if me and (husband) had discussed it I would say 'right I'm doing his wishes' but now I don't know. (Current carer 4, Residential/nursing home 1)

Although some carers appreciated the value of documenting the person with dementia's wishes and preferences to ensure they made the right choices on their relative's behalf and also to provide them with peace of mind, several carers felt that they had missed the chance to have such discussions and expressed regret at this lost opportunity:

> But like I say, we didn't ever have that discussion, 'cause we didn't think it [dementia] would happen to her, and by the time things started to happen, it was too late. (Bereaved carer 1, Specialist EMI service 2)

Trust in professionals

Many of the people with dementia and family carers in this study believed practitioners to be eminently capable of and better equipped for making decisions concerning end-of-life care than themselves. They often felt that healthcare professionals would have a better understanding of the needs of the person with dementia, and therefore would be able to make important decisions concerning treatment and care at end of life. Thus, the confidence that people with dementia had in their families to make decisions on their behalf also extended to healthcare practitioners, particularly around medical decisions:

> Just leave them [healthcare staff] to get on. [with medical decisions at end of life] […] the longer you can keep it in their hierarchy the more success you're likely to have really. Is my view. (Person with dementia, 6)

People with dementia expected healthcare professionals to be knowledgeable and experienced when making care decisions. This trust in healthcare professionals appeared in part to stem from concerns that they would no longer be competent enough to make their own choices due to cognitive deterioration. However, some thought healthcare professionals should act in an advisory, rather than decision-making, capacity:

> Because I think my choices for me care can't always be respected if it's not, the people concerned know it's not good for me. […] because naturally people who are working with people that, that's had things like I have, and they know how to deal with it better than you do yourself. (Person with dementia, 5)

> At least they [healthcare staff] give you help and advice, as to what's the best way to go. But at the end of the day, it's up to the individual as to what… if they want any further medical treatment or not. (Person with dementia 8)

While carers expressed confidence in professionals and care staff to make important decisions regarding end-of-life care, they tended to focus decision-making in the delivery of daily care rather than specific medical decisions. They trusted that current good care would continue as needs changed and end of life approached:

> I think [care home] will go out of their way, and I think they will, but where my mum's concerned, because of the way they treat her now, I know for a fact that if we come to that [end of life care], I know for a fact she'll be well looked after. (Current carer 7, Residential/nursing home 1)

> … care plans have to be changed constantly to like what's going on. […] They [service staff] were right on top of that stuff. I mean…I wasn't reading it. I was just signing it come the end. 'Cause, you had the confidence in the staff to know what was what, and they would just sort it out, you know. (Bereaved carer 2, Supported living service 1)

Fitting care together: co-ordination and the role of families

Tensions between the views of people with dementia and carers also existed around the organisation of practical care at end of life. In addition to upholding their preferences and wishes and making important decisions, people with dementia also trusted that their families would be able to provide or arrange practical aspects of care as they deteriorated and their needs changed. This included working with services to ensure plans were enacted:

> …the youngest one [daughter] […], she is spot on and sharp and, and she would make sure I should, would have help. She is already looking after my affairs. (Person with dementia, 1)

> So it's good to have the plan, but I also think you need the backup of your family, to see that the plan is implemented to its best outcome. (Person with dementia, 11)

Although carers wished to achieve this, some described encountering a range of organisational barriers to co-ordinating good end-of-life care. These included navigating complex systems to access continuing healthcare funding, pressure from service providers to move their relative into institutional care and co-ordinating care providers from different services. These challenges were more apparent when trying to co-ordinate services to enable people to die in their own home:

> The hardest part is actually trying – cos you end up the hub at the middle that's trying, in areas that you don't know what you're doing anyway, but trying to get it all to fit together. (Bereaved carer 2, Supported living service 1)

Bereaved carers faced many practical and emotional aspects of care to manage at a time when they were potentially vulnerable. Some carers described the continued need for support in the co-ordination of care in the period soon after death. Examples included care staff carrying out practical tasks such as making phone calls to relatives and assisting with funeral arrangements. As well as reducing burden for newly bereaved carers at the beginning of the grieving process, this practical support also provided some emotional comfort:

> … another friend was coming that afternoon and so [Manager] made that phone call for me, and I think she also phoned [Husband]'s brother and he came straight away and also our very good friends [name], [Manager] made that phone call, so they were very good, you know, they did all the practical things, so that all worked out well. (Bereaved carer 3, Supported living service 1)

Discussion

Exploring the views of people with dementia and family carers on end-of-life care identifies important shared and divergent views. People with dementia and family carers agreed that maintaining preferred place of care, ensuring comfort and the provision of skilled professional carers were important. However, a key inconsistency lay in the expectations of people with dementia that their families would be sufficiently confident and knowledgeable to act on their behalf while carers felt poorly prepared to fulfil this role.

Having a professional consensus framework on factors contributing to the delivery of optimal end-of-life care for people with dementia is key to informing policy and practice. However, our study highlights the need to incorporate the perspectives of people with dementia and family carers into such recommendations, in order to ensure that such care is both person-centred and of optimal quality.[27] Comparisons of the views of people with dementia and family carers with expert professional consensus views,[5] highlighted interesting areas of agreement and discordance which have important implications for practice (Table 1).

In comparing the findings of our research with professional consensus, a key difference emerged around understanding of dementia as a palliative condition. As demonstrated through their perspectives on planning for the future, many people with dementia and carers did not recognise dementia as a palliative condition. This is unsurprising when, at both a policy and professional level, end-of-life care in dementia has been neglected.[29] In contrast, the professional view emphasises the applicability of a palliative care approach towards dementia care throughout the disease trajectory (domains 1, 5 and 11). These different perspectives on dementia as a palliative condition are likely to contribute to the contrasting views expressed regarding the value and relevance of planning ahead. While the professional view highlights the need to set care goals and engage in proactive advance planning (domain 3) and to avoid overly aggressive, burdensome or futile treatment (domain 6), people with dementia and family carers found it difficult to engage in such discussions in the abstract, particularly at earlier stages in the illness.

Further comparison with the professional view indicated subtle but important differences in emphasis even where there was broad agreement on important components of end-of-life care. For example, in relation to continuity of care, people with dementia and family carers particularly emphasised the importance of maintaining their preferred place of care. The professional consensus focused instead on the importance of un-interrupted care even when transfers occur between settings, assisted by communication between caregivers (domain 4).

Similarly, the importance of skilled and competent staff in the delivery of good end-of-life care was emphasised by people with dementia and carers in this research and the expert consensus view (domain 10). While the consensus view takes a broad view which encompass needing the skills to meet domains 1 to 9, our findings emphasise the skills which are specifically important to people with dementia and family carers.

Timely discussion of the person with dementia's views on future care was identified as a challenging area to enact in practice. Research has shown that older people tend to focus on the post-death period such as making funeral plans,[18,30] rather than on the nature of their care prior to death. Older people in care homes, who are more likely to have cognitive impairment, often considered that their affairs were 'sorted' and 'in order'.[20] People with dementia in this study shared these perspectives on planning ahead and additionally assumed that their family carers would intuitively know their wishes. Although carers were more receptive to the concept of planning ahead, they felt uncomfortable and/or ill-prepared to undertake such responsibility and only with hindsight, often recognised that such planning would have helped with difficult end-of-life decisions.[31] Worryingly, many healthcare professionals also feel equally ill-equipped to initiate future care planning conversations,[11,32] especially in a proactive, rather than reactive, manner.[33] In theory, advance care planning is seen as fundamental to good palliative care, particularly in dementia, where capacity to make decisions may be compromised. There is, however, limited evidence showing any significant difference to either patient/carer outcomes and/or resource use.[34] Although a recent systematic review has revealed it may be potentially cost effective.[35] In view of the many challenges identified in implementation, previous studies have shown there may be a need for staff with specific expertise in this area to ensure timely discussions and their outcomes are accurately documented and disseminated.[5,6]

Previous research has highlighted concerns about a lack of co-ordination of care at end of life for people with dementia.[9,19,24] This contrasts markedly with the expectations of people with dementia in our study who were confident that an overall good standard of future care would be delivered, but concurs with the experiences of bereaved carers. The confidence of people with dementia in their families' ability to co-ordinate and manage their care is at odds with carers' real-life experience of needing, and sometimes failing to receive both practical and emotional support from professionals. In the United Kingdom, specialist palliative care nurses are a core component of usual cancer care and are often involved with a person with cancer from the point of diagnosis, supporting both the patient and their families. Similar specialist dementia nurses, for instance, Admiral Nurses, exist, but are not a core part of usual care and thus not widely available.[36]

Internationally, there have been calls for a greater involvement of specialist palliative services in the care of older people with non-malignant conditions, but there is a lack of clarity on how to provide such care in light of our ageing populations and on whether a traditional hospice approach is appropriate.[2,14] A recent UK study suggested a model of short-term, integrated palliative care, facilitated by a key worker, through usual care services;[37] although a lack of evidence of the effectiveness of palliative care assessments in dementia may hinder such future innovative models.[2,14]

Positive experiences and relationships with healthcare providers have been identified as vital to the experience of good end-of-life care in dementia.[8,24,38,39] However, negative factors also impact on care quality.[38] Interestingly, people with dementia were confident that their future care providers would be both professionally competent and innately compassionate to deliver end-of-life care. Family carers highly valued a person-centred approach to care, but recognised that compassion was not always standard. In the United Kingdom, medical training in dementia is very limited at an undergraduate level.[40,41] Family doctors, the main healthcare providers at the end of life, lack both knowledge and confidence in providing care in general to people with dementia,[42] although this may be improving.[43] It would appear that additional support and/or training is still required in certain challenging areas such as discussing the palliative nature of dementia, planning ahead for future care and providing both emotional and practical support to families.

Strengths and limitations

Our interviews with people with dementia were conducted after they had undertaken a Q-sort exercise in which they ranked 24 pre-generated statements about end-of-life care. Participation in this exercise appeared to facilitate the interviews and may have helped to set the scene to further explore their personal views in more detail. However, topics discussed during participation in the Q-sort exercise may have influenced responses. Also, we cannot assume that the views of people in the early stages of dementia accurately represent those in the more advanced stages of the condition. Qualitative interviews are inappropriate for seeking the views of people with advanced dementia.[44] We decided, therefore, to focus on people with earlier stage dementia to maximise the quality and trustworthiness of the data.

Although death is not a taboo subject for people dying with dementia,[18] those participating in this research did not consider themselves to be approaching the end of life and thus were discussing this aspect of care from a hypothetical perspective. However, with few exceptions, people with dementia could consider their future possible needs, although this may be dependent on different hypothetical health states.[45] People with dementia were recruited from the community, and from one area of England, rather than through healthcare services. Therefore, the views of people with dementia living in residential care or people with dementia without family carers and regional variation were not captured. In addition, the results could not be cross checked in family dyads and the impact of gender issues were not explored. Consequently, these limitations may impact on the generalisability of the findings to more diverse populations. However, despite these limitations, this study addresses a critical research gap by directly seeking the views of people with dementia themselves on end-of-life care rather than only seeking a proxy view from relatives after death,[23,46] or relying on interpretations represented by family caregivers,[47] which may be misinterpreted.

Seeking the views of both current and bereaved carers provided a more balanced perspective between expectations and experience of end-of-life dementia care. Bereaved carers openly discussed end-of-life care; however, a small number of current carers struggled to engage in discussions around end-of-life care. These carers found it difficult to think about the death of their relative. However, it has been suggested that research participation may open up opportunities for such discussions to begin in real life.[30]

Implications for policy, future practice and research

End-of-life care for people with dementia has been neglected at both a policy and professional level.[29] Our study identifies key divergent perspectives of people with dementia and family carers on factors contributing to optimal end-of-life care. It also highlights important discrepancies between the perspectives of people with dementia and family carers and the published consensus views of professionals. Policy and practice must, therefore, reflect the varied perspectives of different stakeholder groups. People with dementia were confident that their families would co-ordinate and manage their care as required; however, carers found this difficult in practice. While in the United Kingdom, cancer patients have access to specialist nurses from the point of diagnosis, who can assist with co-ordinating care, similar specialist dementia nurses (Admiral Nurses) are not a core part of usual care and thus not widely available.[36]

Our study identifies specific areas where additional resources, support or training may be required to improve the delivery of better quality care towards and at the end of life for people with dementia. Examples include better education for people with dementia and families about dementia and its prognosis;[48] involving palliative care expertise earlier in the dementia pathway,[37] especially in terms of emotional support around making difficult decisions;[17] and developing a specialist dementia nurse or 'care co-ordinator' to address the areas of particular difficulty identified by this study.[49] We suggest that further research is needed to (1) identify how best to seek the views of people in different stages of dementia about such a sensitive and potentially distressing topic as end of life, (2) explore approaches to improve understanding of dementia as a palliative condition with people with dementia and family carers and (3) determine how interventions such as advance care planning can be more appropriately and effectively integrated into usual dementia care.

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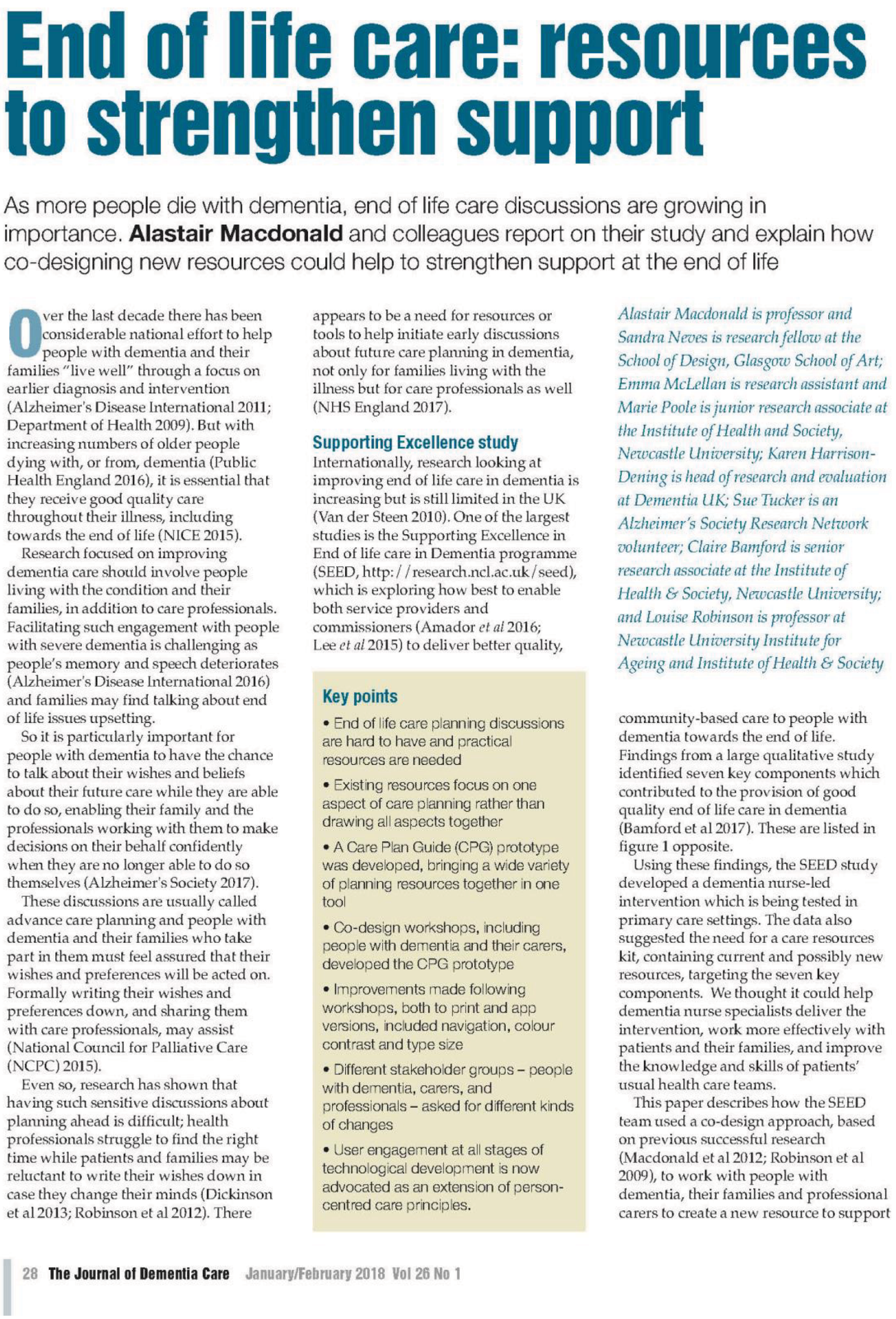

End of life care: resources to strengthen support

As more people die with dementia, end of life care discussions are growing in importance. **Alastair Macdonald** and colleagues report on their study and explain how co-designing new resources could help to strengthen support at the end of life

Over the last decade there has been considerable national effort to help people with dementia and their families "live well" through a focus on earlier diagnosis and intervention (Alzheimer's Disease International 2011; Department of Health 2009). But with increasing numbers of older people dying with, or from, dementia (Public Health England 2016), it is essential that they receive good quality care throughout their illness, including towards the end of life (NICE 2015).

Research focused on improving dementia care should involve people living with the condition and their families, in addition to care professionals. Facilitating such engagement with people with severe dementia is challenging as people's memory and speech deteriorates (Alzheimer's Disease International 2016) and families may find talking about end of life issues upsetting.

So it is particularly important for people with dementia to have the chance to talk about their wishes and beliefs about their future care while they are able to do so, enabling their family and the professionals working with them to make decisions on their behalf confidently when they are no longer able to do so themselves (Alzheimer's Society 2017).

These discussions are usually called advance care planning and people with dementia and their families who take part in them must feel assured that their wishes and preferences will be acted on. Formally writing their wishes and preferences down, and sharing them with care professionals, may assist (National Council for Palliative Care (NCPC) 2015).

Even so, research has shown that having such sensitive discussions about planning ahead is difficult; health professionals struggle to find the right time while patients and families may be reluctant to write their wishes down in case they change their minds (Dickinson et al 2013; Robinson et al 2012). There appears to be a need for resources or tools to help initiate early discussions about future care planning in dementia, not only for families living with the illness but for care professionals as well (NHS England 2017).

Supporting Excellence study

Internationally, research looking at improving end of life care in dementia is increasing but is still limited in the UK (Van der Steen 2010). One of the largest studies is the Supporting Excellence in End of life care in Dementia programme (SEED, http://research.ncl.ac.uk/seed), which is exploring how best to enable both service providers and commissioners (Amador *et al* 2016; Lee *et al* 2015) to deliver better quality, community-based care to people with dementia towards the end of life. Findings from a large qualitative study identified seven key components which contributed to the provision of good quality end of life care in dementia (Bamford et al 2017). These are listed in figure 1 opposite.

Key points

- End of life care planning discussions are hard to have and practical resources are needed
- Existing resources focus on one aspect of care planning rather than drawing all aspects together
- A Care Plan Guide (CPG) prototype was developed, bringing a wide variety of planning resources together in one tool
- Co-design workshops, including people with dementia and their carers, developed the CPG prototype
- Improvements made following workshops, both to print and app versions, included navigation, colour contrast and type size
- Different stakeholder groups – people with dementia, carers, and professionals – asked for different kinds of changes
- User engagement at all stages of technological development is now advocated as an extension of person-centred care principles.

Alastair Macdonald is professor and Sandra Neves is research fellow at the School of Design, Glasgow School of Art; Emma McLellan is research assistant and Marie Poole is junior research associate at the Institute of Health and Society, Newcastle University; Karen Harrison-Dening is head of research and evaluation at Dementia UK; Sue Tucker is an Alzheimer's Society Research Network volunteer; Claire Bamford is senior research associate at the Institute of Health & Society, Newcastle University; and Louise Robinson is professor at Newcastle University Institute for Ageing and Institute of Health & Society

Using these findings, the SEED study developed a dementia nurse-led intervention which is being tested in primary care settings. The data also suggested the need for a care resources kit, containing current and possibly new resources, targeting the seven key components. We thought it could help dementia nurse specialists deliver the intervention, work more effectively with patients and their families, and improve the knowledge and skills of patients' usual health care teams.

This paper describes how the SEED team used a co-design approach, based on previous successful research (Macdonald et al 2012; Robinson et al 2009), to work with people with dementia, their families and professional carers to create a new resource to support

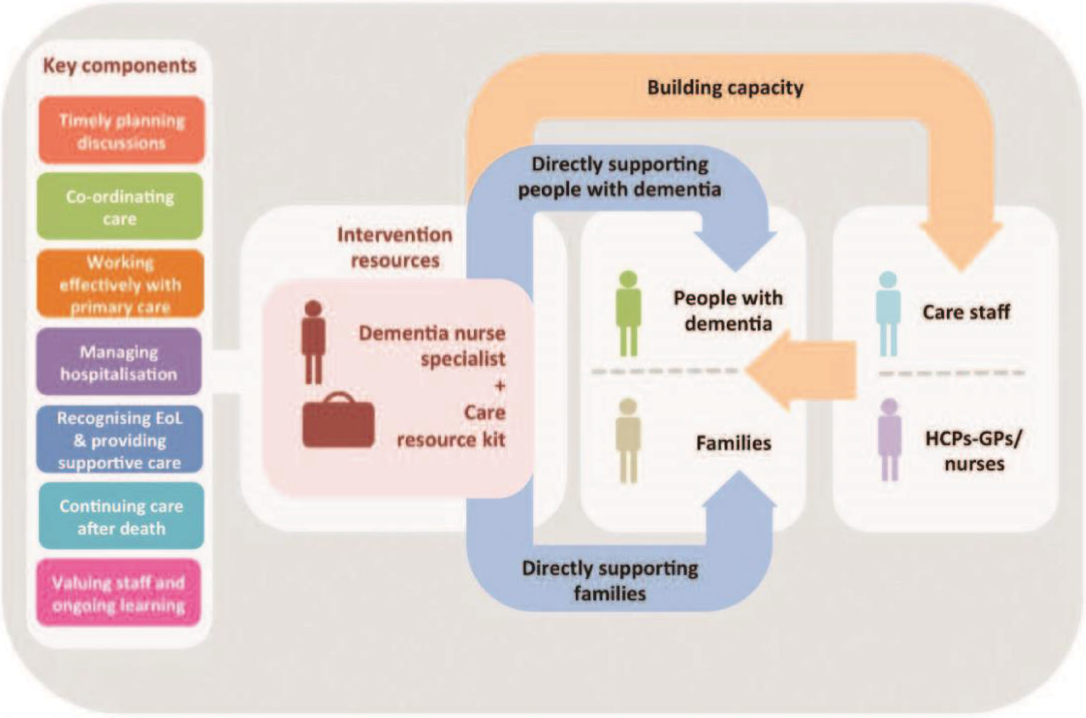

Figure 1: The SEED intervention

discussing, making and documenting plans for future care, particularly towards the end of life.

Development of the new resource comprised two separate but linked pieces of work which progressed concurrently, one informing the other:

- review and mapping of existing resources to assist people with dementia and their families or carers to discuss the end of life
- in the light of gaps in existing resources, a co-design process to develop a new resource.

Mapping existing resources

Resources were initially identified using specific search criteria, including "end of life care" and "dementia", and by targeting key websites, for example Alzheimer's Society, Alzheimer's Association and the National Council for Palliative Care. Identified resources were reviewed and sifted by a small group from the research team with personal and professional experience of dementia care at the end of life. Resources were initially grouped according to:

- title and content
- relevance to one or more of the seven key components
- general end of life care or specific dementia end of life care content
- target audience (people with dementia, family carers, professionals)
- country of origin.

Format and availability (e.g. downloadable, free or paid for) were also considered as a measure of the accessibility of the resources to professionals and people with dementia and their families. Further exploration of resource content was then undertaken with a focus on quality to determine if the development of the resource was grounded in, or influenced by, research evidence.

In a final review process, the most appropriate existing resources were selected to include in our care resources kit. These were prioritised based on the following criteria:

- dementia-specific
- freely available
- UK-based
- grounded in evidence.

International resources for professionals were selected if they were high quality and had a strong evidence base. International resources for people with dementia and their families were included if they were accurate, high quality and judged acceptable by lay members of the SEED team.

Our final list of resources demonstrated considerable variation in the quality and quantity available for the seven key components. A large number of detailed resources were found about "timely planning discussions", but these were either targeted at enhancing professional knowledge and skills or, if patient/family focused, not presented in a simple, accessible manner.

Existing resources for people with dementia and their families also tended to focus on a single area of care planning; there was nothing available to help them bring together all aspects of care planning documentation and information in one place.
This suggested an area of development for our co-design team.

Developing a prototype

A co-design approach was seen as integral to ensuring that meaningful and useful resources were created. An essential aspect of this approach, says the Design Council, is that it "goes beyond consultation by building and ➤

➤ deepening equal collaboration between citizens affected by, or attempting to, resolve a particular challenge. A key tenet of co-design is that users, as 'experts' of their own experience, become central to the design process" (2014).

Involving all relevant stakeholder groups, people with dementia, family carers, paid carers, doctors, nurses, support workers and occupational therapists, was an important aspect of our co-design approach. It comprised two stages:

1. Development of an initial prototype for the new resource via internal project workshops with i) the multidisciplinary SEED team, which included a patient and public involvement (PPI) representative, and ii) the project's external PPI advisory group.
2. Refinement of the prototype through external workshops involving newly recruited participants from the key groups listed above.

Design-led researchers from the Glasgow School of Art, experienced in using co-design and stakeholder engagement for co-developing healthcare interventions, added to the more traditional dementia, palliative and nursing care specialists in the research team.

Our initial prototype was a Care Plan Guide (CPG) which brought together in one tool a wide variety of planning resources, including:

- lasting power of attorney (both health and welfare, and property and financial affairs)
- advance statement
- advance decision to refuse treatment (including non-resuscitation)
- making a will
- funeral planning.

Feedback from the SEED PPI advisory group suggested the need for a digital or web-based version, leading the design team to produce a model of an app which could be used alongside the printed version for testing in the subsequent co-design workshops.

Co-design workshops

One group of professionals (registered nurse and support workers) was recruited from a specially designed community complex with six supported households, which aims to create a family atmosphere for older people requiring full-time care, including those with dementia. Potential participants were identified through the service manager and invited to attend a co-design workshop.

Figure 2: co-design workshop set-up

Participants in two further groups were invited to take part with the support of the project manager at Alzheimer Scotland for Dementia Circle groups. A researcher presented our study to group members and provided information sheets and criteria for participation.

Of course, only people with dementia and carers who were willing to discuss end of life care participated in the co-design groups. Some people with dementia and their carers preferred not to engage and we cannot assume that their views are similar to those of people who did take part.

The format for each co-design workshop was similar (see figure 2 above).

A full-size mock-up of the print-based CPG was given to participants to mark up with their own suggested improvements. They could also try out the model app version of the guide. In the preparation of these mock-ups, guidelines were referred to for age and dementia-appropriate design (Dementia Engagement and Empowerment Project 2013a, 2013b; Knowles 2014). Participants were also each asked to complete a set of workbook questions to capture their individual comments on key aspects of the CPG.

Workshop findings

Three co-design workshops were held with 20 participants in all: group 1 had eight support workers and one registered nurse, group 2 had two people with dementia, three family carers and two occupational therapists, and group 3 had two family carers and two people with dementia.

Participants indicated that the CPG, as a general concept, would not only positively address the intended purpose of facilitating timely planning discussions between people with dementia and their families and carers, but would also assist many others in similar situations.

The CPG structure was seen as helpful, in particular its overview, general introduction to each plan, details and links to further information, and the fact that information was kept in a single place together with the record of progress and decisions against each plan.

Suggested improvements, such as to navigation, the way colour was used to differentiate between sections, font size, and arrangement and amount of text, were embodied in further iterations of the CPG (both paper and app versions) for subsequent workshops. Initially, acronyms and formal legal language were used in the guide, but this was regarded as unhelpful and later revised.

Some individuals preferred the printed version to the app version, which they were either unable to use or uneasy about using. But tablet or phone-based interaction was regarded by younger people as convenient, enabling direct links to further web-based resources. Suggestions included customising the format and text-size, and voice-command features to enhance usage.

Each stakeholder group had particular interests typified in figure 3. For example, people with dementia tended to be concerned more about terminology and avoiding unfamiliar jargon, legibility, layout and navigation within and between sections. Family carers were more typically concerned with alternative formats such as websites and apps for more interactive and engaging discussions, and to enable access to further web-based resources. The concern of support workers and specialist nurses was typically more about how the resource could best help them to support family carers.

Discussion

Our project set out to involve all key stakeholders in the co-design of resources for better quality end of life care. Our experience showed the process to be a positive experience for participants. The iterative evaluation of the paper and app mock-ups helped us identify early not only what was effective, but what was problematic and how features could be improved.

The SEED CPG was conceived specifically to speak directly to people with dementia and their families, so it

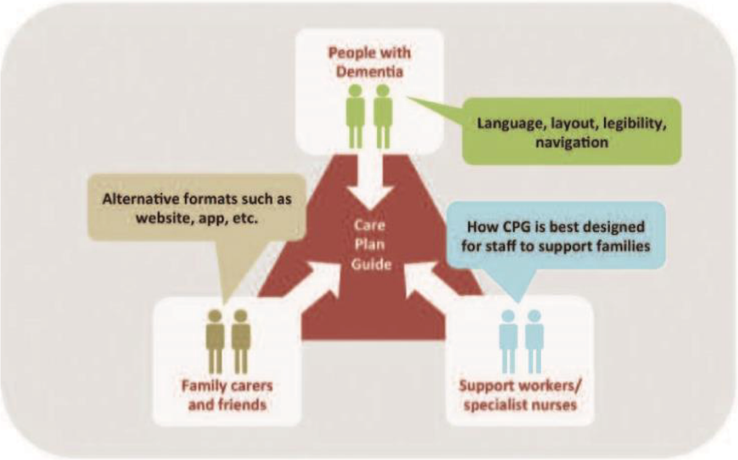

Figure 3. Focus of feedback from different stakeholder groups

had to be accessible and user-friendly in design and language. Interestingly, during the co-design stage, a number of resources aimed at this same audience and with the same general purpose were published, some from established organisations, but our feedback from family carers noted persistent issues with their format and language.

There has been a tendency for new resources and devices to be created for older people by technologists with little reference to the specific requirements of the end users (Brittain *et al* 2010). People with dementia have had very limited involvement in co design and co-development approaches (Span *et al* 2013; Topo 2009), especially in the area of assistive technologies which have the potential to improve quality of life and sustain independence.

Expectations are changing, however, with the realisation that older people can continue to contribute even when compromised by illness or disability. In the case of dementia care, international consensus recently advocated user engagement at all stages of technology development as an extension of the principles of person-centred care (Meiland *et al* 2017).

Next steps

Our next steps will be to create a workable version of the CPG for user testing in terms of acceptability and feasibility. Despite our concerns and anxiety around the research topic, people with dementia and their families were enthusiastic and welcomed and valued research on this sensitive subject.

While our project advisory group raised issues about "generational" comfort or discomfort with particular technologies, evidence (Joddrell & Astell 2016) suggests many more opportunities in future for interactive tablet-based technology for supporting decision-making for end of life planning in dementia care. ■

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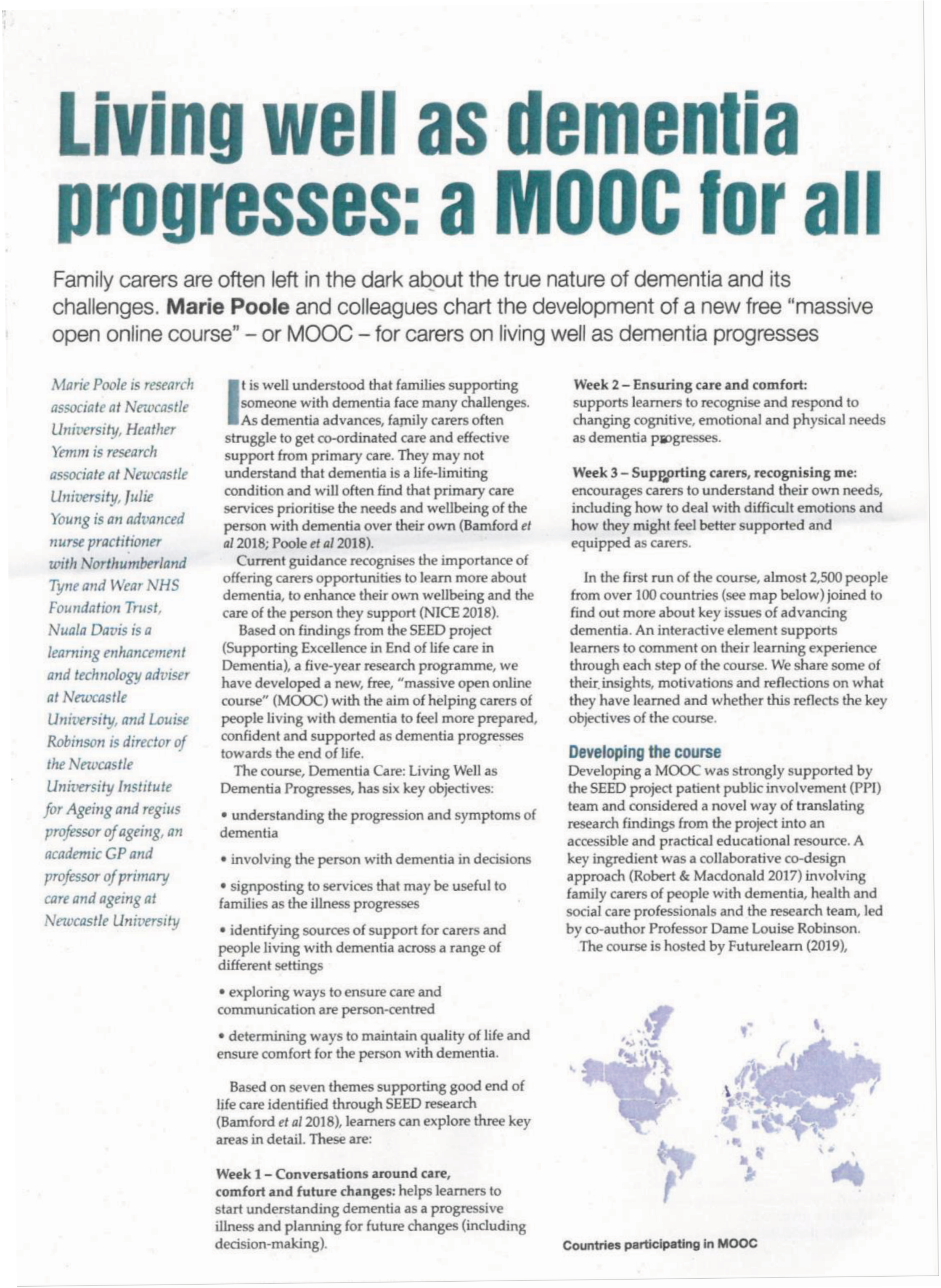


Living well as dementia progresses: a MOOC for all

Family carers are often left in the dark about the true nature of dementia and its challenges. **Marie Poole** and colleagues chart the development of a new free "massive open online course" – or MOOC – for carers on living well as dementia progresses

Marie Poole is research associate at Newcastle University, Heather Yemm is research associate at Newcastle University, Julie Young is an advanced nurse practitioner with Northumberland Tyne and Wear NHS Foundation Trust, Nuala Davis is a learning enhancement and technology adviser at Newcastle University, and Louise Robinson is director of the Newcastle University Institute for Ageing and regius professor of ageing, an academic GP and professor of primary care and ageing at Newcastle University

It is well understood that families supporting someone with dementia face many challenges. As dementia advances, family carers often struggle to get co-ordinated care and effective support from primary care. They may not understand that dementia is a life-limiting condition and will often find that primary care services prioritise the needs and wellbeing of the person with dementia over their own (Bamford *et al* 2018; Poole *et al* 2018).

Current guidance recognises the importance of offering carers opportunities to learn more about dementia, to enhance their own wellbeing and the care of the person they support (NICE 2018).

Based on findings from the SEED project (Supporting Excellence in End of life care in Dementia), a five-year research programme, we have developed a new, free, "massive open online course" (MOOC) with the aim of helping carers of people living with dementia to feel more prepared, confident and supported as dementia progresses towards the end of life.

The course, Dementia Care: Living Well as Dementia Progresses, has six key objectives:

- understanding the progression and symptoms of dementia
- involving the person with dementia in decisions
- signposting to services that may be useful to families as the illness progresses
- identifying sources of support for carers and people living with dementia across a range of different settings
- exploring ways to ensure care and communication are person-centred
- determining ways to maintain quality of life and ensure comfort for the person with dementia.

Based on seven themes supporting good end of life care identified through SEED research (Bamford *et al* 2018), learners can explore three key areas in detail. These are:

Week 1 – Conversations around care, comfort and future changes: helps learners to start understanding dementia as a progressive illness and planning for future changes (including decision-making).

Week 2 – Ensuring care and comfort: supports learners to recognise and respond to changing cognitive, emotional and physical needs as dementia progresses.

Week 3 – Supporting carers, recognising me: encourages carers to understand their own needs, including how to deal with difficult emotions and how they might feel better supported and equipped as carers.

In the first run of the course, almost 2,500 people from over 100 countries (see map below) joined to find out more about key issues of advancing dementia. An interactive element supports learners to comment on their learning experience through each step of the course. We share some of their insights, motivations and reflections on what they have learned and whether this reflects the key objectives of the course.

Developing the course

Developing a MOOC was strongly supported by the SEED project patient public involvement (PPI) team and considered a novel way of translating research findings from the project into an accessible and practical educational resource. A key ingredient was a collaborative co-design approach (Robert & Macdonald 2017) involving family carers of people with dementia, health and social care professionals and the research team, led by co-author Professor Dame Louise Robinson.

The course is hosted by Futurelearn (2019),

Countries participating in MOOC

which has an ethos of online learning through storytelling and discussion. Family carers and health and social care professionals from the SEED project were invited to participate in short videos to tell their stories, reflecting a diverse range of expertise and experiences. Quizzes and tips are also integral to the MOOC, which encourages carers to exchange views to promote peer support and provide an interactive learning experience.

We supplemented our research findings with clinical observations and points raised in discussion with participants to create examples of what people with dementia described to us as bringing them comfort and then presented these through quotes and images. Photographs of some of our participants with dementia were also used to illustrate their presence on the course.

Before we launched the first MOOC in spring this year – we will be re-running it at various stages – we obtained critical feedback from family carers, clinicians, SEED researchers, online learning experts and others. We asked them to comment on content, appropriateness of language, missing topics and the practicalities of completing the course, and, since the feedback was positive, we had only to make minor revisions. Quality assurance checks were also conducted by Futurelearn.

Key objectives

We began by outlining the six key objectives and now we will set out how they relate to the content of the course.

Understanding symptoms

Evidence suggests that many people find it difficult to understand and recognise signs and symptoms of dementia progression (Samsi & Manthorpe 2014; Goodman *et al* 2015). They may not grasp that dementia is a terminal condition (Bamford *et al* 2018; Poole *et al* 2018) and may not be told by GPs (for example) that this is the case (Vassilas & Donaldson 1998).

As dementia progression underpins the course content, the first week introduces learners to the common signs and symptoms seen as the illness advances. This is then explored in more detail in week two, where learners can find out how people are cognitively, emotionally and physically affected by advancing dementia.

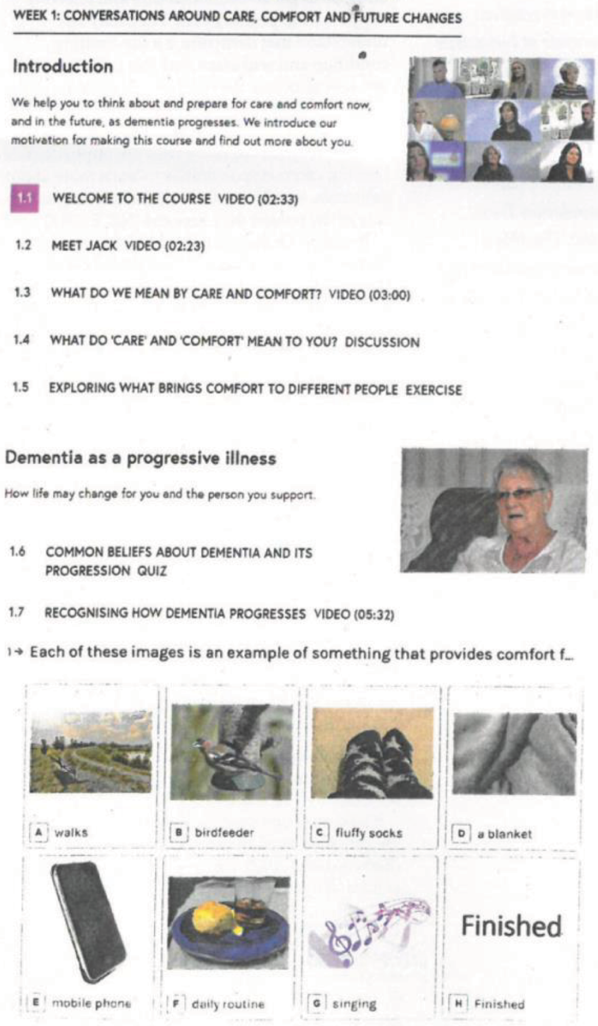
Through comments on the course pages, many participants confirmed that the course gave them a better understanding of what to expect and explained some of the changes they had already experienced. Some said these changes were daunting, but many felt that they were better prepared to face them.

Involvement in decisions

As dementia advances, making decisions can become increasingly difficult as changes in the brain affect the processing of information and communication. People with dementia may be excluded from decision-making even when they could still be involved.

Mental capacity, best interests and the timing of

Left: Advanced nurse practitioner Julie Young with Bill, a SEED participant. Below: pages from the MOOC



WEEK 1: CONVERSATIONS AROUND CARE, COMFORT AND FUTURE CHANGES

Introduction

We help you to think about and prepare for care and comfort now, and in the future, as dementia progresses. We introduce our motivation for making this course and find out more about you.

1.1 WELCOME TO THE COURSE VIDEO (02:33)

1.2 MEET JACK VIDEO (02:23)

1.3 WHAT DO WE MEAN BY CARE AND COMFORT? VIDEO (03:00)

1.4 WHAT DO 'CARE' AND 'COMFORT' MEAN TO YOU? DISCUSSION

1.5 EXPLORING WHAT BRINGS COMFORT TO DIFFERENT PEOPLE EXERCISE

Dementia as a progressive illness

How life may change for you and the person you support.

1.6 COMMON BELIEFS ABOUT DEMENTIA AND ITS PROGRESSION QUIZ

1.7 RECOGNISING HOW DEMENTIA PROGRESSES VIDEO (05:32)

1→ Each of these images is an example of something that provides comfort f...

A walks

B birdfeeder

C fluffy socks

D a blanket

E mobile phone

F daily routine

G singing

H Finished

Left: Comfort care planning at a review meeting.
Above: word cloud image of carer feelings.
Right: Participants at a care home meeting to discuss the MOOC project.
Below right: reviewer comments on MOOC

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advance care planning conversations are therefore a key focus in week one of the course. Based on research findings, professional advice and carers' personal experiences, the course provides tips and advice on how learners might broach "difficult conversations" around planning for end of life care, as well as explaining the law and linking to relevant documents in easy to read formats.

Participants commented that the MOOC had clarified a complex subject, but it was the personal narratives shared by individuals which had reinforced messages about the value of advance care planning and the pitfalls of not making decision-making arrangements before people become unable to make decisions themselves.

Signposting to services

Articles and videos in the MOOC signpost carers to a range of support services for the person with dementia and their family. The course was developed based on UK findings, and many websites link to resources and services in this country. However, some signposts and links to non-uk organisations were included to ensure relevance to international learners.

Learner comments continue to assist us in building this part of the course. Learners exchanged stories about services which had been helpful, or otherwise; those in the UK highlighted regional variations, while international learners pointed to gaps in their own countries and suggested additional resources which are being incorporated into future versions.

Identifying sources of support

Sources of support from well-known national and international organisations are presented as the course unfolds, including direct links to website resources, free helplines and online forums. Week three specifically focuses on carer support and gives some emphasis to the role of technology, where coverage is potentially global rather than local as is often the case with services.

Online forums can provide carers with a space in which to honestly share experiences (McKechnie *et al* 2014) and we found that learners formed their own supportive community with carers from a range of countries and circumstances, sharing stories, emotions and practical advice.

During week three we provided a word cloud based on carers' emotions, derived from our research and clinical experience (see image). Some learners explained that sharing difficult emotions in a safe place was cathartic and enabled them to reflect on their situation in a way they had not previously done.

Person-centred care

The values of person-centred care (Kitwood 1997) underpin the MOOC, which encourages learners to use planning documents to support communication and which promote these values. In weeks one and two, carers are introduced to key documents, such as *This is me* (Alzheimer's Society 2017) and the "comfort care daisy" (Young *et al* 2017), and shown how a short biographical profile of the person with dementia can be completed.

Many carers responded positively to having a practical tool for "comfort care planning" at the end of life. Learners shared their fears and barriers to planning ahead and felt that the document templates, advice and tips provided by the course and fellow learners gave them the confidence to proceed.

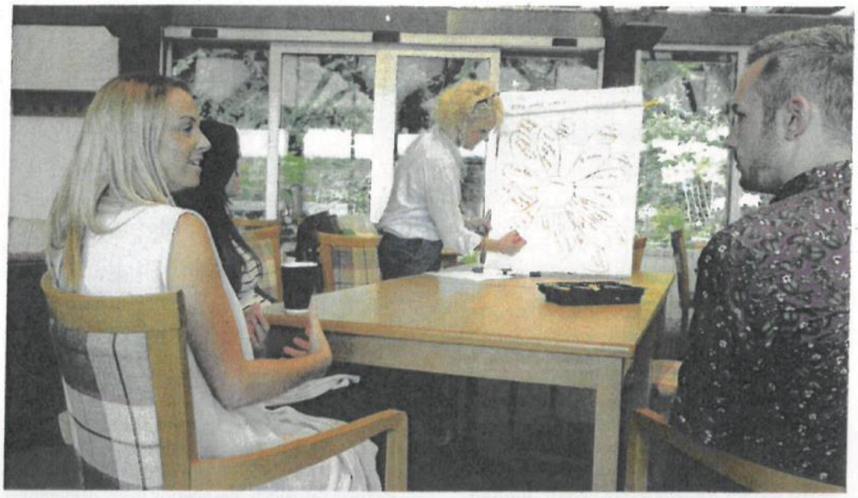
Maintaining quality of life

Maintaining quality of life and ensuring comfort for the person living with dementia is the focus of week two, while helping carers to maintain their own quality of life is emphasised in week three.

In the early stages of the course, we asked learners to share their personal perspective on what care and comfort meant to them and the person they support. The aim was to get carers to reflect on how best to meet changing needs and our request attracted over 300 responses, such as familiarity, love, happiness, expression of autonomy, recognition of individuality and freedom from pain and distress.

Week two goes on to explain some of the common cognitive, emotional and physical changes caused by dementia progression, helping learners to understand and be prepared for them. We then encourage learners to think about meeting these changing needs in the light of a comfort care planning approach.

In week three carers reflect on their own



wellbeing needs and how to maintain their quality of life. Based on our research findings, we look at key factors impacting on wellbeing such as understanding complex emotions and coping with grief. With the help of carers' own stories we consider how to take care of health and wellbeing, and how to access support.

General feedback

Over half of learners in our initial cohort were aged over 46 and almost a quarter were over 65, suggesting that online sources of support are relevant to the family carers who are most likely to be providing care for people with dementia (Boots *et al* 2014). Almost 3,000 comments were generated in feedback and more than 90% of participants were happy with the course.

Many learners were open about the struggles they had faced caring for someone with advancing dementia. They came together to build a supportive global network through sharing their diverse experiences and giving encouragement and advice to other learners. Some participants were care providers rather than family carers, although their motivations for joining the course were similar, namely to better understand dementia and provide better care. Comments suggest that a small number of people with dementia took part; their principal reason for joining was to prepare for the future by better understanding what may be personally in store.

Next steps

Dementia care MOOCs have started to come into their own; there are a number of others available, for example from the University of Tasmania, University College London and Lancaster University.

At Newcastle University we now have two such MOOCs – the one we have described here focusing on living well as dementia progresses and our successful sister MOOC, which introduces family carers to dementia and how to care effectively from the earlier stages.

Both courses are free of charge and we hope dementia care practitioners will encourage family carers to take full advantage of the learning and support they have to offer. They can be accessed as follows:

Dementia Care: Living Well as Dementia Progresses
www.futurelearn.com / courses / comfort-care

Dementia Care: Staying Connected and Living Well
www.futurelearn.com / courses / dementia-care ■

Acknowledgements

We would like to acknowledge the National Institute for Health Research (NIHR) and Newcastle University as our funders; Northumbria Healthcare NHS Trust as our sponsor; Futurelearn as the host platform; Newcastle University Digital Media Team for their production; the wonderful health and social care professionals and family carers who gave up their time to participate; and all those who have joined and taken part in the course.

Palliative Care Consultant: *"Nothing too upsetting. Videos are excellent and just about right length. Views balanced. Clearly recorded."*

Current and bereaved carer: *"I always find personal engagement from real people more engaging and the videos give this. I think the carers stories are particularly relevant to everything I have experienced and am experiencing."*

PPI expert and bereaved carer: *"Particularly liked the opening video, showing the people who would be talking in the videos."*

Current carer: *"I think the course is really good. It is clear and easy to follow. I think it strikes the right note – not overly simplified, but also tackling difficult subjects in a straightforward way... I have enjoyed taking part in the development of the course."*

LTDS member: *"I found it really interesting, thoughtful and considerate/respectful. It normalised dementia and took away some of the stigma and myths, making it real and human, without it being dramatic or emotional. Well pitched, with excellent resources."*

Current carer: *"I did do the quizzes and thought they helped to cement understanding."*

assessment, management and support for people living with dementia and their carers. London: NICE.
Poole M, Bamford C, McLellan E, Lee RP *et al* (2018) End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliative Medicine* 32(3) 631-642.
Robert G, Macdonald AS (2017) Co-design, organisational creativity and quality improvement in the healthcare sector: 'designerly' or 'design-like'?, in Sangiorgi D & Prendiville A (eds) *Designing for service: contemporary issues and novel spaces.* London: Bloomsbury.
Samsi K, Manthorpe J (2014) Care pathways for dementia: current perspectives. *Clinical Interventions in Aging* 9 2055-63.
Vassilas CA, Donaldson J (1998) Telling the truth: what do general practitioners say to patients with dementia or terminal cancer? *British Journal of General Practice* 48(428) 1081-1082.
Young J, Gilbertson S, Reid J (2017) Comfort care plans: a collaborative project. *Journal of Dementia Care* 25(6) 18-20

Appendix 3 The SEED intervention (workstream 3)

Overview

In this appendix we present additional information on how the intervention was developed and operationalised. Further details are available in the SEED manual and appendices available as *Report Supplementary Material 2*. Key areas included in this appendix are:

- overview of phase 1 workshops
- recruitment of the DNSs –
  - job description for DNS
  - person specification for DNS
- materials for the DNSs –
  - example of resources for one key component (timely planning discussions)
  - educational needs assessment
  - example of SEED activities and outcomes for one key component (timely planning discussions)
  - example of SEED activity checklists for one key component (timely planning discussions)
- development of new SEED resources.

Developing an evidence-based intervention

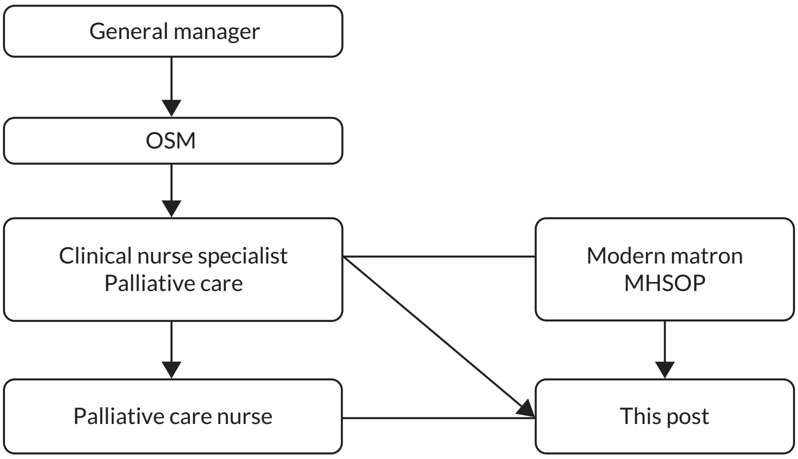
Overview of phase 1 workshops to generate and prioritise ideas

- Workshop 1 comprised small group activities to discuss the purpose of the intervention and potential uses and users, and to clarify the boundaries of the intervention.
- In workshops 2 and 3, care trajectories from the MCDP cohort data and clinical scenarios from WS2 data were used to prompt discussion of the possible content of, and resources needed to support, the intervention.
- Workshop 4 considered how existing national guidance could inform the intervention and reviewed available educational/training resources.
- In workshop 5, key findings from WSs 1 and 2 were presented, followed by team activities to identify gaps in existing care and identify possible ideas for the intervention.

Job description for dementia nurse specialist

Job details			
Job title:	Dementia nurse/care facilitator		
Business unit:	Community		
Department/ward:	Palliative care		
Location:	North Tyneside Community		
Pay band:	Band 6		
CAJE no:	NUR1199	KSF no:	

Main purpose of the job
The SEED programme is funded by NIHR and is led by Professor Louise Robinson at the University of Newcastle, in collaboration with partner organisations. This is a 5-year research programme, which will explore in detail what constitutes 'good practice' care; first by interviewing key groups and observing real-world practice. From these data, we will develop a good-practice intervention to test out and compare with usual care. This post, dementia nurse care facilitator, was developed from the study findings. This fixed-term post for 12 months will aim to support professionals, both commissioning and providers, to deliver good-quality community-based EOLC in dementia through the development of an integrated care pathway
Dimensions
The post-holder will be recognised as an expert in either dementia and/or palliative care and will act as a lead (1) provider of information and (2) facilitator of care/services for people with dementia and their carers In addition, their role will influence, initiate and manage change to influence local health agenda in relation to dementia and EOLC. To be aware of the constantly changing local and national political agenda and respond appropriately, for example national service frameworks. To contribute to the development of clinical governance and quality frameworks and lead as appropriate on the implementation of policies in and across professions and teams
Organisation chart



1. Communications and relationships

- To act as a specialist resource to facilitate community-based professionals to deliver highly complex service, co-ordinated for people with dementia and give expert practical, clinical and emotional support to carers and families living with dementia
- Be influential through the development of communication systems with primary care GP services to improve the access for the person with dementia, whether in their own homes or in a care setting, to specialist community services through the EOL pathway, for example Macmillan nurses and palliative care doctors
- Be influential through the development of communication systems with secondary care services to improve the access for the person with dementia, whether in their own homes, in hospital or in a social care setting, to specialist community services through the EOL pathway, for example Macmillan nurses, palliative care doctors, mental health services for older people, memory services, social care, hospice and respite services

2. Knowledge, skills, training and experience

- Registered nurse-adult or registered nurse-mental health
- Demonstrable level of previous post-registration experience of working with people with dementia and/or EOLC in primary and secondary care settings
- Demonstrable up-to-date knowledge of national/local palliative care/EOLC service frameworks
- Demonstrable up-to-date knowledge of national/local dementia strategies and how they interface with palliative care/EOL services
- Teaching and mentoring qualification, for example ENB 998, C&G 703/7, D32/33
- Experience of delivering or co-facilitating education and training
- Specialist knowledge of the Mental Health Act 1983[200] (amended in 2007)
- Knowledge of the Mental Capacity Act 2005[130] and the Deprivation of Liberty Safeguards amendment
- Knowledge of local authority safeguarding policies and procedures
- Effective use of communication (both written and verbal) and interpersonal skills
- Ability to work autonomously

3. Analytical skills

- Undertake initial patient assessments; formulate, initiate and evaluate treatment plans with the person with dementia, their carers and families
- Use a comprehensive range of specialist knowledge and skills in palliative and dementia care in order to provide expert practical, clinical and emotional support to carers and families living with dementia during EOL

4. Planning and organisational skills

- The postholder will be an autonomous practitioner expected to organise primary care/secondary care meetings and education, and to input to the SEED programme of research, alongside a clinical role
- The provision of support via link meetings and person-centred advice to embed best practice

5. Physical skills

- Standard keyboard skills
- Driving between primary and secondary care

6. Patient/client care

- Exercise accountability for patient care, as set out in the NMC Code of Professional Conduct and at all times act within the policies and procedures of NHCT
- To work in partnership with the palliative care specialist nurse and modern matron for MHSOP in providing leadership and best practice for people with dementia during EOLC in primary, secondary and social care settings
- To be responsible for the planning and delivery of specialist palliative care services in primary and secondary care, prioritising clinical need to provide person-centred care to people with dementia, their carers and families at the EOL
- Act as an advocate to empower the person with dementia, their carers and families to influence and access available specialist services as they move towards the EOL
- To carry out risk assessments and management of the physical environment to safeguard the person with dementia, staff, carers and families to enable complex health needs to be managed in the appropriate environment at the EOL
- To assess, plan, implement and evaluate specialist packages of care for people with dementia as they move towards the EOL, which can include the analysis of highly complex clinical, social and family situations
- Work flexibly to enable timely responses to the changing needs of the person with dementia at the EOL
- Take a full and equal part with MDTs in both primary and secondary care to ensure delivery of person-centered care to the person with dementia, their carers and families as they approach the end of their lives
- Be adaptable to working with the person with dementia who may experience periods of challenging behaviour and how this may affect their EOLC
- To participate in clinical supervision

7. Policy and service development

- Influence, initiate, implement and manage changes in practice and policy relating to people with dementia and EOLC
- Be aware of the constantly changing national and local health agendas and how this relates to people with dementia and EOLC
- Work in partnership with the palliative care specialist nurse and modern matron for MHSOP in contributing to the development of the clinical governance and quality frameworks to support person-centred care delivery to people with dementia, their carers and families as they approach EOL
- Active involvement (leading, when appropriate) in raising the profile of this post within EOL and dementia care

8. Financial and physical resources

- To contribute to the effective and efficient use of equipment and resources belonging to NHCT
- Ensure that all business mileage and expenses are completed and submitted in accordance with NHCT financial procedures

9. Human resources

- Education and training is core to this post. Clinical supervision will be offered by Palliative Care CNS and Modern Matron for MHSOP, as dictated
- Provides clinical supervision to students

10. Information resources

The postholder will have responsibility for ensuring that patient records are up to date, as required

11. Research and development

A key focus of this role is for the postholder to participate in the SEED research programme as a self-directed professional in collaboration with other members of the multiprofessional team. Encourage and support other professional involvement in the relevant research and contribute to the evidence base for the nursing and medical interventions

12. Freedom to act
The postholder of this fixed-term contract will be an autonomous practitioner who will liaise closely with the palliative care CNS/senior consultant in liaison with the research team. The postholder will be accountable for their own actions

C&G, City & Guilds; CAJE, computer-aided job evaluation; CNS, clinical nurse specialist; ENB, English National Board for Nursing, Midwifery and Health Visiting; KSF, Knowledge and Skills Framework; MHSOP, Mental Health Services for Older People; NHCT, Northumbria Healthcare NHS Foundation Trust; NMC, Nursing and Midwifery Council.

Person specification for dementia nurse specialist

Job title: dementia nurse/care facilitator.

Department: palliative care.

Location: North Tyneside Community.

Specification	Essential	Desirable
Qualifications/professional registration	• Registered nurse-adult or registered nurse-mental health • Demonstrable level of previous post-registration experience of working with people with dementia and/or EOLC in primary and secondary care settings • ENB 998, C&G 703/7	• D32/33 • Experience of delivering, co-facilitating education training
Experience and knowledge	Autonomous professional with experience of working with people with dementia at EOL across primary care settings, including specialist knowledge of Mental Health Act 1983[200] legislation	
Skills and abilities	• Communication skills, written and verbal • IT skills to enable post-holder to input data into clinical systems • Leadership skills • Autonomous practitioner	
Personal attributes	Committed to: • Trust-working • Quality care/performance • Personal/service development	
Other requirements	• To be physically capable of carrying out full requirements of this post • It is an essential requirement of the role that the post-holder has a valid driving licence and is either a car owner and able to use the car for work purposes, or has a trust personal lease vehicle that may be used for the role. However, the trust would consider making reasonable adjustments to the role, if necessary, to enable a disabled person to undertake the role	

C&G, City & Guilds; ENB, English National Board for Nursing, Midwifery and Health Visiting.

Example of resources for one key component (timely planning discussions)

Timely planning discussions

Scene-setting (illness trajectory)	People with dementia	Family	Staff
ACP and advance health-care directives with a person with dementia[a] (68-page guidance)			✓
Advanced dementia[a] (online information)			✓
EOLC[a] (12-page fact sheet)		✓	

Scene-setting (illness trajectory)	**People with dementia**	**Family**	**Staff**
Facilitating discussions on future and EOLC with a person with dementia[a] (52-page guidance)			✓
Later stages of dementia[a] (eight-page fact sheet)	✓	✓	
Progression of Alzheimer's disease[a] (two-page fact sheet)	✓	✓	

a Dementia-specific resource.

Planning (value of, types of, who to involve)	**People with dementia**	**Family**	**Staff**
ACP and advance health-care directives with a person with dementia[a] (68-page guidance)			✓
ACP and advance health-care directives with a person with dementia[a] (two-page fact sheet)			✓
ACP[b] (online information)			✓
Advance decisions and advance statements[a] (11-page fact sheet)	✓	(✓)	
Arranging for someone to make decisions on your behalf[b] (42-page fact sheet)	✓	(✓)	
Before you go: planning and support for EOL[b] (48-page information guide)	✓	(✓)	
Caring for someone with dementia[a] (two-page practical guide)		✓	
Create an Advance Decision[b,c] (online tool, £10)	✓	(✓)	
Create an Advance Statement[b,c] (online tool, £5)	✓	(✓)	
Deciding Right App[b,c] (support guide app)			✓
Dementia and decision-making[a] (online information)			✓
Dementia and EOL planning[a] (online information)	✓	✓	
Early planning[a] (two-page fact sheet)	✓	✓	
EOLC: what matters to the person who's dying[b] (11-minute video)			✓
EOLC: why talking about death and dying matters[b,c] (10-minute video)			✓
Exercising choice and control through a living will[b] (online information)	✓	(✓)	
Financial and legal affairs[a] (13-page fact sheet)	✓	✓	
I have dementia, how do I plan for the future?[a] (32-page booklet)	✓	(✓)	
Lasting power of attorney[a] (14-page fact sheet)	✓	(✓)	
Making a will[b] (14-page fact sheet)	✓	(✓)	
Making decisions and planning your care[b] (online information)	✓	✓	
Planning for a funeral[b] (32-page fact sheet)	✓	(✓)	
Planning for your future care[b] (16-page guide)	✓	(✓)	
Powers of attorney[b] (40-page information guide)	✓	(✓)	
Wills and estate-planning[b] (32-page information guide)	✓	(✓)	

a Dementia-specific resource.
b Generic resource.
c Specific tool.

Note

✓ Indicates that family carers are the primary audience for the resource.
(✓) Indicates that the resource is targeted at people with dementia but is also likely to be relevant to family carers.

Process of planning (skills to facilitate discussions)	People with dementia	Family	Staff
Before you go: planning and support for end of life[b] (48-page information guide)	✓	(✓)	
Dementia and decision-making[a] (online information)			✓
EOLC: what matters to the person who's dying[b] (11-minute video)			✓
Facilitating discussions on future and EOLC with a person with dementia[a] (52-page guidance)			✓
Facilitating discussions on future and EOLC with a person with dementia[a] (two-page fact sheet)			✓
Five things to do before I die![b] (trifold leaflet)	✓		
I have dementia . . . how do I plan for the future?[a] (32-page booklet)	✓	(✓)	
Looking ahead[a,c] (four-page tool)			✓
My future well-being tool[a,c] (12-minute demonstration video)	✓	✓	✓
One last thing . . .[b] (trifold leaflet)		✓	
Remember when we . . .[b] (trifold leaflet)		✓	
Thinking ahead: ACP discussions[b,c] (two-page discussion document)			✓
Thinking ahead[a,c] (four-page tool)	✓		
Time to talk?[a] (eight-page leaflet)		✓	
Time to talk, Doc?[a] (4-minute video)			✓
To-do list[b] (trifold leaflet)	✓		

a Dementia-specific resource.
b Generic resource.
c Specific tool.

Educational needs assessment for dementia nurse specialist

Thinking about . . .	Specific skills/knowledge	Confident about this	Need to learn about this
Timely planning discussions	Able to establish relationships and communicate effectively with people with dementia and their families		
	Aware of how to introduce ACP and other possible planning/decisions		
	Understand the legal and clinical status of different approaches to planning (e.g. LPA and DNACPR)		
	Able to work collaboratively with existing staff responsible for discussing EOL planning (e.g. in hospices or with cancer patients) to share skills and knowledge		
	Able to mentor and support staff to take on additional responsibilities related to timely planning discussions with people with dementia		
	Able to advocate on behalf of the people with dementia if family members have reservations about his/her preferences		
	Able to resolve conflict effectively when people with dementia and family members disagree		

Thinking about . . .	Specific skills/knowledge	Confident about this	Need to learn about this
Recognition of EOL and provision of supportive care	Understand common symptoms that may arise at EOL in dementia and how to identify and manage these (including use of appropriate assessment tools)		
	Able to elicit and address fears and concerns of people with dementia /families/professionals about management of crisis, distress and pain		
Co-ordination of care	Able to support community staff in analysing and responding to behavioural and psychological symptoms of dementia		
	Able to support professionals/people with dementia/families to plan for crisis/deterioration		
	Able to identify and analyse support networks of people with dementia and families, and to develop or sustain support		
	Well informed about sources of support locally (including out-of-hours services)		
	Able to negotiate effectively with multiple health and social care agencies		
	Able to foster links between day and night staff to improve integration		
Effective working relationships with primary care	Able to develop good working relationships with members of an established team		
	Able to provide training on dementia and EOL needs to primary care colleagues as required		
	Able to contribute effectively to existing primary care meetings (e.g. district nurse meetings and 'virtual ward rounds')		
	Able to use new systems for recording medical and nursing records effectively		
	Able to review existing systems within primary care relating to EOLC (e.g. prescription of anticipatory medicines) and identify strategies for reducing unwarranted variations in practice		
Managing hospitalisation	Able to command confidence and exhibit negotiation skills in liaison with a MDT		
	Able to advocate on the person's behalf or support them in self-advocacy		
	Able to work with multiple agencies to develop pathways for aspects of EOLC for people with dementia that will minimise unnecessary hospitalisation		
Continuing care after death	Able to offer support to bereaved carers and other members of the support network		
	Understand systems and policies to ensure appropriate care of the deceased (including involvement of services such as the police/coroner)		
Valuing staff and ongoing learning	Able to deliver training at an appropriate level for a range of community staff		
	Able to facilitate detailed case review discussions with a range of community staff to identify successes and areas for development		

Thinking about . . .	Specific skills/knowledge	Confident about this	Need to learn about this
	Identify own support needs and those of other health and social care staff involved in EOLC for people with dementia, and identify ways of addressing these		
	Able to raise awareness of the emotional work involved in EOLC for people with dementia and ways of supporting staff		
Additional skills	Well informed about the range of dying trajectories in dementia		
	Able to contribute to development of interventions by using the theory of change		
	Understand the roles and responsibilities of different individuals and organisations in clinical research		
	Understand the process of receiving informed consent and the roles and responsibilities of those involved in this process		
	Understand the Mental Capacity Act 2005[130] and be able to assess the capacity of people with dementia who are eligible for the pilot trial		

DNACPR, do not attempt cardiopulmonary resuscitation; LPA, lasting power of attorney.

Example of SEED activities and outcomes for one key component (timely planning discussions)

	Activities: individual level	Outcomes
1.1	Discussions about: • EOL trajectory in dementia • Personal values • Preferred decision-makers (including LPA) • Comfort care planning • Unwanted treatments and interventions (including hospitalisation and DNACPR)	Documented in patient notes
1.2	Assessment of capacity, when relevant, prior to completion of formal documentation	Documented in patient notes
	Documentation completed on: • Preferred decision-makers (including LPA) • Comfort care planning • Unwanted treatments and interventions (including hospitalisation and DNACPR)	• Documented in patient notes • Interviews with patients/carers
1.3	Documentation disseminated to: • Care home • Out-of-hours service • Ambulance service	Review of care home and GP records
1.4	Timely review of documents above	Review of care home and GP records

DNACPR, do not attempt cardiopulmonary resuscitation; LPA, lasting power of attorney.

	Conditions: system level	Outcomes
1.1	• Staff trained and competent in assessment of capacity • Responsibility for assessment of capacity and contexts in which assessment is required are agreed	• Training records • Documented responsibility • Informal discussions
1.2	• Staff aware that discussions are an outcome in themselves and should be documented • Responsibility and trigger points for different types of discussion are agreed • Staff have appropriate knowledge of different planning options, access to resources to support discussions (e.g. care planning guide) and can signpost individuals to appropriate professionals for further discussion/documentation	• Informal discussions • Documented responsibility and trigger points • Resources available • Informal discussions
1.3	Staff aware of documentation and requirements for completion (including time frame for review)	• Training records • Informal discussions
1.4	A protocol for appropriate dissemination of completed documents	Protocol exists, is accessible and has date for review
1.5	Protocol that sets out appropriate intervals and trigger points for reviewing EOL documentation	Protocol exists, is accessible and has date for review

Example of SEED activity checklists for one key component (timely planning discussions)

1. Timely planning discussions to:

- 1.1 provide opportunities for discussions about EOLC with patients and families
- 1.2 provide opportunities for documenting preferences for EOLC
- 1.3 ensure appropriate dissemination of completed documents
- 1.4 ensure timely review of completed documents.

	Activities: individual level	Achieved (yes/no)	Date	Plan of action
1.1	• Discussions about EOL trajectory in dementia • Unwanted treatments and interventions (including hospitalisation and DNACPR)			
	Discussions about personal values			
	Discussions about preferred decision-makers (including LPA)			
	Discussions about comfort care planning			
	Discussions about unwanted treatments and interventions (including hospitalisation and DNACPR)			
1.2	Assessment of capacity, when relevant, prior to completion of formal documentation			
	Documentation completed on preferred decision-makers (including LPA)			
	Documentation completed about comfort care planning			
	Documentation completed about unwanted treatments and interventions (including hospitalisation and DNACPR)			
1.3	Documentation disseminated to care home			
	Documentation disseminated to out-of-hours service			
	Documentation disseminated to care home ambulance service			
1.4	Timely review of documents			

DNACPR, do not attempt cardiopulmonary resuscitation; LPA, lasting power of attorney.

	Conditions: system level	Achieved (yes/no)	Date	Plan of action
1.1	• Staff trained and competent in assessment of capacity • Responsibility for assessment of capacity and contexts in which assessment is required are agreed			
1.2	• Staff aware that discussions are an outcome in themselves and should be documented • Responsibility and trigger points for different types of discussion are agreed • Staff have appropriate knowledge of different planning options, access to resources to support discussions (e.g. care planning guide) and can signpost individuals to appropriate professionals for further discussion/documentation			
1.3	Staff aware of documentation and requirements for completion (including time frame for review)			
1.4	A protocol for appropriate dissemination of completed documents			
1.5	Protocol that sets out appropriate intervals and trigger points for reviewing EOL documentation			

Development of new SEED resources

The review of existing resources highlighted gaps in three key areas:

1. a simple introductory guide to planning for the future
2. clinical scenarios illustrating common issues in EOLC in dementia and strategies to address these
3. online training focused on advanced dementia and EOLC.

The rationale for selecting these areas and a description of the progress made in developing new resources are described below.

Introductory guide to planning for the future

Although a wide range of resources addressed planning for the EOL, there was no simple, introductory overview of the different options available or that provided key information on completed plans (e.g. where such plans were stored and whether or not they had been discussed with the GP). WS2 highlighted the lack of knowledge of ACP and misconceptions over the validity and status of completed documents. For example, even when preferences for invasive treatment had been discussed, these had not necessarily been shared with the GP or documented in a way that would ensure that these preferences were followed in the event of an emergency. A simple document, outlining the range of plans to consider, prompting discussion of key plans with the GP and indicating where the plans were stored, was, therefore considered a potentially useful resource.

A co-design approach was seen as integral to the development of a meaningful and useful care planning guide (CPG) to meet the needs outlined above.[103,104] A key tenet of co-design is that users, as experts of their own experience, become central to, and embedded within, the design process.[105,201] The process was led by researchers from the Glasgow School of Art who were experienced in using co-design and stakeholder engagement for co-developing health-care interventions. A combination of approaches was used, beginning with full project team workshops and then moving onto small task group work[202] with potential users of the CPG (i.e. people with dementia, families and professionals). The development of the prototype involved two stages:

1. initial ideas and prototypes were developed during internal project workshops with the multidisciplinary SEED team, which included PPI, and the PPAB convened to support the SEED programme
2. refinement of the prototype CPG through three external workshops involving 20 newly recruited participants from key stakeholder groups (people with dementia, family carers, paid carers, doctors, nurses, support workers and occupational therapists).

These external workshops resulted in a mock-up of the CPG in paper format and diagrams to illustrate a potential digital/app format. The latter was subsequently developed into a demonstration prototype app. However, it became apparent that different stakeholder groups had different needs and wishes. Meanwhile, the NHS created a new EOLC website,[203] which was widely recommended for national use. Consequently, further development of the SEED CPG was considered unnecessary as this new resource covered much of the same ground.

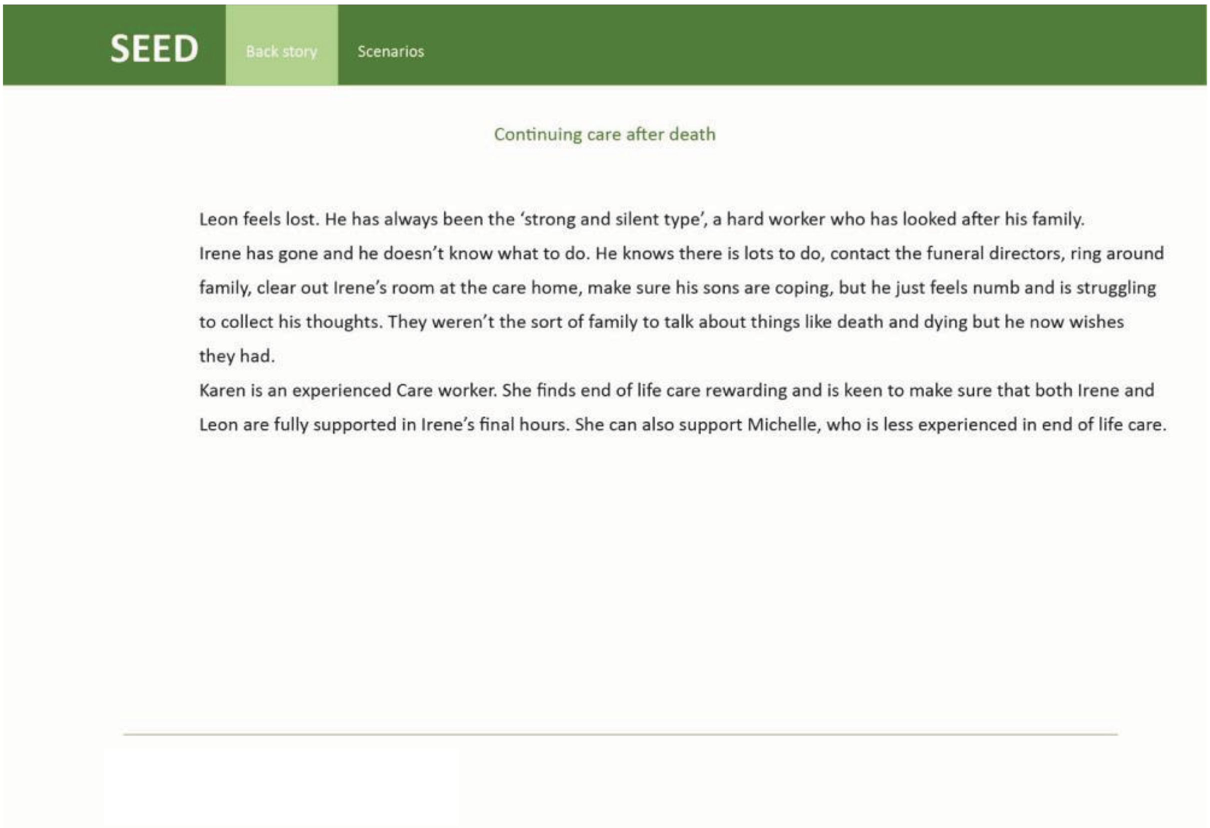
Clinical scenarios to illustrate common issues in end-of-life care in dementia

Workstream 2 findings highlighted a number of areas in which user-friendly resources were needed to support good EOLC. The comparative case studies suggested that developing clinical scenarios to illustrate common issues and facilitate discussion would be valued. Such resources could either be used for staff training or be used with people with dementia and carers as a way of opening up discussions. Using electronic learning (e-learning) resources was identified as a key way of reaching a large number of participants, with limited input required post development. Examples that illustrated common clinical situations and areas of difficult decision-making that are likely to be encountered towards, and at, the EOL in dementia were identified. One example, relating to continuing care after death, was developed (see *Appendix 3*, *Clinical scenario: continuing care after death*). The WS2 team developed the initial content using WS2 data. This was then refined and further developed by the WS3 team. The presentation was informed by the review of existing resources, including The Sound Doctor (films focused on a wide variety of long-term illnesses, including dementia)[204] and Breech Birth (an animated film exploring decision-making).[205] The Sound Doctor resource for dementia comprises a series of films for people with dementia and their families, which cover the trajectory from diagnosis to the later stages of the illness. The films are designed for people with dementia and carers, but are also relevant to health-care and social care staff. Owing to resource constraints, it was not feasible to develop the clinical scenarios further; however, the work was subsequently used in the development of the MOOC (see below).

Massive open online course

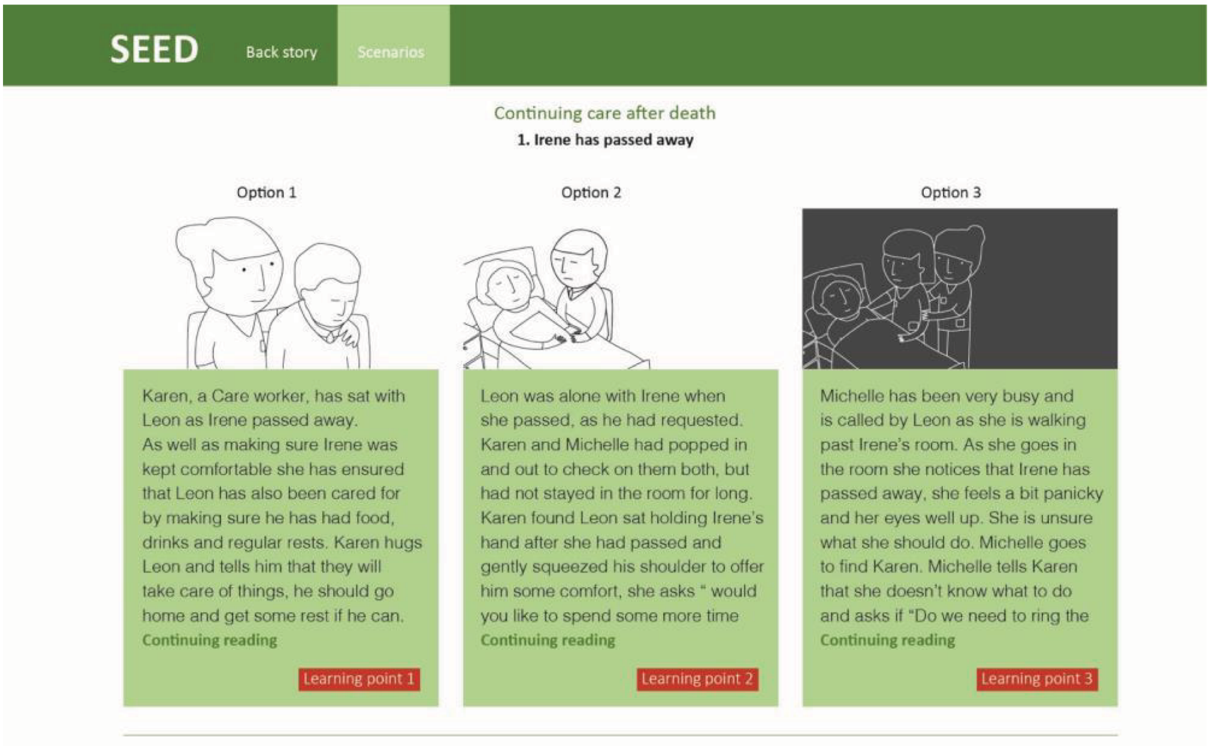
Newcastle University had already developed a MOOC that focused on the earlier stages of dementia: *Dementia Care: Living Well and Staying Connected*. This MOOC was hosted by FutureLearn (part of the Open University) and had attracted > 7000 active learners across 168 countries since its launch in 2016. Having presented the findings of the resource review and a demonstration of the dementia MOOC to the PPAB, it recommended that a second dementia MOOC should be developed focusing on the more advanced stages of dementia and based on the key findings from the SEED programme. Additional funding from Newcastle University was secured for the development of the MOOC. Further details of the MOOC are provided in *Workstream 3: development of the SEED intervention*.

Clinical scenario: continuing care after death



Continuing care after death

Leon feels lost. He has always been the 'strong and silent type', a hard worker who has looked after his family.
Irene has gone and he doesn't know what to do. He knows there is lots to do, contact the funeral directors, ring around family, clear out Irene's room at the care home, make sure his sons are coping, but he just feels numb and is struggling to collect his thoughts. They weren't the sort of family to talk about things like death and dying but he now wishes they had.
Karen is an experienced Care worker. She finds end of life care rewarding and is keen to make sure that both Irene and Leon are fully supported in Irene's final hours. She can also support Michelle, who is less experienced in end of life care.



Continuing care after death

1. Irene has passed away

Option 1

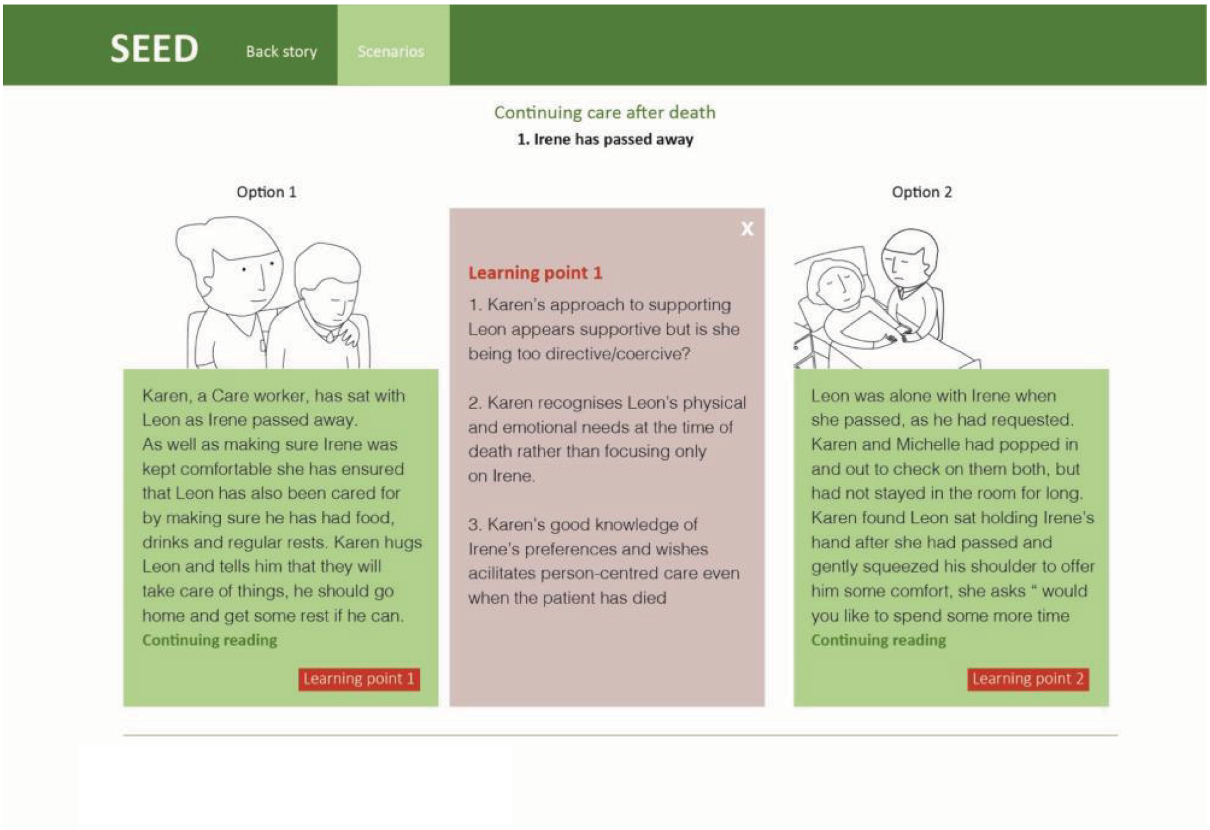
Karen, a Care worker, has sat with Leon as Irene passed away. As well as making sure Irene was kept comfortable she has ensured that Leon has also been cared for by making sure he has had food, drinks and regular rests. Karen hugs Leon and tells him that they will take care of things, he should go home and get some rest if he can.
Continuing reading

Option 2

Leon was alone with Irene when she passed, as he had requested. Karen and Michelle had popped in and out to check on them both, but had not stayed in the room for long. Karen found Leon sat holding Irene's hand after she had passed and gently squeezed his shoulder to offer him some comfort, she asks " would you like to spend some more time
Continuing reading

Option 3

Michelle has been very busy and is called by Leon as she is walking past Irene's room. As she goes in the room she notices that Irene has passed away, she feels a bit panicky and her eyes well up. She is unsure what she should do. Michelle goes to find Karen. Michelle tells Karen that she doesn't know what to do and asks if "Do we need to ring the
Continuing reading



Continuing care after death

1. Irene has passed away

Option 1

Karen, a Care worker, has sat with Leon as Irene passed away. As well as making sure Irene was kept comfortable she has ensured that Leon has also been cared for by making sure he has had food, drinks and regular rests. Karen hugs Leon and tells him that they will take care of things, he should go home and get some rest if he can.

Continuing reading

Learning point 1

1. Karen's approach to supporting Leon appears supportive but is she being too directive/coercive?

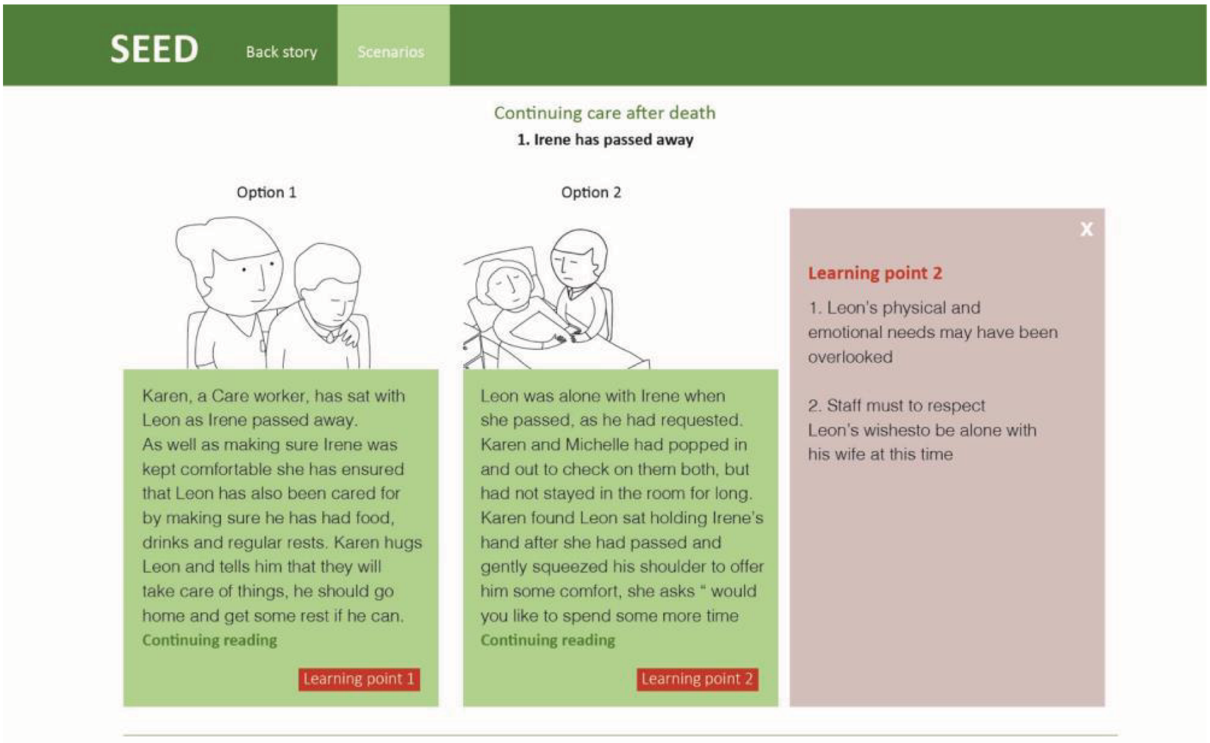
2. Karen recognises Leon's physical and emotional needs at the time of death rather than focusing only on Irene.

3. Karen's good knowledge of Irene's preferences and wishes acilitates person-centred care even when the patient has died

Option 2

Leon was alone with Irene when she passed, as he had requested. Karen and Michelle had popped in and out to check on them both, but had not stayed in the room for long. Karen found Leon sat holding Irene's hand after she had passed and gently squeezed his shoulder to offer him some comfort, she asks " would you like to spend some more time

Continuing reading



Continuing care after death

1. Irene has passed away

Option 1

Karen, a Care worker, has sat with Leon as Irene passed away. As well as making sure Irene was kept comfortable she has ensured that Leon has also been cared for by making sure he has had food, drinks and regular rests. Karen hugs Leon and tells him that they will take care of things, he should go home and get some rest if he can.

Continuing reading

Option 2

Leon was alone with Irene when she passed, as he had requested. Karen and Michelle had popped in and out to check on them both, but had not stayed in the room for long. Karen found Leon sat holding Irene's hand after she had passed and gently squeezed his shoulder to offer him some comfort, she asks " would you like to spend some more time

Continuing reading

Learning point 2

1. Leon's physical and emotional needs may have been overlooked

2. Staff must to respect Leon's wishesto be alone with his wife at this time

Appendix 4 Pilot trial of the SEED intervention with process evaluation to ascertain feasibility and acceptability (workstream 4)

Pilot trial methods

The aim of WS4 was to investigate whether or not a definitive multicentre RCT of the SEED intervention is feasible. This appendix provides additional details of the methods, including key areas from the relevant reporting guidelines.[124–127]

The study was set in North East England in two urban sites (in North Tyneside/Newcastle) and two rural sites (in Northumberland). North Tyneside's older population is representative of the general population, whereas Northumberland has a higher percentage of older people than the national average.[7] All practices were invited to use the Dementia Quality Toolkit to review their dementia register and ensure that it was as complete as possible prior to the start of the trial.

The sample size of 66 participants was estimated to provide standard errors around the recruitment rate of $\approx$ 4.7%, and standard errors around the completion of outcome data no larger than 6.2% at 4 and 8 months, rising to 8.7% at 12 months, assuming a 50% mortality rate.

Inclusion criteria

People with dementia on the dementia register who:

- received a diagnosis of dementia in the previous 2 years
- were on the palliative care register
- were considered to be within 12 months of EOL as judged by a member of the clinical care team (e.g. GP, district nurse, care home nurse) who knows them well using the 'surprise' question 'Would you be surprised if this patient were to die in the next 12 months?'.

Family carers:

- main family carer of the participating person with dementia
- aged $\geq$ 18 years.

Key informants:

- health or social care professionals who know the person well, who are in direct service provision to the person with dementia and are able to report on QoL, behavioural and psychological symptoms of dementia, symptom management and so on.

Exclusion criteria for all participants

- Potential participants who refuse consent.
- Individuals aged < 18 years.
- Potential participants who are judged as inappropriate for the study by a member of the primary care team (e.g. because of concurrent life events such as bereavement).

- Participants who are not fluent English speakers, because they would be unable to complete the standardised outcome measures (people with dementia, family carers and key informants) and are likely to have difficulties in participating in a qualitative interview (people with dementia, family carers and professionals).

Process evaluation

The process evaluation aimed to understand the implementation, feasibility and acceptability of the intervention. The aim was also to explore stakeholder views on recruitment processes and outcome measures (in terms of burden, ease of completion and perceived relevance). Inclusion criteria for the process evaluation were as follows:

- people with dementia who have consented to participate in the pilot trial and agreed to contact from the qualitative research team
- family carers of people with dementia recruited to the study who have consented to participate in the pilot trial and agreed to contact from the qualitative research team
- health and social care professionals linked to intervention sites who provide EOLC to people with dementia and their families
- members of the intervention supervision team
- members of the primary care team most closely involved in screening and study recruitment.

People with dementia and/or family carers who did not consent to contact from the qualitative team during the initial trial consent process were not eligible for the process evaluation. Potential participants who refused consent were excluded, as were any individuals aged < 18 years.

Interviews, training and supervision were audio-recorded, transcribed verbatim, anonymised and checked prior to analysis. Field notes were written during or soon after events were observed, and were anonymised and checked.

Outcome data

As this is a pilot trial, the main outcomes were feasibility outcomes. We ascertained data completeness of the instruments and any potential bias in the completion of follow-up data to inform the choice of instruments in a future trial. Complete responses were defined as participants completing all items on the questionnaire, and partial responses were defined as participants completing at least 80% of the items but not fully completing the questionnaire. Missing was defined as answering < 80% of the questionnaire items. Details of scoring procedures are provided in *Table 12*. Data were analysed using Stata® version 14 (StataCorp LP, College Station, TX, USA).

The majority of the outcome data are presented in simple descriptive tables with percentages, means and standard deviations and/or a five number summary (as appropriate), for each arm of the study. This information will inform the design, choice of primary outcome, necessary sample size and approach to the analysis of a future definitive trial.

Trial management

Research ethics and governance

The study received ethics approval from the Newcastle and North Tyneside 1 Research Ethics Committee (REC) on 16 January 2017 (reference number 16/NE/0356). Health Research Authority approval was granted on 18 January 2017. Scheduled reports were submitted to the REC as planned: an annual progress report was submitted on 15 January 2018 and the end-of-study notification was submitted on 8 January 2018. No concerns or queries were received from the REC after report submissions. The SEED WS4 study was sponsored by Northumbria Healthcare NHS Foundation Trust [reference number Integrated Research Application System (IRAS) 211291]. Study management,

TABLE 12 Details of outcome measures, scoring procedures and interpretation

Questionnaire	Scale/subscale details	Question scoring	Overall score	Notes
HADS	14 questions in total; seven questions each for anxiety and depression subdomains	Questions scored 0–3 and 3–0 (ranging from not at all/never/hardly at all, etc. to very often/most of the time, etc.)	0–21 for each domain; overall score range is 0–42 when scores from each question are added	If ≥ 80% (at least 12/14 questions) of questions have been answered, then the median value for each participant's questionnaire score will be ascribed to any missing questions Higher scores indicate greater impact of anxiety and depression
CAD-EOLD	14 symptoms on comfort assessment scale	Each question is scored 1–3 The last three items are reverse coded (3–1), so higher score is positive. A score of 1 represents 'a lot', 2 represents 'somewhat' and 3 represents 'not at all'	14–42 when scores from each question are added	Symptoms listed are discomfort, pain, restlessness, shortness of breath, choking, gurgling, difficulty swallowing, fear, anxiety, crying, moaning, serenity, peace and calm. Lower scores indicate greater symptom burden
CCI	17 comorbidity disease/condition categories	Each question scored as 1	0–17 when scores from each question are added	If no condition is identified, score would be 0; if all conditions indicated, then total score would be 17, which is merely the total number of comorbidities
NPI and NPI-NH	12 symptom domains form total score	Each domain is screened; if no, then scored zero, if yes, then additional questions explore frequency (scored 1–4 where 1, 'rarely'; 2, 'sometimes'; and 3, 'often'; and 4, 'very often') severity (1–3, where 1 'mild'; 2, 'moderate'; and 3, 'severe') and distress (for family carers) or occupational disruptiveness (for key informants) both scored 0–5, where 0, 'not at all'; 1, 'minimal'; 2, 'mild'; 3, 'moderate'; 4, 'severe'; and 5, 'very severe or extreme'	• Each domain is scored by multiplying frequency by severity. Total score is then the sum of the 12 domains (possible range is 0–144) • Occupational disruptiveness also added up over all 12 domains and reported separately (range 0–60)	• 5, 'very severely or extremely' The overall score can be recoded into three categories: 1. < 20 = mild behaviour problems 2. 20–50 = moderate behavioural disturbance 3. > 50 = severe behavioural disturbance Higher scores indicate greater symptom burden

continued

TABLE 12 Details of outcome measures, scoring procedures and interpretation (*continued*)

Questionnaire	Scale/subscale details	Question scoring	Overall score	Notes
• PAINAD 1: during rest • PAINAD 2: during movement	Five indicator categories for each PAINAD domain	Each indicator is scored 0–2. Indicator categories roughly correspond to 0, representing 'no, normal or none'; 1, representing 'occasional, some, etc.'; and 2, representing 'a lot, repeated, severe, etc.'	Total scored by adding all five indicators, so total score range is 0–10 on each PAINAD domain	Higher scores indicate greater impact of symptoms
QUALID	11 responses that best describe person with dementia over the previous week	Each response is scored 1–5	Total scored by adding all 11 indicators, so total score range is 11–55	The questionnaire includes options on smiles, appears sad, cries, facial expression/discomfort, physically uncomfortable, discontent/unhappiness, irritable/aggressive, eating, touching, interacting and emotions Lower scores represent higher QoL There are also options for quality of interview (scored 0–2) and knowledge of caregiver (0–2), with lower scores indicating more favourable outcome
SM-EOLD	Nine domains on symptom management at the EOL in dementia	Each response is scored 5–0; the calm domain is reverse-coded, 0–5	Total scored by adding all nine indicators, so total score range is 0–45	Domains include pain, shortness of breath, skin breakdown, calm, depression, fear, anxiety, agitation and resistiveness to care Higher scores indicate greater comfort
SWC-EOLD • Before end of life • Post death	10 domains on satisfaction with care at the EOL in dementia	Each response is scored from 1 to 4 (1 = strongly disagree, 2 = disagree, 3 = agree, 4 = strongly agree). Items 2, 5 and 10 are reverse-scored	Total scored by adding all 10 questions, so total score range is 10–40	Each domain includes just one question about satisfaction with care at EOL and includes questions such as feelings on getting all necessary nursing assistance to feeling that better medical care at the EOL is/was needed Higher scores indicate more satisfaction

Questionnaire	Scale/subscale details	Question scoring	Overall score	Notes
BANS-S	Seven items on dressing, sleeping, speech, eating, mobility, muscles and eye contact	Each item is scored on a four-point scale (1–4). The scoring system is specified [e.g. for speech: (a) completely intact ability to speak, (b) somewhat decreased ability to speak, (c) moderately decreased ability to speak, (d) totally mute]. Absence of impairment in a given item is credited with 1 point, whereas 4 points are given for complete impairment	Total scored by adding all seven items; thus, the total score ranges from 7 (no deficit in any item) to 28 (complete impairment in all items)	Higher scores indicate greater impairment
EQ-5D-5L, proxy EQ-5D-5L	Five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression	Responses to each dimension are scored on a five-point scale (1–5) where: 1 = no problems, 2 = slight problems, 3 = moderate problems, 4 = severe problems and 5 = extreme problems	No total score is calculated across the five items	• Responses to the five questions are descriptive, with higher scores indicating greater impairment • The VAS component is reported descriptively. Higher scores indicate better health. This component is part of the EQ-5D-5L, but is not used
Resource utilisation questionnaire (person with dementia) Resource utilisation questionnaire (family carer)	12 broad domains covering respondent characteristics, use of health and social services, and use of the welfare system	Descriptive framework. Responses are reported either categorically (0, absent; 1, present) or cardinal 0 to ∞	No total score is calculated	Data are descriptive. Data can be used to estimate costs. This will not be considered in this study

BANS-S, Bedford Alzheimer Nursing Severity Scale; CCI, Charlson Comorbidity Index; HADS, Hospital Anxiety and Depression Scale; NPI, Neuropsychiatric Inventory; NPI-NH, Neuropsychiatric Inventory-Nursing Home; QUALID, Quality of Life in Late-stage Dementia; SM-EOLD, Symptom Management at the End of Life in Dementia; VAS, visual analogue scale.

including database management, was delegated to the Newcastle Clinical Trials Unit; full details, including amendments and protocol deviations, are provided below.

Key site dates

Site initiation visits were conducted at each site by the study senior research associate and trial manager. Key site dates are shown in *Table 13*. The date of the 'last patient, last visit' was 6 August 2018.

Clinical Research Network

Discussions with primary care sites have indicated that they often struggle to find the capacity to support some research administration tasks, for example maintenance of essential documentation in the investigator site file. With this in mind, assistance was requested from the local Clinical Research Network. Facilitators from Clinical Research Network North East and North Cumbria provided support to sites by ensuring that the investigator site file was complete, particularly when new documentation was implemented as a result of substantial amendments.

Protocol amendments

Protocol amendments are listed in *Table 14*.

TABLE 13 Key site dates

	Date		
Site	**Of site initiation visit**	**Opened**	**First person with dementia participant recruited**
Practice 1 (intervention)	2 March 2017	15 March 2017	10 May 2017
Practice 2 (control)	15 February 2017	1 March 2017	30 March 2017
Practice 3 (intervention)	14 March 2017	12 April 2017	15 May 2017
Practice 4 (control)	5 April 2017	24 April 2017	5 July 2017

TABLE 14 Study amendments

Amendment reference	Summary	REC approval	Health Research Authority approval
SA01 (re-categorised as non-substantial)	Replacement of site (listed in error)	N/A	4 April 2017
SA02	Increase in participant recruitment to allow either a family carer and/or a key informant to be recruited for each person with dementia	18 April 2017	2 May 2017
SA03	Removal of SEED manual from list of REC-approved documents	15 May 2017	15 May 2017
SA04	Update to consultee declaration form	11 August 2017	23 August 2017
SA05	Collecting aggregated data on date of death from screened person with dementia without consent	25 May 2018	25 May 2018

N/A, not applicable; SA study amendment.

Trial management group

The trial management group was scheduled to meet monthly from the study set-up period until the first draft of the study final report. In total, over 32 months, 24 trial management group meetings were held.

Trial Oversight Committee

An independent Trial Oversight Committee provided external oversight of the WS4 clinical trial. Members comprised four independent members of the SEED ESC (dementia care physicians and a statistician), and an independent patient representative. The Trial Oversight Committee met three times during the trial, and no concerns relating to the safety of the participants or scientific integrity of the trial were raised.

Safety

Adverse events were not recorded in this study. Practice managers were contacted on a quarterly basis and asked to review the practice patient complaints log. There were no complaints from participants, and no concerns were raised by the DNSs or by the SEED research team regarding participant safety and well-being as a result of their participation in the study.

Deviations

Three protocol deviations took place; all were reviewed by the Newcastle Clinical Trials Unit quality assurance team and the sponsor. Full details of the deviations and sites affected are provided in *Table 15*.

Trial monitoring

Monitoring was conducted according to the trial monitoring plan. As well as the site initiation visits, the trial manager carried out planned on-site monitoring at each site at the end of the recruitment window. The SEED WS4 research team also received two on-site monitoring visits, primarily to monitor original consent and case report forms. In total, 100% of the eligibility criteria for 100% of the participants with dementia were monitored. No ineligible participants were identified. A total of 100% of the informed consent and consultee declaration forms for the participants with dementia were monitored. No deviations from the informed consent process were identified. After the research team confirmed that data collection was complete, a close-out monitoring visit was conducted by the trial manager at each site.

TABLE 15 Protocol deviations

Protocol deviation	Details
Not allowing the participant at least 1 week to read the PIS before a member of the primary care team makes a follow-up telephone call to seek consent to pass the details of the person with dementia on to the university research team	• Practice 2 – five people with dementia affected (3–6 days before contacted by staff) • Practice 3 – three people with dementia affected (2–6 days before contacted by staff)
Screening person with dementia without signing delegation log	Two GPs from an intervention practice signed screening forms for people with dementia without being delegated to do so on the site delegation log
Participants moved from a SEED GP site to a non-SEED GP and remained in the study	• Two people with dementia from an intervention GP site • The care home required residents to register with the care home-preferred GP. The participants were removed from the intervention, but remained in the study for data collection purposes. Registered with a non-SEED GP, the participants were essentially 'site-less' for 2 months. Both were withdrawn from the study

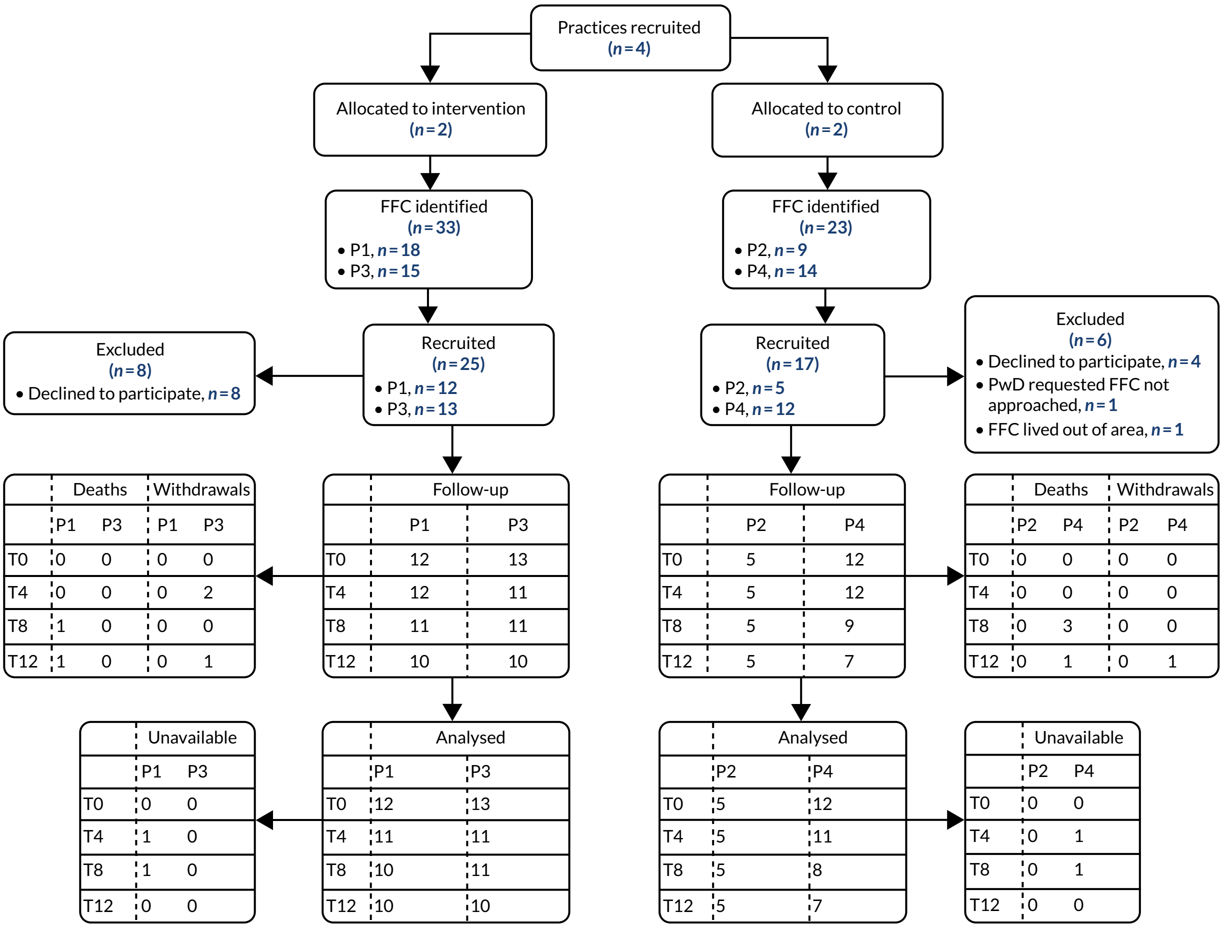
Feasibility and acceptability of recruitment and retention

Recruitment and retention of family carers and key informants are summarised in CONSORT flow diagrams (*Figures 5* and *6*).

Participant characteristics

The characteristics of all participants were reasonably well balanced between the intervention and the control arms, given the relatively small study (see *Tables 16–22*). Participating people with dementia were predominantly female, and more than one-third owned and lived in their own home (*Table 16*). More people with dementia in the intervention arm than in the control arm lived in a dementia-specific care home (10 intervention, compared with one control). The average age was around 85 years (*Table 17*). In terms of the eligibility criteria, 32 people with dementia were recently diagnosed and 43 were potentially approaching EOL (13 met both eligibility criteria). Place of residence was fairly stable during the study: three people with dementia moved house, five moved into a care home and one changed care home. Most people with dementia had at least two comorbidities according to the Charlson Comorbidity Index questionnaire at baseline (*Table 18*).

Most family carers were female and more than half lived in the same household as the person with dementia (*Table 19*). Most family carers had frequent contact with the person with dementia (60% had contact for 6 days of the week). Although average contact time per week appeared to be more extensive in the control arm, and the control arm had slightly more males and family carers living in the same home as the people with dementia (see *Table 19*), these slight imbalances were to be expected given the relatively small number of family carers and the non-randomised nature of the study. On average, family carers had known the person with dementia for > 56 years and the average contact time with them in the previous week was substantial (mean of 15 hours per week; *Table 20*).



	Deaths		Withdrawals	
	P1	P3	P1	P3
T0	0	0	0	0
T4	0	0	0	2
T8	1	0	0	0
T12	1	0	0	1

	Follow-up	
	P1	P3
T0	12	13
T4	12	11
T8	11	11
T12	10	10

	Follow-up	
	P2	P4
T0	5	12
T4	5	12
T8	5	9
T12	5	7

	Deaths		Withdrawals	
	P2	P4	P2	P4
T0	0	0	0	0
T4	0	0	0	0
T8	0	3	0	0
T12	0	1	0	1

	Unavailable	
	P1	P3
T0	0	0
T4	1	0
T8	1	0
T12	0	0

	Analysed	
	P1	P3
T0	12	13
T4	11	11
T8	10	11
T12	10	10

	Analysed	
	P2	P4
T0	5	12
T4	5	11
T8	5	8
T12	5	7

	Unavailable	
	P2	P4
T0	0	0
T4	0	1
T8	0	1
T12	0	0

FIGURE 5 The CONSORT flow diagram for family carers. FFC, family and friend carers; P, practice; PwD, people with dementia.

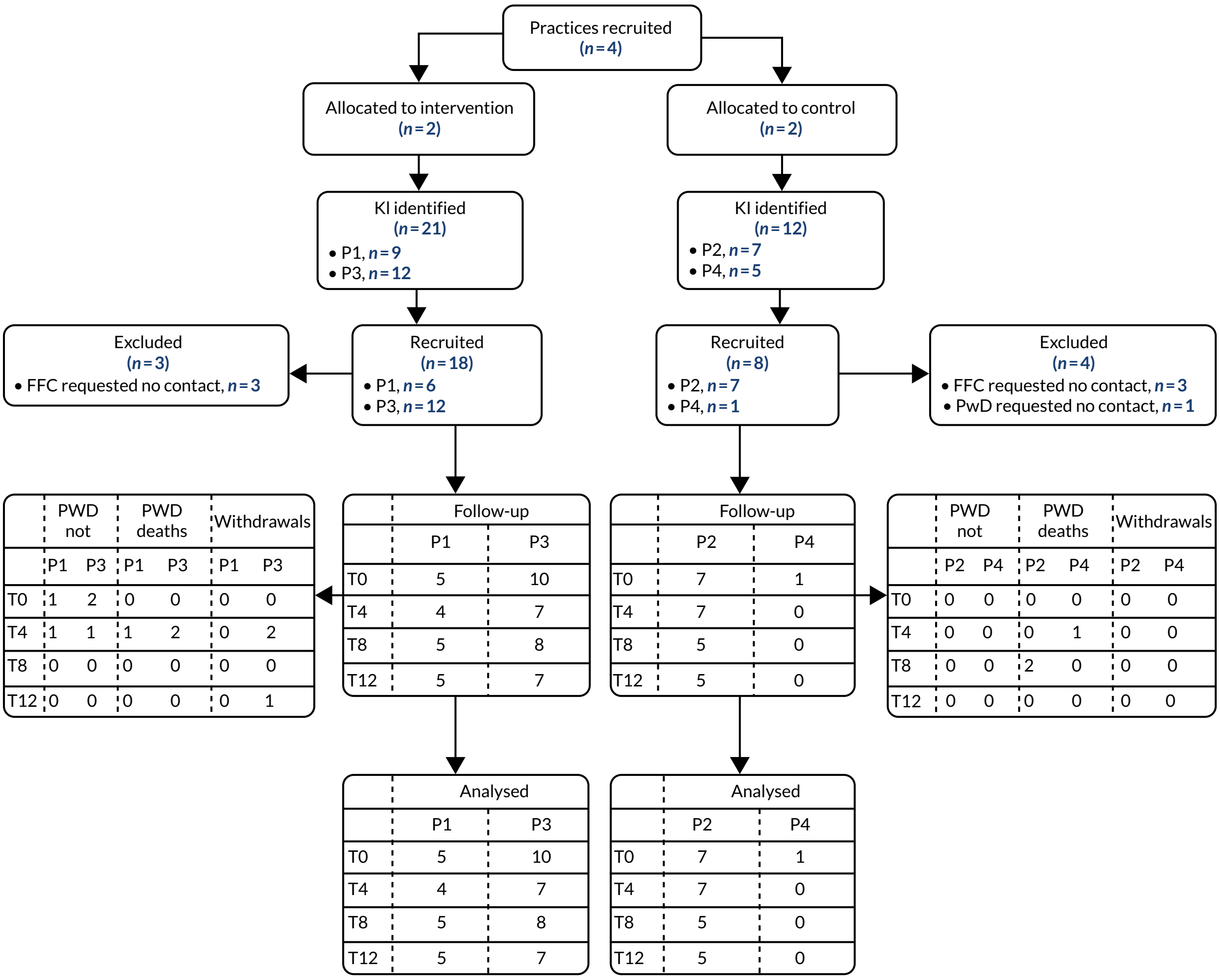


FIGURE 6 The CONSORT flow diagram for key informants. FFC, family and friend carers; P, practice; PwD, people with dementia.

TABLE 16 Baseline patient characteristics by intervention arm (categorical variables)

	Trial arm, *n* (%)		
Categorical variable	**Intervention (*N* = 37)**	**Control (*N* = 25)**	**Total (*N* = 62), *n* (%)**
Gender			
Male	17 (46)	9 (36)	26 (42)
Female	20 (54)	16 (64)	36 (58)
Type of living accommodation			
Owner–occupier housing	13 (35)	12 (48)	25 (40)
Privately rented housing	1 (3)	1 (4)	2 (3)
Local authority housing	1 (3)	1 (4)	2 (3)
Care home (not dementia specific)	7 (19)	9 (36)	16 (26)
Dementia-specific care home	10 (27)	1 (4)	11 (18)
Sheltered housing/warden control	3 (8)	1 (4)	4 (6)
Other/not otherwise specified	2 (5)	0 (0)	2 (3)

TABLE 17 Baseline patient characteristics by intervention arm (continuous variables)

	Intervention arm ($n = 37$)				Control arm ($n = 25$)				Total ($n = 62$)			
Continuous variable	**Participants (*n*)**	**Mean (SD)**	**Median (IQR)**	**Range**	**Participants (*n*)**	**Mean (SD)**	**Median (IQR)**	**Range**	**Participants (*n*)**	**Mean (SD)**	**Median (IQR)**	**Range**
Age (years)	37	85.0 (6.7)	84.8 (80.9–88.5)	72.0–98.1	25	84.8 (7.2)	87.2 (80.4–89.2)	66.9–96.7	62	84.9 (6.8)	85.0 (80.7–89.2)	66.9–98.1

IQR, interquartile range; SD, standard deviation.

TABLE 18 Summary of CCI questionnaire scores of people with dementia at baseline and 12 months by intervention arm

	Baseline, *n* (%)		**12 months, *n* (%)**	
CCI	**Intervention (*N* = 37)**	**Control (*N* = 25)**	**Intervention (*N* = 37)**	**Control (*N* = 25)**
CCI score				
1	11 (30)	4 (16)	11 (30)	3 (12)
2	10 (28)	7 (28)	7 (19)	6 (24)
3	11 (30)	4 (16)	6 (16)	4 (16)
4	3 (8)	6 (24)	4 (11)	3 (12)
5	2 (5)	3 (12)	2 (5)	1 (4)
6	0 (0)	1 (4)	0 (0)	1 (4)
Dead	0 (0)	0 (0)	5 (14)	7 (28)
Missing	0 (0)	0 (0)	2 (5)	0 (0)

CCI, Charlson Comorbidity Index.

TABLE 19 Baseline family carer characteristics by intervention arm (categorical variables)

	Trial arm, *n* (%)		
Categorical variable	**Intervention (*N* = 25)**	**Control (*N* = 17)**	**Total (*N* = 42), *n* (%)**
Gender			
Male	4 (16)	6 (35)	10 (24)
Female	21 (84)	11 (65)	32 (76)
Live in same house as person with dementia			
Yes	12 (48)	12 (71)	24 (57)
No	13 (52)	5 (29)	18 (43)
Relationship with person with dementia			
Spouse	11 (44)	8 (47)	19 (45)
Child	13 (52)	8 (47)	21 (50)
Other family member	1 (4)	1 (6)	2 (5)
Friend	0 (0)	0 (0)	0 (0)
Neighbour	0 (0)	0 (0)	0 (0)
Paid carer	0 (0)	0 (0)	0 (0)
Other	0 (0)	0 (0)	0 (0)
Contact in previous week with person with dementia (0–7 days)			
0	0 (0)	0 (0)	0 (0)
1	1 (4)	0 (0)	1 (2)
2	1 (4)	2 (12)	3 (7)
3	6 (24)	1 (6)	7 (16)
4	0 (0)	0 (0)	0 (0)
5	5 (20)	0 (0)	5 (12)
6	0 (0)	1 (6)	1 (2)
7	12 (48)	13 (76)	25 (60)

TABLE 20 Baseline family carer characteristics by intervention arm (continuous variables)

	Intervention (*N* = 25)				**Control (*N* = 17)**				**Total (*N* = 42)**			
Continuous variable	**Participants (*n*)**	**Mean (SD)**	**Median (IQR)**	**Range**	**Participants (*n*)**	**Mean (SD)**	**Median (IQR)**	**Range**	**Participants (*n*)**	**Mean (SD)**	**Median (IQR)**	**Range**
Age (years)	23	67.4 (11.6)	65.8 (58.8–78.4)	44.6–85.9	15	67.0 (12.4)	64.1 (58.6–77.8)	48.1–87.1	38	67.2 (11.7)	65.7 (58.8–77.8)	44.6–87.1
Length of time known to person with dementia (years)	25	56.2 (10.6)	58 (51–65)	30–69	17	58.0 (6.9)	60 (51–62)	45–70	42	56.9 (9.2)	59 (51–64)	30–70
Average contact time with person with dementia in previous week (hours/day)	25	13.0 (11.1)	14 (1.5–24)	0–24	17	18.1 (9.5)	24 (5–24)	2–24	42	15.0 (10.7)	24 (2.5–24)	0–24

IQR, interquartile range; SD, standard deviation.

Family carers of people with dementia in care homes were more likely to decline to participate in the trial ($n = 11$) than family carers of people living at home ($n = 1$). Typically, carers were happy for the person with dementia to take part and for care home staff to act as key informants, but did not wish to be involved themselves.

Because the number of key informants fluctuated during the study, data are presented for the 23 key informants recruited at baseline. Key informants were predominantly female and had mixed working roles, but most were managers (*Table 21*). Key informants had at least 3 days' contact with the person with dementia per week (average contact time per week was 7.3 hours; *Table 22*). The average length of time key informants had known the person with dementia was 30.2 months, but there was an apparent difference between arms, with key informants in the intervention arm having known the person with dementia for longer, although numbers are sparse.

Qualitative data on recruitment processes

The process of completing the screening forms was generally considered too onerous, particularly by one control practice. In this practice, the situation was resolved by paying for a locum to enable a senior GP to spend half a day screening the forms. A researcher checked the screening forms as they were completed, and this proved an efficient approach as it minimised missing data and subsequent queries. The approach taken by GPs to the 'surprise' question varied. The question was sometimes left blank, for example when the GP had not seen the person with dementia for some time, or when the

TABLE 21 Baseline key informant characteristics by intervention arm (categorical variables)

	Trial arm, *n* (%)		
Categorical variable	**Intervention (*N* = 15)**	**Control (*N* = 8)**	**Total (*N* = 23), *n* (%)**
Gender			
Male	1 (7)	1 (13)	2 (9)
Female	14 (93)	7 (88)	21 (91)
Role			
Care assistant	0 (0)	3 (38)	3 (13)
Senior care assistant	2 (13)	0 (0)	2 (9)
Nurse	3 (20)	2 (25)	5 (22)
Deputy manager	0 (0)	1 (13)	1 (4)
Manager	10 (67)	2 (25)	12 (52)
Contact in previous week with person with dementia (0–7 days)			
0	0 (0)	0 (0)	0 (0)
1	0 (0)	0 (0)	0 (0)
2	0 (0)	0 (0)	0 (0)
3	1 (7)	2 (25)	3 (13)
4	3 (20)	4 (50)	7 (30)
5	11 (73)	2 (25)	13 (57)
6	0 (0)	0 (0)	0 (0)
7	0 (0)	0 (0)	0 (0)

TABLE 22 Baseline key informant characteristics by intervention arm (continuous variables)

	Intervention ($n = 15$)				Control ($n = 8$)				Total ($n = 23$)			
Continuous variables	**Participants (*n*)**	**Mean (SD)**	**Median (IQR)**	**Range**	**Participants (*n*)**	**Mean (SD)**	**Median (IQR)**	**Range**	**Participants (*n*)**	**Mean (SD)**	**Median (IQR)**	**Range**
Length of time known to person with dementia (months)	15	40.8 (34.8)	30 (30–39)	12–156	8	10.4 (2.5)	10.5 (9–12.5)	6–13	23	30.2 (31.5)	30 (12–30)	6–156
Average contact time with person with dementia in previous week (hours/day)	14	6.7 (3.8)	8 (2.5–8)	1–12	8	8.5 (3.6)	9.75 (7–10.75)	1–12	22	7.3 (3.7)	8 (6–10.5)	1–12

person with dementia was new to the practice. Some GPs found it difficult to make a judgement and questioned the validity of the 'surprise' question:

> *It was almost impossible to answer that [surprise] question . . . we've got lots of our patients that are old and frail that go on for a longer period of time than we might expect. It's just a very difficult – if you ask 10 GPs about the same patient 'would you be surprised?', you might not get the same 10 answers.*
>
> *Interview, GP 3.2, site 3*

To try to manage the recruitment process, practices staggered recruitment, approaching a few people at a time, rather than approaching all of those who were eligible. This may have led to some 'cherry-picking' of potential participants. Although the intention was for the researchers to assist with the selection of people with dementia to be approached, this was feasible in only one practice, with other practices preferring to make the decisions themselves of who to approach.

The invitation letters gave potential participants the opportunity to opt out of further contact by telephoning the general practice. Only nine potential participants opted out and no complaints were received about this approach, suggesting that it is acceptable to this group of patients and carers. One control practice would have preferred to have used an opt-in approach, whereby potential participants contacted the research team directly. This would have reduced the workload for GPs and DNSs (who made the follow-up telephone calls), but would also probably have reduced recruitment.

Those who did not opt out were followed up by telephone by either the DNS (intervention practices) or a GP (control practices). The DNSs found these calls challenging, partly because they saw them as a research activity (and of which they had no previous experience), but also because the telephone calls were made at the outset of the study when they were uncertain about what the intervention would entail:

> *The actual recruiting bit wasn't particularly comfortable . . . you didn't know who you were ringing . . . And also because I didn't really know what the role was, we were trying to persuade people to become involved in something that I didn't actually know what it was going to be.*
>
> *Interview, DNS1*

Although concerns were expressed that the follow-up telephone calls might turn into 'mini consultations', they proved less time-consuming than anticipated. Relatively few people with dementia or carers raised additional issues during the telephone calls, and one GP viewed the opportunity to deal with urgent problems as a benefit:

> *We would never have known she had problems because she was just trying to carry on on her own. But it meant we got her sorted and it was great. That was a really nice thing to do. There were only a couple of those or 'I can get the nurse to come out to you. That's not a problem while I'm on the phone to you'. There has been a benefit for the practice from that point of view.*
>
> *Interview, GP 4.1, site 4*

One GP in a control practice commented that recruitment might have been easier if it had taken place prior to allocation to trial arm:

> *I think it might have made it easier to, I think 'sell' is a strong word, but to promote to patients if we thought that there may have been a possible gain in terms of a nurse specialist being involved with them. . . . obviously it's a control practice, we were going in and saying 'we are not going to do anything to help your relative, we are really just going to sort of ask questions and things for a trial', you know. I think it's harder to market or promote to patients than if you are saying 'I don't know which arm you are going to. It's possible that you might get extra support from a nurse specialist.'*
>
> *Interview, GP 2.1, site 2*

Few comments specifically about recruitment processes were made by people with dementia and carers. Consistent with previous studies, the primary motivation for participating was altruism, with people with dementia and carers hoping that their involvement would help others in the future:

> *I'm happy to get involved in any sort of research that's going to help people. I mean, I might be one of these people in the future, who knows. So I think it's a really good thing.*
>
> *Interview, family carer 3018*

Some people with dementia who had been recently diagnosed, and their family carers, did not see the SEED intervention as appropriate to their situation. Although they felt that the immediate post-diagnostic period was too early for the intervention, they found it difficult to identify the most appropriate time:

> *(What is the best point at which to offer some kind of nurse specialist role?) When you need help. I'm sorry, but that is 'How long is a piece of string?'.*
>
> *Interview, family carer 1070*

The key issues relating to recruitment and potential strategies to maximise recruitment to a future trial are summarised in *Table 23*.

TABLE 23 Key issues and proposed strategies for recruitment to a future trial of the SEED intervention

Issue	Proposed strategy
Pre-trial work to facilitate recruitment	
Poor-quality information on next of kin (i.e. often no address, telephone numbers out of date and little information on full name/relationship)	Provide funding for practice administrative staff to update information on next of kin for all patients on the dementia register prior to the start of recruitment
Clear contract with general practices to clarify responsibilities and timelines	
Practices agreed to participate but did not necessarily have the resources or will to deliver	Providing a written contract with explicit responsibilities and timelines may be helpful
Reducing workload and responsibility of GPs	
GPs found various aspects of screening and recruitment onerous • Completing the screening logs was time-consuming for some GPs, particularly for new patients whom they did not know or patients who had not recently consulted • Making telephone calls was seen as onerous since patients did not always pick up the phone and/or treated the phone call as a consultation opportunity • GPs did not feel confident enough about the project to respond to questions from patients/next of kin	To fund a locum (to free up GP time) or a research nurse in each practice to lead on screening and recruitment. Their role would be to: • Complete a screening log for each patient on the dementia register • Discuss each patient with an appropriate member of the primary care team to complete questions requiring knowledge of the individual • Identify eligible patients and follow protocol to select sample for approach • Mail out information to selected patients/next of kin • Log patients/next of kin who telephone the practice to opt out • Make follow-up telephone calls to remaining patients/next of kin
Maximising buy-in for practices	
One control practice had limited engagement with the study and GPs were not clear what they were getting out of participation	Recruitment prior to randomisation should help, as practices will not know whether or not they will be in the intervention arm until after recruitment is complete We offered a teaching session on the SEED study as an incentive – can we make this more attractive (e.g. CPD points)? Emphasise that, generally, patients in trials tend to have better outcomes even if they are in the control arm; contact with researchers may be beneficial

TABLE 23 Key issues and proposed strategies for recruitment to a future trial of the SEED intervention (*continued*)

Issue	Proposed strategy
Recruitment staff to be blinded to trial arm	
As practices knew which arm of the study they were in, this may have influenced their approach to recruitment	The research nurses and practices should be blind to randomisation until recruitment is complete
The DNSs in the pilot trial were known to some potential participants from their previous role and this probably increased consent rates	The research nurse responsible for recruitment would not be the person delivering the intervention
Streamlining of screening log	
Screening log was considered to be both too 'big' and missing key information (e.g. whether or not patient on palliative care register, patient address)	Delegating responsibility for most of the screening log to a research nurse should help this, as GPs would no longer be expected to complete any sections of the form
Despite inclusion of stop/go criteria, there were still inconsistencies in completion of the forms	Amend the form in the light of feedback Consider alternative formats [e.g. SurveyMonkey® (Palo Alto, CA, USA)] with built-in controls to prevent screening errors Provide a detailed protocol and training for the research nurses Increase monitoring and supervision to identify errors at an early stage and provide additional training
Transferring data from the screening logs for analysis was time-consuming	Moving to an electronic system (e.g. SurveyMonkey) would avoid the need to transfer data and data entry errors
Clarification of inclusion/exclusion criteria	
Some GPs found the 'surprise' question difficult, because they did not know the patient, the patient had not consulted recently or they felt that it was 'giving them a death sentence'	Consider whether to continue to try to target the intervention on specific groups of patients to whom it might be more relevant, or to include all patients on the dementia register
Some GPs automatically selected that they would not be surprised if the patient died in the next 12 months for any patients living in care homes	Consider whether to treat all people with dementia living in care homes as eligible for the study, rather than completing the 'surprise' question for these patients
Some GPs in control practices thought that it was inappropriate to contact those on the palliative care register as the study was thought too burdensome for no return	This may be less of an issue if patients are recruited prior to randomisation; providing feedback from the 'pilot' study may also help in demonstrating that patients and carers found participation acceptable regardless of which arm they were in
Clear procedures for sampling from completed screening logs	
We lost control of the process of selecting eligible patients for approach in all but one practice. This may have led to oversampling of people within 2 years of diagnosis, as they were typically easier (and quicker) to recruit because they could usually give consent and, therefore, a consultee did not have to be identified and approached	Provision of clear guidelines as to how to sample patients and additional training and supervision should ensure a more consistent approach whereby the sample is selected to include people with dementia within 2 years of diagnosis, those thought to be approaching the EOL, those with capacity to consent for themselves, those requiring a consultee, those living in their own home and those living in care homes
Streamlining recruitment processes	
The protocol was too specific about who would make the follow-up telephone call and when the call would be made	Be less precise about the time period between sending the letter and making the follow-up call, for example 'a few days' The protocol should state that an appropriate member of the primary care team will make the follow-up telephone call

continued

TABLE 23 Key issues and proposed strategies for recruitment to a future trial of the SEED intervention (*continued*)

Issue	Proposed strategy
Completion of the section on the timing of follow-up calls was poor	Ensure that the research nurse understands the rationale for providing this information and increase monitoring and supervision to identify errors at an early stage
Managing workload for care homes	
The process of being a key informant required a fairly significant time commitment (30 minutes for each participant on four occasions over 1 year). To avoid overburdening individual care homes, should we set a maximum number of patients to be recruited from each home?	Agree a maximum number of participants per home, for intervention sites; other residents may still benefit from the intervention as changes may be to systems or staff training
Monitoring of screening and recruitment process	
The screening logs were systematically reviewed by a member of the research team in only one practice; this lack of oversight led to errors, inconsistencies and missing information	To have an explicit, formal monitoring plan and to ensure that this is implemented so that additional training/support can be provided to practices at an early stage

CPD, continuing professional development.

Feasibility and acceptability of the SEED intervention

Training and supervision of the dementia nurse specialists

Table 24 provides an overview of training and supervision arrangements. The initial 3-day training and induction programme was provided by the research team and clinical leads (*Table 25* contains the agenda) and included an educational needs assessment (see *Appendix 3*, *Educational needs assessment for dementia nurse specialist*). Additional training needs were met through supervision, tailored training sessions and self-directed learning using the care resource kit and e-learning. One general practice provided a 1-week induction programme to help the DNSs integrate with the primary care teams.

TABLE 24 Training and supervision of the DNSs

Characteristic	Training and induction	Intervention supervision	Clinical supervision (old-age psychiatry/ palliative care)	Clinical supervision (GP dementia lead)
Frequency	Once at start of study	Monthly	Monthly	Approximately monthly
Number of sessions	6	12	27 individual and 4 joint sessions	9
Duration	3 full days	90–120 minutes	Unknown	120 minutes
Content	Introduction to the SEED intervention, advanced dementia, palliative care, primary care, study recruitment, process evaluation	Review training needs, progress with individual and systems work, use of the seven components. Additional issues raised by the DNSs	Additional specialist training, case-based discussions	Case-based discussions, development of dementia review template, implementing changes in general practice
Main aims	To familiarise the DNSs with the SEED intervention and build confidence to start their new role	To monitor intervention delivery and address emerging training needs	To ensure that the DNSs felt supported within their existing discipline and provide additional training	To facilitate embedding in practice and maximise impact of the DNSs

TABLE 25 Agenda for the initial 3-day training programme

Day	Agenda
1	Introduction to the SEED programme
	Key findings to date
	The SEED intervention
	The care resource kit
	Advanced dementia: signs, symptoms and challenges
	Mental Capacity Act
	Primary care and dementia
2	Primary and community care
	Local service mapping
	Developing a clinical support network
	Getting started with the SEED intervention
	Ongoing support and supervision
3	Understanding the study design
	• Pilot trial • Process evaluation
	Screening and approaching people with dementia
	Accessing existing resources
	Managing a new role

To address the issues of anxiety and deskilling, which were inevitably associated with taking on a new role, bespoke supervision arrangements provided support with recruitment processes, the content and delivery of the intervention, palliative care and dementia. Establishing a MDT to provide supervision was not feasible. Instead, support for the first two areas was provided through monthly intervention supervision sessions led by the research team and a palliative care clinical lead. The palliative care clinical lead and an old-age psychiatrist provided clinical support and case supervision. In addition, both DNSs continued to receive supervision from their previous work teams. The DNSs also met regularly for peer support. Their different backgrounds (in palliative care and mental health) proved useful in joint working and mutual support.

Both DNSs found the monthly supervisions with the research team a helpful way of working through ideas, identifying problems and sharing solutions. From the lead researcher's perspective, these meetings were useful in clarifying boundaries, promoting systems work and obtaining feedback on the intervention. More administrative and IT support from the host general practices would have been useful. Only one DNS received supervision from the dementia lead GP; without this, the role was potentially isolating and scope for improving systems within the practice was limited. In addition to formal supervision arrangements, both DNSs valued informal contact with the researchers.

Delivery of the SEED intervention

In this section, we illustrate how the SEED intervention was translated into practice using data from activity logs, the vignettes and the resources developed by the DNSs.

Activity analysis

The activity logs enabled us to examine the proportion of days on which prespecified activities were recorded, the focus of direct work with patient–carer dyads, and collaborative working. The initial analysis focused on the number of days on which specific activities were recorded (*Figure 7* and *Table 26*). Details of activities were recorded for 206 days for DNS1 and 180 days for DNS2, reflecting their different working hours and patterns. In terms of the proportion of days on which specific activities were recorded, major components of the intervention were addressing the current needs of people with dementia, current needs of family carers, and networking and service mapping (with all of these activities being recorded on > 50% of working days). The proportion of days on which different activities were recorded was similar for both DNSs, with the exception of developing and implementing systems and research activities. DNS1 had more scope for developing systems because she worked with a larger number of care homes and in a practice that was more open to change. The difference in research activities reflects the different approach to recruitment in the two practices. DNS1 attended daily MDT meetings in the practice and discussed a few potential participants each day, whereas DNS2 distributed screening forms to the most appropriate GP and then collated the completed forms, which was less time-consuming.

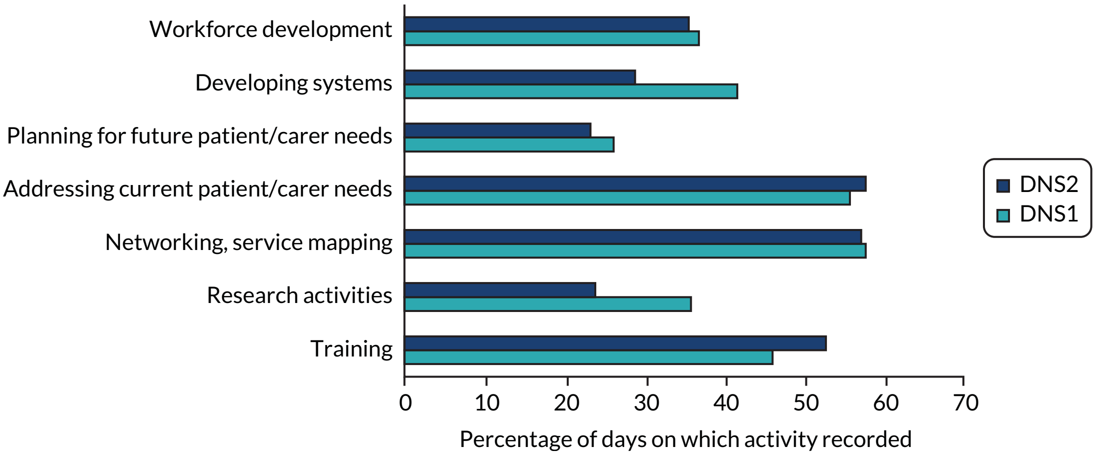


FIGURE 7 Proportion of days on which activities were recorded by DNSs.

TABLE 26 Number and proportion of days on which selected activities were recorded

	Days, *n* (%)		
Activity	**DNS1**	**DNS2**	**Total days, *n* (%)**
Training	95 (46.1)	95 (52.8)	190 (49.2)
Study activities	74 (35.9)	43 (23.9)	117 (30.3)
Networking, service mapping	119 (57.8)	103 (57.2)	222 (57.5)
Addressing current needs of person with dementia/carer	115 (55.8)	104 (57.8)	219 (56.7)
Planning for future with person with dementia/carer	54 (26.2)	42 (23.3)	96 (24.9)
Developing and implementing systems to improve EOLC	86 (41.7)	52 (28.9)	138 (35.8)
Workforce development	76 (36.9)	64 (35.6)	140 (36.3)
Total days	206 (100)	180 (100)	386 (100)

We also examined the number and type of direct contacts (i.e. face-to-face meetings and telephone calls) with individual patient–carer dyads. The number of such contacts ranged from 0 to 18 (median 7) for people with dementia and from 0 to 31 for carers (median 4). Nearly all contacts were in their place of residence, with only seven contacts elsewhere. The most common activities with participating dyads related to the well-being of the person with dementia (97%), family carer well-being (35%) and future planning (33%). With the exception of future planning, people with dementia living in care homes and their family carers tended to receive fewer contacts relating to all other activities than those living in their own homes (*Figure 8* and *Table 27*).

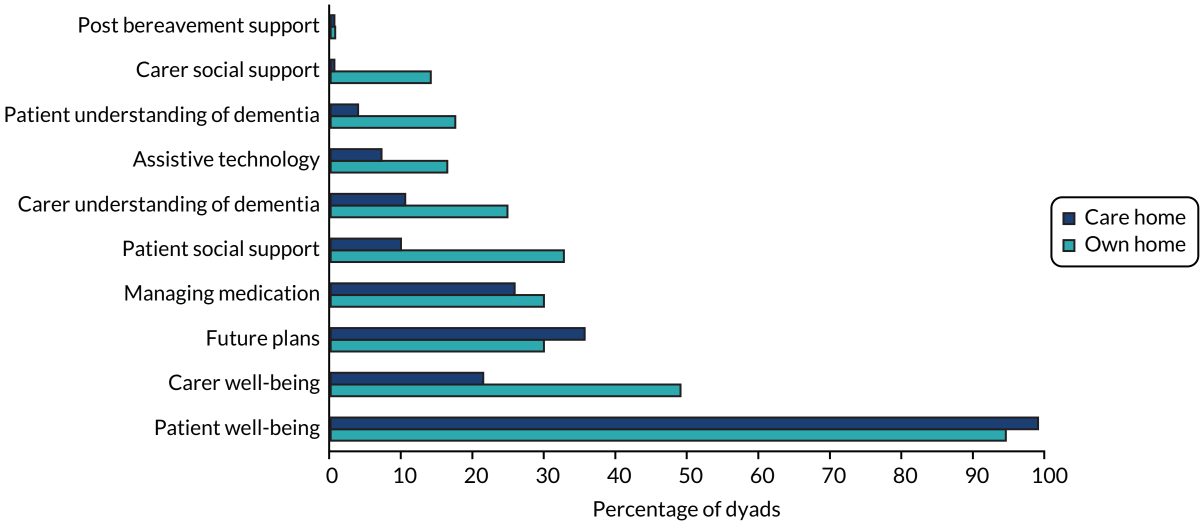


FIGURE 8 Focus of direct work with participating dyads by place of residence.

TABLE 27 Activities during direct contacts with participating dyads by place of residence

Activity	Number of direct contacts, *n* (%)		
	Community dwelling (*n* = 178)	Care home residents (*n* = 183)	All (*n* = 361)
Patient well-being	168 (94.4)	181 (98.9)	96.7 (361)
Carer well-being	87 (48.9)	39 (21.3)	126 (34.9)
Future plans	53 (29.8)	65 (35.5)	118 (32.7)
Managing medication	53 (29.8)	47 (25.7)	100 (27.7)
Patient informal networks and social support	58 (32.6)	18 (9.8)	76 (21.1)
Carer informal networks and social support	25 (14.0)	1 (0.5)	26 (7.2)
Patient understanding of dementia	31 (17.4)	7 (3.8)	38 (10.5)
Carer understanding of dementia	44 (24.7)	19 (10.4)	63 (17.5)
Environment and assistive technology	29 (16.3)	13 (7.1)	42 (11.6)
Post-bereavement support	1 (0.6)	1 (0.5)	2 (0.6)

Further analysis of aggregated data for individual patient–carer dyads showed high levels of collaborative working or informal discussions (83.8% of dyads) and indicated that just over half (51.4%) were referred to another service, most frequently the third sector (*Figure 9* and *Table 28*). Collaborative working was most common with colleagues in primary care, care home staff and MDTs. The high proportion of dyads (70%) discussed with primary care colleagues is likely to have been facilitated by physical proximity, which enabled brief informal discussions with GPs. Further analyses showed that people with dementia living in care homes and their family carers were referred less frequently (33.3%) than those living in their own homes (75%), but no differences were found in the frequency of informal discussions according to place of residence.

Despite the challenges of recording and analysing activity data, the analyses were generally consistent with the findings of observation and interviews, suggesting that the data were reasonably robust. For example, the DNS who was more embedded in the general practice discussed a higher proportion (89%) of dyads with primary care colleagues than the DNS based in the less engaged practice (53%).

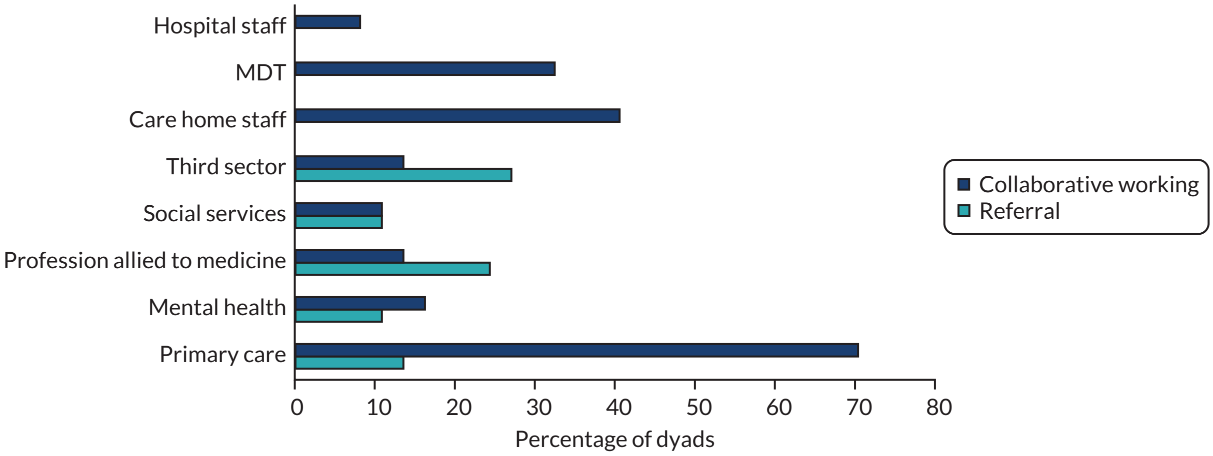


FIGURE 9 Referrals and collaborative working with participating dyads.

TABLE 28 Referrals and collaborative working with participating dyads

	***n* (%)**	
Sector/professional	**Referrals (*N* = 37)**	**Collaborative working (*N* = 37)**
Primary care	5 (13.5)	26 (70.3)
Mental health	4 (10.8)	6 (16.2)
Profession allied to medicine	9 (24.3)	5 (13.5)
Social services	4 (10.8)	4 (10.8)
Third sector	10 (27)	5 (13.5)
Care home staff	0 (0)	15 (40.5)
MDT	0 (0)	12 (32.4)
Hospital staff	0 (0)	3 (8.1)

Vignettes illustrating the SEED intervention

Greater insight into the SEED intervention and the way in which the seven components were translated into practice is provided by the vignettes in *Boxes 2–6*. Pseudonyms were used for the individuals to ensure confidentiality. The key components covered by different vignettes are:

- timely planning discussions (vignettes 3, 4 and 5)
- recognising EOL and providing supportive care (vignettes 1, 2, 4 and 5)
- co-ordinating care (vignettes 1, 2, 3, 4 and 5)
- working effectively with primary care (vignettes 3, 4 and 5)
- managing hospitalisation (vignettes 2 and 5)
- continuing care after death (vignette 2)
- valuing staff and ongoing learning (vignettes 1 and 5).

BOX 2 Vignette 1: Mr Jennings and his daughter (DNS 1)

Mr Jennings has been in a nursing home for 4 years. He has had dementia for around 10 years and is considered by his GP to be approaching the EOL. His wife is in another care home and his daughter visits regularly. The DNS reviews Mr Jennings' care needs with his daughter and care home staff. All agree that he seems to be having more difficulties with communication, and his mobility and ability to self-care have declined. Mr Jennings is frustrated by these changes. The care home staff are keen to provide the best care possible, but feel that they are currently struggling to meet his needs.

The DNS suggests using the comfort care plan to explore and address Mr Jennings' changing needs. Using Mr Jennings as an example, she delivers a training session at the care home for staff involved in Mr Jennings' care (including the care home manager and senior staff). Prior to the session, the DNS met with Mr Jennings' daughter to talk about her father's care needs, and whether or not and how these were changing as his dementia progressed. This enabled the DNS to include these insights from his daughter in the training session for care home staff. In the training session, staff considered his likes and dislikes, identified ways of enhancing his physical and emotional well-being and then developed a draft plan. The DNS encourages the care home staff to think about comfort care planning for others in the care home.

The DNS discusses the plan with Mr Jennings' daughter, who supports the suggested changes. She works with the care home to implement small changes in her father's care, such as improving access to, and variety in, his favourite music and television programmes, and interventions to calm Mr Jennings during his personal care.

One month later, the DNS reviews the comfort care plan with the staff and Mr Jennings' daughter. They are pleased with the changes and Mr Jennings is now calmer and more relaxed. This makes his daughter's visits more enjoyable and the staff feel that Mr Jennings is less distressed and that they are now meeting his needs around comfort. The care home manager and the DNS work on more comfort care plans for other residents and have implemented a system of 'flash meetings' to ensure that as many staff as possible are aware of individual comfort care plans for residents.

BOX 3 Vignette 2: Mr Thompson, his wife and their daughter (DNS 1)

Mr Thompson and his wife live in their family home. Their daughter and son-in-law live locally and visit regularly, supporting their parents with some everyday tasks, such as shopping. Their daughter feels that her mum struggles to cope with her dad and would benefit from some extra support; however, Mrs Thompson is reluctant to accept help. Using the newly developed template, the DNS completes a comprehensive annual dementia review with the couple. Although the couple seemed to be coping well on the surface, the assessment reveals that the couple need support with managing Mr Thompson's physical health, particularly his continence needs. Mrs Thompson confides in the DNS about her own emotional struggles. Mrs Thompson had previously refused to engage with services, but the DNS persuades Mrs Thompson to accept support. She refers Mr Thompson to the Community Mental Health Team and Mrs Thompson to psychology, to meet their individual psychological needs. The DNS also feeds back her findings to the GP, highlighting concerns around safeguarding for the couple.

Mr and Mrs Thompson engage with the mental health services and receive support. However Mr Thompson is taken ill with an infection and is admitted to hospital. While in hospital, he becomes ill with viral gastroenteritis, and is increasingly frail. The DNS discusses Mr Thompson's health with the hospital MDT. Mr and Mrs Thompson's daughter is concerned that her mother will no longer be able to cope with her dad on discharge from hospital, but Mrs Thompson is adamant that she wants her husband to come home when he is able. The DNS has built up a relationship of trust with Mrs Thompson and asks her to consider a placement in a local care home to help her husband to recuperate. The DNS visits Mr Thompson in hospital and keeps the hospital MDT and family informed of each other's wishes and preferences around the best care for Mr Thompson.

Mr Thompson deteriorates further and the hospital staff and his daughter believes that he would be best cared for in hospital. He is moved to a side ward, and dies a few days later. The DNS visits Mrs Thompson and her daughter soon after Mr Thompson's death to continue to support them. They feel that Mr Thompson died peacefully and comfortably. The DNS stays in touch, and refers Mrs Thompson for bereavement support. Her daughter feels that this is very helpful for her mother.

BOX 4 Vignette 3: Mrs Robertson (DNS 2)

Mrs Robertson has had a recent diagnosis of dementia. She lives alone in a flat and her son visits every day on the way home from work. She is in good physical health and loves going out in town, but recognises that changes in her short-term memory are starting to affect her ability to get out and about.

Again, using the new dementia review template, the DNS completes a comprehensive assessment of Mrs Robertson's physical and emotional well-being. The DNS realises that Mrs Robertson is fit and active, and very sociable, but needs support in maintaining a good social network.

Owing to the severity of Mrs Robertson's short-term memory loss, the DNS feels that it is appropriate to discuss planning future care and decision-making while she is able to do so. The DNS broaches this cautiously over several visits. Mrs Robertson is initially reluctant, shrugging off the need to think about the future. The DNS uses documentation, such as 'This is me', as a way of discussing future preferences and establishes that her son already has lasting power of attorney for health and welfare in place.

BOX 4 Vignette 3 (*continued*)

The DNS also suggests different day centres and clubs that Mrs Robertson may be interested in. She agrees to attend the day hospice at the local hospital, but is less keen on local interest groups, such as a choir. The DNS arranges a referral to the day hospice and ensures transport is arranged. The DNS telephones Mrs Robertson's son to discuss the new service and decision-making around future care. Her son is open to discussions about planning for the future.

The DNS follows up with Mrs Robertson and also liaises with the day hospice team. Mrs Robertson and the hospice team are very positive, both describing how she enjoys her weekly visits to the centre. However, the hospice team are concerned that they currently provide only short-term placements and will have to discharge Mrs Robertson from the service after 3 months. They discuss options for re-referral if the service has capacity. Providing a service for Mrs Robertson is unusual for the hospice. It has led them to question whether or not their service is appropriately organised and equipped for people with dementia. They plan to implement changes to adapt the service for people with conditions that have uncertain trajectories, and to develop staff training on dementia. The DNS and Mrs Robertson continue to explore alternative local organisations and groups to meet Mrs Robertson's psychosocial needs.

BOX 5 Vignette 4: Mrs O'Shea and her daughter (DNS 2)

Mrs O'Shea is a widow and lives alone with the support of her daughter and son-in-law. They visit frequently and provide support around housework, shopping, home maintenance and some personal care. They also have other family support commitments and Mrs O'Shea sometimes goes into respite care at a local care home when her daughter and son-in-law are away. They already have support from social work and the local Admiral Nursing team.

Mrs O'Shea is in her 90s, but her diagnosis of dementia is recent. Her daughter is concerned that her mother is unable to appreciate the amount of support she now needs, and she is uncertain whether or not she and her husband can continue to meet this increasing need. Although she has lasting power of attorney for her mother's health and welfare, and finance, she is worried about making decisions on behalf of her mother because of complications with a sibling who lives abroad.

During a follow-up visit, the DNS reviews these concerns with Mrs O'Shea, her daughter and her son-in-law, together. Mrs O'Shea's daughter is keen for her mother to be involved in her own decision-making as much as possible. They talk about future plans together, but choose to fill in documentation together at a time when they can focus on this as a family. Her daughter finds it helpful that the DNS is involved in these discussions so that she cannot be accused of overinfluencing her mother. They also discuss managing Mrs O'Shea's increasing needs and her family's need for respite. This is a tricky issue and, again, the DNS acts as a third party, facilitating a discussion about why respite care is necessary and explaining carefully how it can be mutually beneficial in meeting both their needs. Mrs O'Shea's daughter finds it helpful to have these conversations jointly. Although she values the support from the Admiral nurse, the nurse has never met with her mother and is there to support her and her husband.

BOX 6 Vignette 5: care home 2 (DNS 1)

Some of the residents in care home 2 were participants in the research. As well as visiting the individual residents, the DNS met with the manager and senior staff to explore ways of improving the care provided to benefit other residents and the care home. The DNS supported the care home staff to identify and make changes in ways that enabled staff to take ownership and maintain changes once the study was over.

The manager and clinical lead were keen to secure outstanding status on EOLC from the independent regulators. They identified that improvements were needed in their ACP documentation before this could be achieved. The DNS worked with the senior staff, a community matron and the local hospice to improve their documentation so it both captured key information and was more user friendly. The manager subsequently shared the revised documentation with the senior management team of the care home group, of which her home was a part; they were keen to adopt the documents in their other homes. In addition, the community matron discussed the new documentation at a meeting of local care homes with a view to wider adoption in the area.

Ad hoc opportunities for systems change also arose. On one visit to review a resident, the clinical lead confided in the DNS that some of the local GPs seemed unclear about which forms to use for Emergency Healthcare Planning, and how to personalise the content for individual residents. The DNS was able to discuss this with practice staff at a multidisciplinary meeting, and developed a flow chart for the GPs to use when completing documentation with the care home staff.

Through joint visits with GPs, the DNS was able to introduce staff and residents to her colleagues and facilitate stronger links between the care home and the general practice. The DNS and the practice pharmacist also worked together on medication reviews for residents in the study. This paved the way for the pharmacist to work with the clinical lead to monitor and review medications for all residents in the home.

Resources developed by the dementia nurse specialists to support end-of-life care

Further insight into the delivery of the intervention is provided by the resources developed by the DNSs. To improve the context for EOLC, they developed and implemented several new resources during the study (*Table 29*). These resources highlight the breadth of their work, and the potential benefits of the intervention for care homes and general practices. Interview data consistently indicated the value of these resources to stakeholders (see *Table 29*).

Stakeholder views on feasibility and acceptability of the SEED intervention

Location in primary care

All participants agreed that primary care was the right location for the DNS, with the majority seeing the general practice as the most appropriate. However, a small number of health-care professionals suggested that the DNS could be located with other primary care teams (e.g. district nurses or palliative care teams).

TABLE 29 Resources developed by the DNSs

Characteristic	Mapping local resources	Comfort care planning	Training	Template for annual dementia review
Contributors	DNSs	DNSs	DNSs	DNSs and dementia lead GP
Activities	Networking and mapping local services	• Developing and delivering training to care home staff • Liaison with families • Developing and reviewing plans • Encouraging care homes to extend this approach to all residents	Developing and delivering training on: • EHCPs (GPs) • Dementia (care home staff, practice staff) • EOLC (care home staff) • ACP (care home staff) • Delirium (care home staff)	• Drafting and reviewing template • Using template to complete reviews • Working with practice manager to add template to system
Outputs	Summary sheet for general practice	• Comfort care plans for people with dementia in care homes and the community • Training materials	• Flow chart for GPs on EHCP • Training materials	Template to improve consistency of annual reviews, which includes prompts to discuss next of kin and ACP
Illustrative stakeholder feedback	*[DNS2] put together information sheets for us about local sources of other help, which has been probably one of the most helpful things* Interview, GP 3.3, site 3	*Well the main thing she's done is to develop a comfort care plan for my dad, which I think was really lovely, actually. I think not only has she listened to what I was saying, which she clearly did, but she'd obviously been out to the care home a couple of times and had spoken to staff . . . I felt reading it, that it was yes, this is what my dad is like now and what he needs now* Interview, family carer 1058	*One of the nursing homes, when I did the pain assessment [training], one of the carers said she would like more end-of-life training, so I'll work on that as a form of education and awareness* Intervention supervision, DNS2	*I've done a few [dementia annual reviews] myself and I find it a really user-friendly template. We need to go around the care homes and do all of those . . . So I'm going to be putting [it] into a lot more practice within the next couple of months. But I think it's fantastic* Interview, GP 1.1, site 1

EHCP, Emergency Healthcare Plan.

Key benefits of the DNS being based in a general practice were ease of access for people with dementia and carers, opportunities for face-to-face contact with GPs, access to patient records and the established links to other services:

> *We used to have district nurses based on-site, we used to have health visitors based on-site. Now the health visitors are based in their own little silo away, and the district nurses are based in their silo off-site. But you can't beat that interaction, with a GP, down a corridor. 'Actually Mrs Smith is struggling, can we do something about this?'. So yes you could probably do it off-site, but you're not going to get that quality input.*
>
> *Interview, practice manager 3.1, site 3*

As most people with dementia receive most of their care from primary care, this was seen as an appropriate location, although the need for the DNS to liaise with, and co-ordinate, other services as needed was emphasised:

> *Many patients will go through long periods of the dementia illness, without being in touch with secondary care services. So, from that point alone it makes sense to be embedded with primary care, one of the core roles . . . is developing links with other parts of the wider system.*
>
> *Interview, consultant old-age psychiatrist, intervention supervision team*

To maximise the benefits of co-location in the general practice, being recognised and valued as a member of the team was essential. This was facilitated by providing a planned induction, regular supervision meetings with the dementia lead GP, and attending key meetings. The frequent changes in the host general practices (e.g. merging with a neighbouring practice, managing staff shortages) highlighted the need for DNSs to be adept at managing change. Furthermore, their confidence in their specialist knowledge and ability to develop their role in the practice influenced the extent to which they were successfully embedded:

> *. . . but the challenges were sitting in a group of people that I don't know, like the MDT, and thinking, 'right, I'm going to have to speak up here, I've got to fight for some recognition'. I don't want to just be somebody who disappears into the background, otherwise I'm not going to make a difference. Having to sort of steel myself to go and speak to GPs about people*
>
> *Interview, DNS 1*

Relevance of the seven key components to real-world practice

The DNSs delivered interventions relating to all seven components for participants living at home and in care homes, at both an individual and a systems level (see *Table 6* and the vignettes in *Boxes 2–6*). Components that were most commonly reported in interviews with people with dementia and carers were co-ordinating care, working effectively with primary care and timely planning discussions. It was through these activities that other components were often addressed, for example recognising EOL and providing supportive care, and managing hospitalisation. No additional components were identified.

Carers valued the continuity of care provided by their DNS, which was in marked contrast to their experience of other services, where they sometimes needed to recount events multiple times. Continuity was also identified as important by other health-care professionals:

> *Well you don't have to start from scratch. I mean, obviously they've got notes, but you feel like they know you. You don't feel like it's a stranger and you're having to say 'Well my dad doesn't know this', because she knows.*
>
> *Interview, family carer 3014*

> *When there are lots of people involved, for the family, they don't obviously know which nurse belongs to which service, and that family might have had a crisis and are run ragged and they've got different nurses going in, and they think 'Oh, who's been in?'. When lots of services are involved, it's sometimes difficult, and obviously difficult for families as well to interpret who is who.*
>
> *Interview, district nurse HCP 5, site 3*

Some of the barriers to planning ahead identified in our earlier work,[96] for example reluctance to talk about the future and a preference to focus on the present, were encountered by the DNSs:

> *To be honest, I haven't given it a thought, because I thought 'just take things as they come'. That's the only way I think of it. You can't plan ahead, you just don't know what's going to happen. So, you just take one day at a time.*
>
> *Interview, person with dementia 3035*

Both DNSs developed a range of strategies to encourage discussions around planning future care, including providing documentation to allow people to digest information in their own time, exploring planning future care as part of annual dementia reviews, or using changes in circumstances to prompt 'what if' discussions:

> *. . . you have that opening to start on that conversation. For example, they noticed a deterioration so that was the perfect opportunity to say 'If we don't get you help and start planning ahead now, you're not going to be able to look after him at home, and I assume that is your ultimate wish'. 'Oh, yes'.*
>
> *Intervention supervision, DNS1*

The ability of the DNSs to address future planning was particularly important, as health-care professionals described a lack of responsibility around discussing and documenting future care preferences with people with dementia:

> *. . . well we don't really do any [ACP] as part of the memory service because we don't really have time, but who does in effect? Actually that might be a role of the support.*
>
> *Interview, consultant old-age psychiatrist HCP 6 site 3*

Opportunities for continuing care after death were limited owing to the small number of deaths during the study. Only two contacts with family carers relating to continuing care after death were recorded in the activity logs, suggesting that relatively little attention was paid to this component. Discussion in an intervention supervision meeting highlighted a mismatch between the intention of one DNS to use a structured checklist for post-death review meetings in care homes and the intended focus on a more discursive exploration of the positive aspects of EOLC, identifying areas for improvement, and considering the emotional impact on staff. However, a more reflective approach was subsequently used:

> *I did one [post-death review] with the lady that died in the home. Similar to DNS2, I highlighted who was the best person to do this. They came up with some interesting stuff, because there were a couple of new staff there, and they'd had quite a few deaths.*
>
> *Intervention supervision, DNS1*

Feasibility and acceptability of individual- and systems-level work

The DNSs were assigned a small caseload to enable tailored proactive working with individuals and to secure time for strategic and systems-level working. The DNSs were experienced in working with individual patients in their previous roles and were confident in identifying the needs of people with dementia and family carers and then providing tailored interventions (see the vignettes in *Boxes 2–6*). In this aspect of their role, the DNSs worked autonomously, seeking clinical supervision as needed.

Most families viewed the frequency and duration of visits as appropriate. The small case load was, however, questioned by some primary care staff:

> *The only downside, I suppose, for me and the practice is the numbers. Providing that very expensive nurse for a few people isn't something that we're used to in primary care . . . We are a large practice, we've got a multiskilled workforce, I've got a practice pharmacist, I've just employed a paramedic, so we're looking at how we can really skill-mix across the practice and [DNS1] fitted in with that. If it was a full time role, we'd have to look at how that worked with the numbers.*
>
> *Interview, practice manager 1.1, site 1*

At a systems level, the role offered freedom to work autonomously and proactively, and to make changes to benefit service users more broadly. Despite some anxieties about working at this more strategic level, both DNSs grew in confidence and successfully developed a range of systems primarily, although not exclusively, in the general practices and care homes. Working at a more strategic level required support through intervention supervision, but the DNSs enjoyed the chance to make changes that would have a wider impact on EOLC for people with dementia. A key example of systems-level work was the development of a template for the annual dementia reviews. This work was encouraged by the dementia lead GP in one of the practices:

> *So when [DNS1] and I sat down when she started her job, in terms of systems within the practice, what we looked at were ways that we could improve the quality of the dementia reviews, to ensure that they were done to a high standard, but also done consistently throughout the practice.*
>
> *Interview, GP 1.1, site 1*

Qualifications and experience needed for the dementia nurse specialist role

Some professionals considered that the knowledge and skills required to fulfil the role effectively were facilitated by a nursing background. The medical knowledge of the DNSs was particularly valued by carers and care home staff. Some carers described how both they and the person with dementia were more likely to accept help and support when it was framed medically and advice was given from a professional:

> *I think it's quite good that she has got the nursing background because when we were talking about him having problems with his incontinence . . . he would go 'There is nothing wrong'. I said 'Well actually, [DNS2] is a nurse'. I think when I said 'She's actually from the doctors. She's medical', then he'll go 'Oh.'. I think he feels a bit better then.*
>
> *Interview, family carer 3014*

Others considered professional background less important, but emphasised the need for knowledge and skills in managing the physical and psychological needs of people with dementia and carers. Other personal attributes, such as inspiring confidence, being reliable, being tenacious, being approachable and putting people with dementia and their families at ease, were also emphasised:

> *I think [DNS1] is such a professional, very knowledgeable. She just makes you feel at ease. She's just really experienced.*
>
> *Interview, care home manager CH 13, site 1*

Carers commonly regarded the DNS as having expertise to meet both their own needs and those of the person with dementia. They were confident that the DNS would be able to respond to a range of problems and issues, seeking input from others as necessary and even helping with problems beyond the scope of their remit (e.g. identifying relevant social groups, facilitating parking at the practice when attending for appointments).

Fit with existing models of care

The majority of professionals and carers considered the DNS role as complementary to existing services, and valued their inclusion as part of the multidisciplinary care team. When a degree of overlap with existing services was identified, this was generally considered beneficial rather than problematic:

> *. . . I think, undoubtedly, there's overlap with our roles, but very much, they're complementary. We find that throughout palliative care, that there's quite a lot of blurring of roles, but it is about teamwork.*
>
> *Interview, Macmillan Nurse HCP 5, site 1*

The role perceived as having the most in common with the DNS was Admiral nursing. However, a key difference was the integration of the DNS in general practice, which, as already described, had a number of benefits for all stakeholders. Furthermore, Admiral nurses are not universally available to people with dementia and carers, and they were perceived by some participants as being primarily focused on carers, with less attention to the needs of people with dementia. Carers and professionals acknowledged a significant gap around post-diagnostic support in dementia, and felt that the DNSs were well placed to address this need and provide ongoing support:

> *. . . my experience of the GPs basically 'Here's the diagnosis and see you.'. That's it, because there's no medication and you don't get offered anything at all, that was it.*
>
> *Interview, family carer 1058*

Tensions over role boundaries were experienced only in relation to a local hospice seeking to expand its services to include people with dementia.

Factors influencing implementation of the SEED intervention

The framework of NPT[114] was used to identify factors influencing the implementation of the SEED intervention.

1. Coherence

   This considers whether or not the SEED intervention made sense to all stakeholders, was easy to understand and was distinct from existing services. The intervention was not perceived as relevant to some people with dementia and family carers because of the focus on EOLC; this aspect of the intervention was also contested by the DNSs and other stakeholders who were keen to expand the intervention to all people with dementia. The location of the intervention in primary care was valued by nearly all stakeholders. The fact that the SEED intervention was seen as overlapping with existing interventions was nearly always viewed positively, although tensions occasionally arose over role boundaries.

   A recurring theme in early intervention supervision and initial interviews with the DNSs was uncertainty over their new role, suggesting a lack of coherence:

   > *From the outside looking in, people probably think it's quite a straightforward role. Often, I feel like a duck that looks quite calm on the outside, but paddling like mad underneath, thinking 'What on earth am I supposed to be doing?'. I think there's a lot of self-motivation and discipline required around mapping out what the role is.*
   >
   > *Interview, DNS1*

   Many of these anxieties were resolved over time as they began working with individual people with dementia and carers, established their role in the practice and gained confidence around the seven components.

2. Cognitive participation
   Cognitive participation focuses on whether or not stakeholders engaged with, and invested in, the SEED intervention. The temporary nature of the intervention influenced the buy-in of all stakeholders. Relationship-building was key to engaging people with dementia, family carers and care homes. Investing time in getting to know study participants often led to the identification of unmet needs, opportunities to intervene and the potential avoidance of crises. Differing levels of engagement and commitment were observed in the two general practices:

   > *Well, I think I've been unlucky in the fact that there hasn't been a dementia lead GP with a vested interest in dementia. I think that's been an obstacle, really, from the start, because none of the GPs have shone out with a great enthusiasm for dementia, and even end of life. I think they are so under pressure just doing their job. But, I think it does need to start with a GP who wants to invest in care of people with dementia.*
   >
   > *Interview, DNS2*

   > *I had a 2-week induction at the surgery, which was really well planned, so [name], who is the sort of head administrator come everything really, she had organised for me to go out with different people, and that was great.*
   >
   > *Interview, DNS1*

3. Collective action
   Intervention implementation depends on whether or not work is allocated to the right individuals and whether or not they are adequately trained and resourced. The different professional backgrounds of the DNSs were complementary, enabling them to share specialist knowledge and work together effectively:

   > *I think the key thing, really, about [DNS1] being in role is the fact that she is a mental health nurse. It's the fact that she's got that knowledge and those links that have made it work . . . Because a lot of the focus hasn't been on the last few days of somebody's life, it's not been on that palliative, necessarily, care, it's been on their future care and planning, and an understanding around dementia diagnosis and things.*
   >
   > *Interview, GP 1.1, site 1*

   Supervision arrangements proved successful in ensuring access to specialist knowledge and support relating to different aspects of their role. Intervention supervision was particularly important because of the initial uncertainties of the DNSs over the scope of the intervention. The relationships that people with dementia and family carers developed with the DNSs were valued and were key to engaging them in ACP:

   > *She gave a very emotional account of having discussed it [do not attempt cardiopulmonary resuscitation (DNACPR)] with DNS2, but didn't feel ready. However, soon after she read an article in the Sunday newspaper (which she found quite harrowing) about the ambulance service 'forcing' people to do CPR [cardiopulmonary resuscitation] on their relatives who were clearly already dead (she became tearful when talking about this), and drew on her knowledge as a prior first aider, knowing that performing the procedure could often break bones, and decided that DNACPR was probably right for her mother . . . At a later visit, the wish to complete DNACPR was discussed with DNS2 who signposted to the GP and this was arranged with the GP over the telephone. So it seemed that DNS2 had 'planted the seed', and then given the carer space to make her decisions in the time frame appropriate to her.*
   >
   > *Field notes, site 3*

   The extent to which the host general practices supported the intervention varied. This was evident through the level of involvement of the lead dementia GP, but was also demonstrated through the lack of support provided with practice IT systems.

4. Reflexive monitoring
   A key aspect of successful implementation is the extent to which stakeholders are aware of the difference made by a new intervention, whether this is through formal or informal means. The ability to reflect on, and adapt, the intervention in the light of this appraisal is also crucial. Although no formal mechanisms for evaluating impacts were in place, informal feedback from study participants, including care home staff and some GPs, was positive:

   > *I mentioned it to [DNS1], I said 'I'm having a real struggle for them to realise that dad can't physically get to the surgery any more'. Then within a day, 2 days, the district nurses were there, taking his samples and giving him the blood.*
   >
   > *Interview, family carer 1053*

   > *She's been proactive in picking up medical problems. So she would be speaking to them, and relatives would maybe mention something, and before I know it, she's coming back to me, saying 'I wonder whether this person might actually have an underlying physical health problem. We need to do a blood test.'. So that proactive work, I'm sure, has decreased the burden on secondary care.*
   >
   > *Interview, GP 1.1, site 1*

   > *She's also helped to implement emergency health-care plans and DNRs [do not resuscitate], which we previously didn't do, which has been a big help, because the GPs have been understaffed and struggling, and we haven't been able to get them, basically, since the community matron left post.*
   >
   > *Interview, clinical lead, care home 2, site 1*

   Although such comments were not necessarily directly fed back to the DNSs, the benefits identified often led to ongoing work with individual patient–carer dyads and requests from care homes for further input confirming the value of the DNS input. Access to different perspectives through supervision also facilitated reflection on the intervention.

   Overall, the individual and collective work required for successful implementation of a new intervention was largely achieved. Although investment in the intervention was relatively poor in one GP practice, and other stakeholders were, understandably, reluctant to engage with a short-term intervention, the interpersonal skills of the DNSs and having time to develop relationships enabled them to build engagement throughout the trial.

Feasibility and acceptability of outcome measures

Data completion of outcome measures

Analysis of outcome measures focused initially on missing data. Imputed scores for partially completed responses made little difference to overall attrition rates, with the exception of the SWC-EOLD questionnaire, for which there were predominantly partial responses. As there was little evidence that completion rates varied between intervention arms, summary figures provide an overview of baseline data, and tables present the full data for intervention and control arms at each time point.

Outcome measures relating to symptoms and well-being of people with dementia and family carers

Completion rates for these outcome measures were generally good (*Figure 10*, *Tables 30–33*). Several family carers were unable to complete the Quality of Life in Late-stage Dementia (QUALID) because they had not spent the required time with the person with dementia in the previous week. Data on the PAINAD during movement were missing for the significant number of people with dementia who remained seated throughout the assessment.

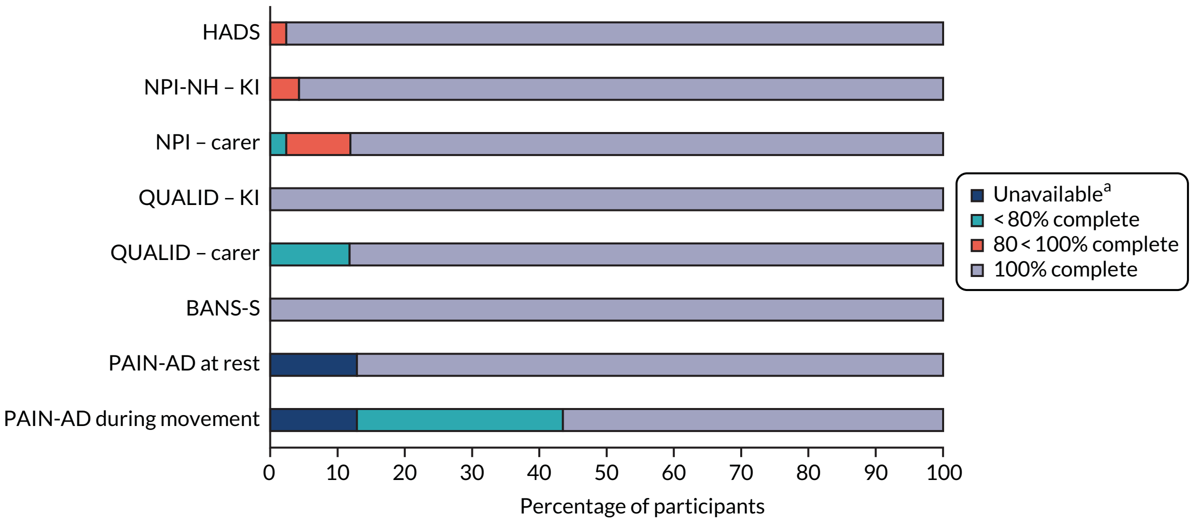


FIGURE 10 Data completion of outcome measures relating to symptoms and well-being of people with dementia and family carers at baseline. a, Unavailable includes those who were not approached or were unwell. BANS-S, Bedford Alzheimer Nursing Severity Scale; HADS, Hospital Anxiety and Depression Scale; KI, key informant; NPI-NH, Neuropsychiatric Inventory-Nursing Home; QUALID, Quality of Life in Late-stage Dementia.

TABLE 30 Summary of questionnaire completeness at baseline and at 4 months in the intervention arm

	Baseline, *n* (%)			**4 months, *n* (%)**		
Questionnaire	**Missing[a]**	**Partial[b]**	**Complete[c]**	**Missing[a]**	**Partial[b]**	**Complete[c]**
***Questionnaires completed by family carers* (*n* = 25)**				(*n* = 23)[d]		
HADS						
Anxiety	0 (0)	0 (0)	25 (100)	1 (4)	0 (0)	22 (96)
Depression	0 (0)	0 (0)	25 (100)	1 (4)	0 (0)	22 (96)
Overall score	0 (0)	0 (0)	25 (100)	1 (4)	0 (0)	22 (96)
NPI	0 (0)	4 (16)	21 (84)	1 (4)	3 (13)	19 (83)
QUALID	3 (12)	0 (0)	22 (88)	3 (13)	0 (0)	20 (87)
SM-EOLD	1 (4)	1 (4)	23 (92)	2 (9)	2 (9)	19 (83)
SWC-EOLD	3 (12)	10 (40)	12 (48)	1 (4)	14 (61)	8 (35)
***Questionnaires completed by key informants* (*n* = 15)**				(*n* = 11)[d]		
NPI-NH	0 (0)	1 (7)	14 (93)	2 (18)	1 (9)	8 (72)
BANS-S	0 (0)	0 (0)	15 (100)	0 (0)	0 (0)	11 (100)
QUALID	0 (0)	0 (0)	15 (100)	1 (9)	1 (9)	9 (81)
SM-EOLD	0 (0)	0 (0)	15 (100)	0 ()	0 (0)	11 (100)
SWC-EOLD	1 (7)	7 (47)	7 (47)	1 (9)	9 (81)	1 (9)
***Questionnaires completed by both key informant and family carer*[e] (*n* = 37)**				(*n* = 30)[d]		
QUALID	3 (8)	0 (0)	34 (92)	2 (7)	1 (3)	27 (90)
SM-EOLD	2 (5)	1 (3)	34 (92)	2 (7)	0 (0)	28 (93)
SWC-EOLD	5 (14)	17 (46)	15 (41)	2 (7)	19 (63)	9 (32)

TABLE 30 Summary of questionnaire completeness at baseline and at 4 months in the intervention arm (*continued*)

	Baseline, *n* (%)			**4 months, *n* (%)**		
Questionnaire	**Missing**[a]	**Partial**[b]	**Complete**[c]	**Missing**[a]	**Partial**[b]	**Complete**[c]
***Questionnaire completed by research team* (n = 37)**				**(n = 32)**[d]		
PAINAD						
At rest	6 (16)	0 (0)	31 (84)	7 (22)	0 (0)	25 (78)
During movement	18 (49)	0 (0)	19 (51)	18 (56)	0 (0)	14 (44)

BANS-S, Bedford Alzheimer Nursing Severity Scale; HADS, Hospital Anxiety and Depression Scale; NPI-NH, Neuropsychiatric Inventory-Nursing Home.

a Missing is defined as answering < 80% of questions on the questionnaire.
b Partial responses are defined as at least 80% of the questions on the questionnaire being completed, but not all questions.
c Complete responses are defined all questions on the questionnaire being completed.
d Excludes withdrawn participants and people with dementia who died between baseline and the 4-month assessment.
e Questionnaires completed by both the key informant and the family carer, but completion by either is deemed a response.

TABLE 31 Summary of questionnaire completeness at baseline and at 4 months in the control arm

	Baseline, *n* (%)			**4 months, *n* (%)**		
Questionnaire	**Missing**[a]	**Partial**[b]	**Complete**[c]	**Missing**[a]	**Partial**[b]	**Complete**[c]
***Questionnaires completed by family carers* (n = 17)**				**(n = 17)**		
HADS						
Anxiety	0 (0)	0 (0)	17 (100)	1 (6)	0 (0)	16 (94)
Depression	0 (0)	1 (6)	16 (94)	1 (6)	0 (0)	16 (94)
Overall score	0 (0)	1 (6)	16 (94)	1 (6)	0 (0)	16 (94)
NPI	1 (6)	0 (0)	16 (94)	1 (6)	1 (6)	15 (88)
QUALID	2 (12)	0 (0)	15 (88)	3 (18)	0 (0)	14 (82)
SM-EOLD	0 (0)	2 (12)	15 (88)	1 (6)	0 (0)	16 (94)
SWC-EOLD	5 (29)	10 (59)	2 (12)	3 (18)	8 (47)	6 (35)
***Questionnaires completed by key informants* (n = 8)**				**(n = 7)**[d]		
NPI-NH	0 (0)	0 (0)	8 (100)	0 (0)	0 (0)	7 (100)
BANS-S	0 (0)	0 (0)	8 (100)	0 (0)	0 (0)	7 (100)
QUALID – key informant	0 (0)	0 (0)	8 (100)	2 (29)	0 (0)	5 (71)
SM-EOLD – key informant	0 (0)	0 (0)	8 (100)	0 (0)	0 (0)	7 (100)
SWC-EOLD – key informant	1 (12)	5 (63)	2 (25)	1 (14)	4 (57)	2 (29)
***Questionnaires completed by both key informant and family carer*[e] (n = 25)**				**(n = 23)**[d]		
QUALID	2 (8)	0 (0)	23 (92)	4 (17)	0 (0)	19 (83)
SM-EOLD	1 (4)	2 (8)	22 (88)	1 (4)	0 (0)	22 (96)
SWC-EOLD	7 (28)	14 (56)	4 (16)	4 (17)	11 (48)	8 (35)

continued

TABLE 31 Summary of questionnaire completeness at baseline and at 4 months in the control arm (*continued*)

Questionnaire	Baseline, *n* (%)			4 months, *n* (%)		
	Missing[a]	Partial[b]	Complete[c]	Missing[a]	Partial[b]	Complete[c]
Questionnaire completed by research team* (n = *25)				**(n = *24)*[d]**		
PAINAD						
At rest	2 (8)	0 (0)	23 (92)	3 (12)	0 (0)	21 (88)
During movement	9 (36)	0 (0)	16 (64)	12 (50)	0 (0)	12 (50)

BANS-S, Bedford Alzheimer Nursing-Severity Scale; HADS, Hospital Anxiety and Depression Scale; NPI-NH, Neuropsychiatric Inventory-Nursing Home.

a Missing is defined as answering < 80% of questions on the questionnaire.

b Partial responses are defined as at least 80% of the questions on the questionnaire being completed, but not all questions.

c Complete responses are defined all questions on the questionnaire being completed.

d Excludes withdrawn participants and people with dementia who died between baseline and the 4-month assessment.

e Questionnaires completed by both the key informant and the family carer, but completion by either is deemed a response.

TABLE 32 Summary of questionnaire completeness at 8 and 12 months in the intervention arm

Questionnaire	8 months, *n* (%)			12 months, *n* (%)		
	Missing[a]	Partial[b]	Complete[c]	Missing[a]	Partial[b]	Complete[c]
***Questionnaires completed by family carers* (n = *22)*[d]**				**(n = *20)*[e]**		
HADS						
Anxiety	0 (0)	0 (0)	22 (88)	0 (0)	0 (0)	20 (100)
Depression	0 (0)	0 (0)	22 (88)	0 (0)	0 (0)	20 (100)
Overall score	0 (0)	0 (0)	22 (88)	0 (0)	0 (0)	20 (100)
NPI	0 (0)	5 (23)	17 (77)	0 (0)	5 (25)	15 (75)
QUALID	3 (14)	0 (0)	19 (86)	5 (25)	0 (0)	15 (75)
SM-EOLD	1 (5)	0 (0)	21 (95)	1 (5)	0 (0)	19 (95)
SWC-EOLD	1 (5)	13 (59)	8 (36)	0 (0)	10 (50)	10 (50)
***Questionnaires completed by key informants* (n = *13)*[d]**				**(n = *12)*[e]**		
NPI-NH	0 (0)	1 (8)	12 (92)	0 (0)	1 (8)	11 (92)
BANS-S	0 (0)	1 (8)	12 (92)	0 (0)	1 (8)	11 (92)
QUALID	1 (8)	0 (0)	12 (92)	1 (8)	0 (0)	11 (92)
SM-EOLD	0 (0)	0 (0)	13 (100)	0 (0)	0 (0)	12 (100)
SWC-EOLD	0 (0)	8 (62)	5 (38)	2 (17)	5 (42)	5 (42)
***Questionnaires completed by both key informant and family carer*[f] (n = *30)*[d]**				**(n = *29)*[e]**		
QUALID	2 (7)	0 (0)	28 (93)	5 (17)	0 (0)	24 (83)
SM-EOLD	0 (0)	0 (0)	30 (100)	1 (3)	0 (0)	28 (97)
SWC-EOLD	1 (3)	19 (63)	10 (33)	2 (7)	12 (41)	15 (52)

TABLE 32 Summary of questionnaire completeness at 8 and 12 months in the intervention arm (*continued*)

	8 months, *n* (%)			**12 months, *n* (%)**		
Questionnaire	**Missing[a]**	**Partial[b]**	**Complete[c]**	**Missing[a]**	**Partial[b]**	**Complete[c]**
***Questionnaire completed by research team* (n = *30)*[d]**				**(n = *29)*[e]**		
PAINAD						
At rest	5 (17)	0 (0)	25 (83)	3 (10)	0 (0)	26 (90)
During movement	14 (47)	0 (0)	16 (53)	15 (52)	0 (0)	14 (48)

BANS-S, Bedford Alzheimer Nursing Severity Scale; HADS, Hospital Anxiety and Depression Scale; NPI-NH, Neuropsychiatric Inventory-Nursing Home.

a Missing is defined as answering < 80% of questions on the questionnaire.

b Partial responses are defined as at least 80% of the questions on the questionnaire being completed, but not all questions.

c Complete responses are defined all questions on the questionnaire being completed.

d Excludes withdrawn participants and people with dementia who died between the 4- and 8-month assessments.

e Excludes withdrawn participants and people with dementia who died between the 8- and 12-month assessments.

f Questionnaires completed by both the key informant and the family carer, but completion by either is deemed a response.

TABLE 33 Summary of questionnaire completeness at 8 and 12 months in the control arm

	8 months, *n* (%)			**12 months, *n* (%)**		
Questionnaire	**Missing[a]**	**Partial[b]**	**Complete[c]**	**Missing[a]**	**Partial[b]**	**Complete[c]**
***Questionnaires completed by family carers* (n = *14)*[d]**				**(n = *12)*[e]**		
HADS						
Anxiety	1 (7)	0 (0)	13 (93)	0 (0)	0 (0)	12 (100)
Depression	1 (7)	0 (0)	13 (93)	0 (0)	0 (0)	12 (100)
Overall score	1 (7)	0 (0)	13 (93)	0 (0)	0 (0)	12 (100)
NPI	1 (7)	2 (14)	11 (79)	0 (0)	1 (8)	11 (92)
QUALID	3 (21)	0 (0)	11 (79)	2 (17)	0 (0)	10 (83)
SM-EOLD	1 (7)	0 (0)	13 (93)	0 (0)	0 (0)	12 (100)
SWC-EOLD	5 (36)	4 (29)	5 (36)	3 (25)	4 (33)	5 (42)
***Questionnaires completed by key informants* (n = *5)*[d]**				**(n = *5)*[e]**		
NPI-NH	0 (0)	0 (0)	5 (100)	0 (0)	1 (20)	4 (80)
BANS-S	0 (0)	0 (0)	5 (100)	0 (0)	0 (0)	5 (100)
QUALID	1 (20)	0 (0)	4 (80)	1 (20)	0 (0)	4 (80)
SM-EOLD	0 (0)	0 (0)	5 (100)	0 (0)	0 (0)	5 (100)
SWC-EOLD	1 (20)	2 (40)	2 (40)	0 (0)	3 (60)	2 (40)
***Questionnaires completed by both key informant and family carer*[f] (n = *17)*[d]**				**(n = *16)*[e]**		
QUALID	2 (12)	0 (0)	15 (88)	2 (13)	0 (0)	14 (88)
SM-EOLD	0 (0)	0 (0)	17 (100)	0 (0)	0 (0)	16 (100)
SWC-EOLD	5 (29)	6 (35)	6 (35)	3 (19)	6 (38)	7 (44)

continued

TABLE 33 Summary of questionnaire completeness at 8 and 12 months in the control arm (*continued*)

	8 months, *n* (%)			12 months, *n* (%)		
Questionnaire	**Missing**[a]	**Partial**[b]	**Complete**[c]	**Missing**[a]	**Partial**[b]	**Complete**[c]
Questionnaire completed by research team (n = *19*)[d]				(n = *17*)[e]		
PAINAD						
At rest	3 (16)	0 (0)	16 (84)	1 (6)	0 (0)	16 (94)
During movement	6 (32)	0 (0)	13 (68)	7 (41)	0 (0)	10 (59)

BANS-S, Bedford Alzheimer Nursing Severity Scale; HADS, Hospital Anxiety and Depression Scale; NPI-NH, Neuropsychiatric Inventory-Nursing Home.

a Missing is defined as answering < 80% of questions on the questionnaire.
b Partial responses are defined as at least 80% of the questions on the questionnaire being completed, but not all questions.
c Complete responses are defined all questions on the questionnaire being completed.
d Excludes withdrawn participants and people with dementia who died between the 4- and 8-month assessments.
e Excludes withdrawn participants and people with dementia who died between the 8- and 12-month assessments.
f Questionnaires completed by both the key informant and the family carer, but completion by either is deemed a response.

Outcome measures relating to end-of-life care

Although completion rates for the SM-EOLD were good, completion rates were poor for the SWC-EOLD (*Figure 11*) (see *Tables 30–33*). Given the high numbers of missing data on the SWC-EOLD, completion rates for individual items were examined (*Table 34*). This indicated that responses to the following two items were particularly low:

1. The health-care team are sensitive to my needs and feelings (Q4).
2. I feel that my relative needs better medical care at the end of his or her life (Q10).

Further exploration of the pattern of missing data for family carers and key informants is warranted as it may be that questions are not equally relevant to both; this is certainly suggested by the qualitative data on the SWC-EOLD (see *Qualitative data on outcome measures*). The SWC-EOLD and CAD-EOLD were also administered to family carers and key informants at the post-death interviews (*Table 35*). All participating family carers completed all items on both measures (SWC-EOLD and CAD-EOLD). Key informants completed the CAD-EOLD with no missing data but, consistent with the results in

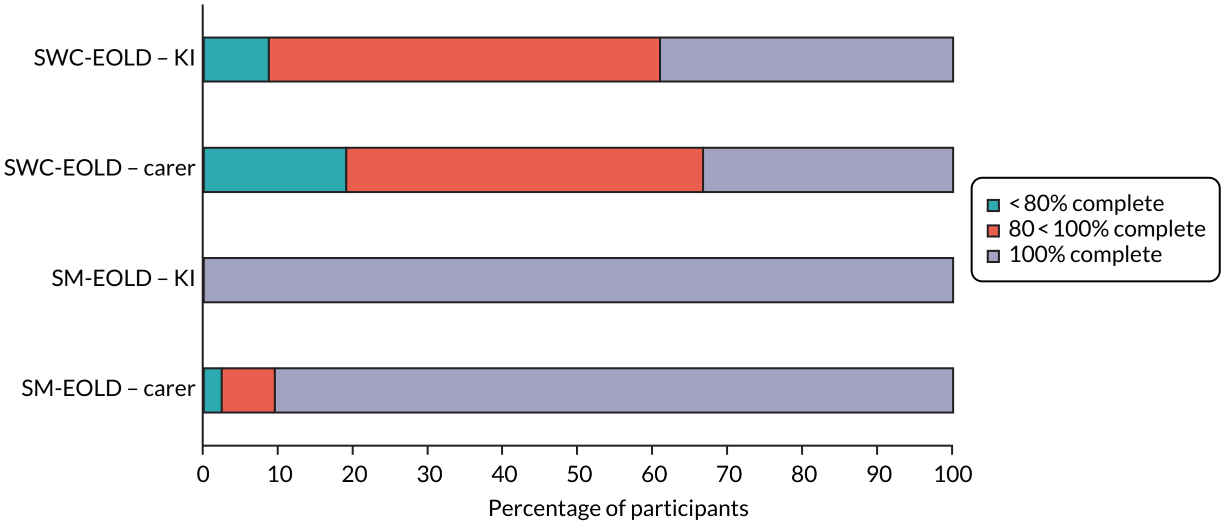


FIGURE 11 Data completion of outcome measures relating to EOLC at baseline. KI, key informant.

TABLE 34 Completion of individual items from the SWC-EOLD questionnaire by time point and intervention arm

	Intervention arm, *n* (%)				**Control arm, *n* (%)**			
SWC-EOLD question	**Baseline (*N* = 37)**	**4 months (*N* = 30)**	**8 months (*N* = 30)**	**12 months (*N* = 29)**	**Baseline (*N* = 25)**	**4 months (*N* = 23)**	**8 months (*N* = 17)**	**12 months (*N* = 16)**
Nursing assistance (Q1)	35 (95)	25 (83)	29 (97)	27 (93)	17 (68)	18 (78)	11 (65)	13 (81)
Treatments (Q2)	35 (95)	29 (97)	29 (97)	27 (93)	21 (84)	21 (91)	16 (94)	14 (88)
Comfortable (Q3)	34 (92)	28 (93)	30 (100)	28 (97)	21 (84)	20 (87)	16 (94)	16 (100)
Sensitive (Q4)	26 (70)	20 (67)	22 (73)	19 (66)	15 (60)	16 (70)	12 (71)	14 (88)
Decision-making (Q5)	32 (86)	28 (93)	26 (87)	26 (90)	23 (92)	19 (83)	16 (94)	15 (94)
Not understand (Q6)	34 (92)	27 (90)	30 (100)	28 (97)	23 (92)	21 (91)	16 (94)	16 (100)
Different (Q7)	33 (89)	28 (93)	29 (97)	27 (93)	22 (88)	22 (96)	14 (82)	16 (100)
Doctor/nurse (Q8)	33 (89)	29 (97)	30 (100)	27 (93)	22 (88)	22 (96)	17 (100)	16 (100)
Medication (Q9)	34 (92)	29 (97)	30 (100)	27 (93)	22 (88)	21 (91)	15 (88)	14 (88)
Medical care (Q10)	25 (68)	19 (63)	21 (70)	20 (69)	7 (28)	15 (65)	10 (43)	7 (44)

Figure 11, only half provided complete data on the SWC-EOLD. The reasons for better completion by family carers at the post-death interview are unclear, but better completion at the post-death interview suggests that the items may be more relevant to family carers when the person with dementia is approaching the EOL. *Table 35* shows the completion of the questionnaires relating to EOL by family carers and key informants of people with dementia who died, by intervention arm.

TABLE 35 Summary of EOL questionnaire completeness of 12 people with dementia who died, by intervention arm

	Intervention arm, *n* (%) (*N* = 5)			**Control arm, *n* (%) (*N* = 7)**		
Questionnaire	**Missing**[a]	**Partial**[b]	**Complete**[c]	**Missing**[a]	**Partial**[b]	**Complete**[c]
***Questionnaires completed by family carers* (n = *6*)**						
HADS						
Anxiety	0 (0)	0 (0)	2 (100)	1 (25)	0 (0)	3 (75)
Depression	0 (0)	0 (0)	2 (100)	1 (25)	0 (0)	3 (75)
Overall score	0 (0)	0 (0)	2 (100)	1 (25)	0 (0)	3 (75)
CAD-EOLD	0 (0)	0 (0)	2 (100)	1 (25)	0 (0)	3 (75)
SWC-EOLD	0 (0)	0 (0)	2 (100)	1 (25)	0 (0)	3 (75)
***Questionnaires completed by key informants* (n = *6*)**						
CAD-EOLD	0 (0)	0 (0)	3 (100)	0 (0)	0 (0)	3 (100)
SWC-EOLD	0 (0)	2 (67)	1 (33)	0 (0)	1 (33)	2 (67)
***Questionnaires completed by both key informants and family carers*[d] (n = 12)**						
SWC-EOLD	0 (0)	2 (40)	3 (60)	1 (14)	1 (14)	5 (72)
CAD-EOLD	0 (0)	0 (0)	5 (100)	1 (14)	0 (0)	6 (86)

a Missing is defined as answering < 80% of questions on the questionnaire.
b Partial responses are defined as at least 80% of the questions on the questionnaire being completed, but not all questions.
c Complete responses are defined all questions on the questionnaire being completed.
d Questionnaires completed by both the key informant and the family carer, but completion by either is deemed a response.

Feasibility of collecting data on health-related quality of life and resource use

Completion rates for the EQ-5D-5L varied by type of respondent. Only baseline data are shown in *Figure 12* for clarity; full details by time point and intervention arm are provided in *Table 36*. The results show that, although there were few missing data for the family carer (when rating their own QoL) or for proxy respondents, there were substantial missing data for people with dementia, only 57% of whom were able to complete all items at baseline (see *Figure 12*). Some people with dementia were not approached at the request of their family carer or key informant and, therefore, did not have the opportunity to try to complete the questionnaire; these are classed as 'missing not at random'. However, the majority of missing data were missing because of the inability of people with dementia to respond to the questions (from a statistical perspective, this might be classed as 'missing at random'). Distinguishing between different types of missing data is important because it dictates the approaches that might be used to impute missing data in a full analysis.

Completion rates for the resource use questionnaire relating to the person with dementia at 4, 8 and 12 months and after death are provided in *Table 37*. The majority of the questions relating to the person with dementia were answered, with two exceptions: weekly charge of the care home (if applicable) and the total income of the person with dementia. We also piloted the resource use questionnaire with five family carers regarding their own use of services; this pilot suggested that the questions were acceptable and feasible for respondents, although researchers commented on the additional burden.

Capturing data on advance care planning

Details of the proportions of people with dementia for whom a range of planning documents were filed in either GP or care home records are summarised in *Figure 13* and provided in detail in *Table 38*.

With the exception of DNACPRs, documents relating to future care were generally available in either care home or GP records for fewer than half of the study participants (see *Table 38*). DNACPR was the most commonly documented aspect of ACP: it was recorded for 57% of people with dementia in the intervention arm at the 12-month follow-up or after death (see *Table 38*). Advance care plans were least likely to be documented at all time points. There was a tendency for all types of documents to increase between baseline and 12 months (or after death) in both trial arms (see *Figure 13*).

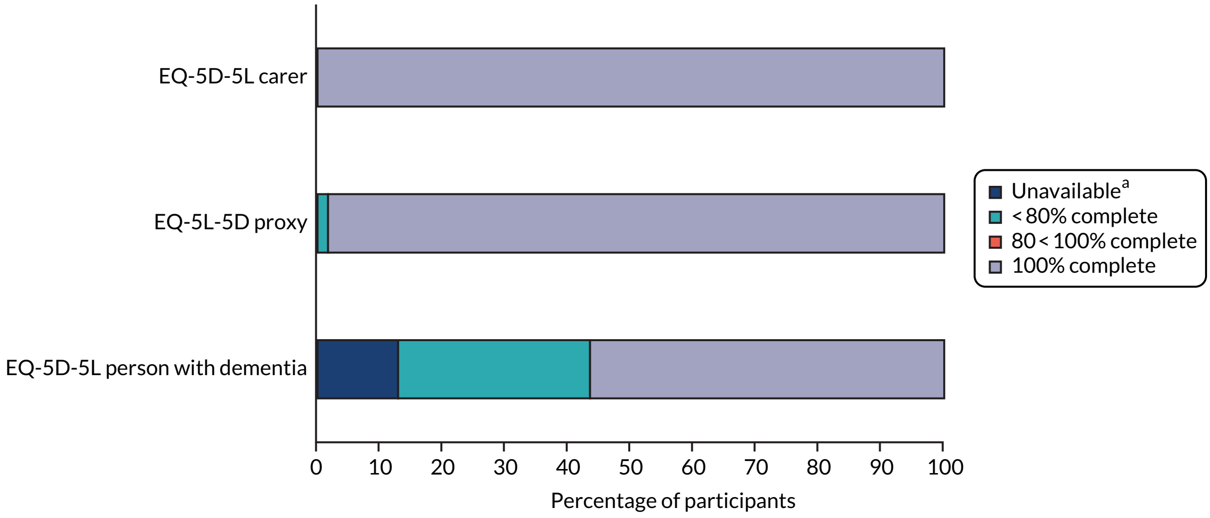


FIGURE 12 Data completion of EQ-5D-5L at baseline by respondent. a, Unavailable includes those who were not approached or were unwell.

TABLE 36 Summary of EQ-5D-5L completeness up to 12 months in the intervention and control arms

	Time point (*n*)																			
	Baseline				4 months				8 months				12 months				Follow-up after death			
Respondent	Dead/ with[a]	Missing[b] (too ill[c])	Partial[d]	Complete[e]	Dead/ with[a]	Missing[b] (too ill[c])	Partial[d]	Complete[e]	Dead/ with[a]	Missing[b] (too ill[c])	Partial[d]	Complete[e]	Dead/ with[a]	Missing[b] (too ill[c])	Partial[d]	Complete[e]	Dead/ with[a]	Missing[b] (too ill[c])	Partial[d]	Complete[e]
Intervention arm																				
Carer	0	0 (0)	0	25	0	1 (0)	0	22	0	0 (0)	0	22	0	0 (0)	0	20	0	0 (0)	0	2
Proxy	0	2 (0)	0	35	5	3 (0)	0	29	2	0 (0)	1	29	1	2 (0)	0	27	0	0 (0)	0	0
Person with dementia	0	20 (14)	0	17	5	14 (8)	3	15	2	12 (7)	0	18	1	14 (9)	2	13	N/A	N/A	N/A	N/A
Control arm																				
Carer	0	0 (0)	0	17	0	1 (0)	0	16	0	1 (0)	0	13	0	0 (0)	0	12	0	0 (0)	0	3
Proxy	0	1 (0)	0	24	1	2 (0)	0	22	5	2 (0)	1	16	2	1 (0)	0	16	0	0 (0)	0	0
PWD	0	7 (6)	0	18	1	8 (6)	0	16	5	5 (2)	1	13	2	4 (3)	1	12	N/A	N/A	N/A	N/A

N/A, not applicable.

a 'Dead/with' refers to people with dementia who died who did not complete the questionnaire because they passed away or were withdrawn between data collection points.

b Missing is defined as answering < 80% of questions on the questionnaire.

c Missing responses as a result of the person with dementia being too ill to complete are shown in brackets. The remaining missing responses are assumed to be missing at random.

d Partial responses are defined as at least 80% of the questions on the questionnaire being completed, but not all questions.

e Complete responses are defined as all questions on the questionnaire being completed.

TABLE 37 Number of participants providing responses to the resource use questionnaire[a]

Resource	Time point, *n* (%)							
	4 months		8 months		12 months		After death[b]	
	Intervention (*N* = 34)	Control (*N* = 23)	Intervention (*N* = 35)	Control (*N* = 18)	Intervention (*N* = 32)	Control (*N* = 17)	Intervention (*N* = 5)	Control (*N* = 6)
Patient's living accommodation	32 (94)	23 (100)	33 (94)	18 (100)	32 (100)	17 (100)	4 (80)	6 (100)
Usual living accommodation	32 (94)	22 (96)	33 (94)	18 (100)	32 (100)	17 (100)	4 (80)	6 (100)
Temporary accommodation (previous 3 months)	32 (94)	23 (100)	34 (97)	18 (100)	32 (100)	16 (94)	4 (80)	6 (100)
Organisation managing care facility (if applicable)[c]	11 (73)	2 (66)	12 (80)	2 (100)	14 (100)	1 (100)	2 (66)	3 (100)
Patient's weekly charge (if applicable)[c]	3 (20)	2 (66)	4 (27)	0 (0)	4 (29)	0 (0)	0 (0)	1 (33)
Inpatient health services used	32 (94)	23 (100)	34 (97)	18 (100)	32 (100)	16 (94)	4 (80)	6 (100)
Outpatient health services used	32 (94)	23 (100)	34 (97)	18 (100)	31 (97)	15 (88)	4 (80)	6 (100)
Day activity services used	32 (94)	23 (100)	34 (97)	18 (100)	31 (97)	17 (100)	4 (80)	6 (100)
Community care services used	31 (91)	23 (100)	31 (89)	18 (100)	29 (91)	15 (88)	4 (80)	5 (83)
Patient's main employment status	33 (97)	23 (100)	34 (97)	18 (100)	32 (100)	17 (100)	4 (80)	6 (100)
Carer asked about patient's income	33 (97)	23 (100)	34 (97)	18 (100)	32 (100)	17 (100)	4 (80)	6 (100)
Main source of patient's income (if applicable)[c]	15 (100)	8 (100)	12 (80)	6 (86)	14 (100)	4 (100)	N/A[d]	1 (100)
Type of benefit patient receives (if applicable)[c]	5 (100)	3 (100)	6 (100)	6 (100)	7 (100)	4 (100)	N/A[d]	N/A[d]
Patient's total income (if applicable)[c]	10 (67)	8 (100)	12 (80)	6 (86)	12 (92)	4 (100)	N/A[d]	0 (0)

N/A, not applicable.

a Missing responses may be due to the question not being asked, the question not being appropriate, the answer not being known, the participant not knowing the answer to the question or the participant declining to answer the question.

b Based on responses from carers and KIs about the person with dementia's use of services in the 3 months prior to death.

c These questions were asked on subsamples of the data set. This is reflected in the percentages.

d Not applicable.

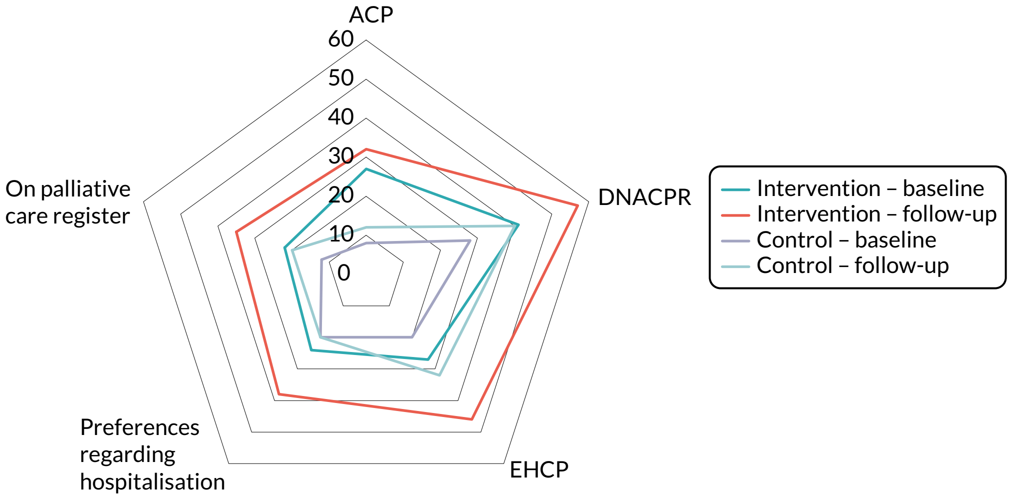


FIGURE 13 Percentage of GP and/or care home records containing information on advance care plans by intervention arm and time point. EHCP, Emergency Healthcare Plan.

TABLE 38 Number of people with dementia with evidence of ACP in GP and/or care home records at baseline and at 12 months or after death, by intervention arm

	Baseline, *n* (%)		12 months or after death, *n* (%)	
Outcome	**Intervention (*N* = 37)**	**Control (*N* = 25)**	**Intervention (*N* = 37)**	**Control (*N* = 25)**
Advance care plan				
No	27 (73)	23 (92)	22 (60)	21 (84)
Yes	10 (27)	2 (8)	12 (32)	3 (12)
Missing	0 (0)	0 (0)	3 (8)	1 (4)
DNACPR				
No	22 (59)	18 (72)	13 (35)	14 (56)
Yes	15 (41)	7 (28)	21 (57)	10 (40)
Missing	0 (0)	0 (0)	3 (8)	1 (4)
Emergency Healthcare Plan				
No	27 (73)	20 (80)	17 (46)	16 (64)
Yes	10 (27)	5 (20)	17 (46)	8 (32)
Missing	0 (0)	0 (0)	3 (8)	1 (4)
Views on hospitalisation				
No	28 (76)	20 (80)	20 (54)	19 (76)
Yes	9 (24)	5 (20)	14 (38)	5 (20)
Missing	0 (0)	0 (0)	3 (8)	1 (4)
On palliative care register				
No	29 (78)	22 (88)	21 (57)	19 (76)
Yes	8 (22)	3 (12)	13 (35)	5 (20)
Missing	0 (0)	0 (0)	3 (8)	1 (4)

Further investigation of responses indicated wide variation in documentation recorded for patients registered with different practices: those registered with practice 4 had very low rates of completion of the various ACP documents, particularly at baseline (*Table 39*). This suggests that the percentage change in documentation within practices may be a more appropriate way of analysing data. However, numbers are generally sparse, so it is difficult to make any firm inferences.

Outcome measure scores

Questionnaire scores were tabulated by intervention arm and time point. To investigate the shape of the distributions, the mean and standard deviation, as well as median, interquartile range and range, in each arm were examined (*Tables 40–47*). There were no notable differences in any of the questionnaire scores between the arms at the 8- and 12-month follow-ups, for which numbers were small (especially in questionnaires completed by key informants only). For the purpose of this pilot trial, the actual scores at these time points are of limited interest because the primary purpose was to assess attrition. The findings are not described in detail, although attention is drawn to the skewed responses noted on the PAINAD (see *Tables 46* and *47*), on which people with dementia were usually assessed as being in no pain, with only an occasional non-zero score. This raises the issue as to who is the most appropriate person to complete this questionnaire; it was generally accepted that a family carer or key informant may be better placed to complete it than a member of the research team, owing to their better knowledge of the person with dementia and opportunity to spend more time with him/her.

The detailed responses to each domain of the EQ-5D-5L (*Tables 48–50*) highlight differences between types of respondent. There was a tendency for respondents with dementia (see *Table 48*) to report 'no' or 'slight' problems, with relatively few respondents reporting that problems were 'severe' or that they were 'unable to do' the activity. This pattern was relatively consistent across the intervention and control arms. This is consistent with the qualitative data that suggest that people with dementia may overestimate their abilities on the EQ-5D-5L, although it could be that people with dementia able to complete the questionnaire have fewer health problems.

Comparing responses between the person with dementia and the proxy, a striking finding is the very different number of proxy respondents reporting that the person with dementia had severe restrictions on mobility or were unable to perform self-care or usual activities (see *Tables 48–50*). Responses for family carers and key informants have been combined, with precedence given to key

TABLE 39 Variation in advance care plans recorded for people with dementia registered with different general practices

Documentation	Time point	Practice 1 ($n = 18$)[a,b]	Practice 2 ($n = 11$)[a,b]	Practice 3 ($n = 19$)[a] ($n = 16$)[b]	Practice 4 ($n = 14$)[a] ($n = 13$)[b]	All ($n = 62$)[a] ($n = 58$)[b]
ACP, *n* (%)	Baseline	2 (11)	2 (18)	8 (42)	0 (0)	12 (19)
	Follow-up	5 (28)	4 (36)	9 (56)	5 (39)	23 (40)
DNACPR, *n* (%)	Baseline	7 (39)	5 (46)	8 (42)	2 (14)	22 (36)
	Follow-up	10 (56)	6 (55)	9 (56)	0 (0)	25 (43)
EHCP, *n* (%)	Baseline	2 (11)	5 (46)	8 (42)	0 (0)	14 (24)
	Follow-up	8 (44)	5 (46)	10 (63)	3 (23)	26 (45)
Hospitalisation, *n* (%)	Baseline	1 (6)	5 (46)	8 (42)	0 (0)	14 (23)
	Follow-up	6 (33)	4 (36)	8 (50)	2 (15)	20 (35)

EHCP, Emergency Healthcare Plan.
a Baseline.
b Follow-up.

TABLE 40 Summary of numeric outcome measures completed by family carers by intervention arm at baseline and at the 4-month follow-up

	Intervention arm						**Control arm**					
	Baseline (*n* = 25)			**4 months (*n* = 23)**			**Baseline (*n* = 17)**			**4 months (*n* = 17)**		
Questionnaire	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**
HADS												
Anxiety	5.4 (4.4)	4 (2–9)	0–15	5.5 (4.1)	5 (3–7)	0–17	5.4 (3.3)	5 (3–7)	0–11	5.5 (3.8)	5 (2–7.5)	1–15
Depression	4.5 (3.3)	3 (2–7)	0–11	4.1 (3.3)	3.5 (2–5)	0–13	4.4 (3.6)	4 (1–6)	0–11	5.3 (4.0)	5.5 (2–8)	0–15
Overall score	9.8 (7.6)	7 (3–17)	0–23	9.5 (7.2)	8 (5–13)	0–30	9.8 (6.6)	9 (4–14)	0–22	10.8 (7.4)	10.5 (4–14.5)	2–27
NPI												
Overall score	22.4 (19.9)	20 (9–30)	1–90	19.0 (15.5)	19.5 (5–28)	0–59	22.0 (25.5)	15.5 (3–27.5)	0–99	26.1 (30.0)	18.5 (9–35.5)	0–126
Distress domain	10.4 (7.5)	10 (5–15)	0–31	8.3 (7.5)	7 (2–12)	0–24	9.4 (11.5)	6.5 (1–12)	0–44	10.1 (14.5)	4.5 (2.5–10.5)	0–55

IQR, interquartile range; SD, standard deviation.

TABLE 41 Summary of numeric outcome measures completed by family carers by intervention arm at the 8- and 12-month follow-ups

	Intervention arm						**Control arm**					
	8 months (*n* = 22)			**12 months (*n* = 20)**			**8 months (*n* = 14)**			**12 months (*n* = 12)**		
Questionnaire	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**
HADS												
Anxiety	4.8 (4.4)	3.5 (2–8)	0–18	6.7 (4.9)	6 (3–9)	0–17	7.5 (4.1)	8 (4–10)	2–14	6.0 (3.7)	5.5 (2–10)	1–11
Depression	4.7 (3.2)	4 (3–7)	0–12	6.0 (3.6)	5.5 (3–8.5)	0–13	7.4 (3.6)	7 (6–10)	2–13	5.4 (2.8)	4.5 (3–7.5)	2–10
Overall score	9.5 (7.3)	8 (3–14)	1–30	12.6 (8.2)	13 (6–16)	1–29	14.8 (7.6)	14 (9–20)	4–26	11.4 (6.3)	10.5 (5–18)	4–20
NPI												
Overall score	22.5 (20.2)	21.5 (5–32)	0–88	22.6 (15.0)	22.5 (12.5–36)	0–49	29.8 (29.3)	26 (8–34)	1–112	27.4 (25.6)	16.5 (10–41.5)	4–80
Distress domain	9.7 (10.0)	7 (2–15)	0–35	10.0 (8.9)	6 (4–14.5)	0–32	9.9 (11.0)	7 (4–11)	0–42	9.3 (11.5)	5 (0–17)	0–38

IQR, interquartile range; SD, standard deviation.

TABLE 42 Summary of numeric outcome measures completed by key informants by intervention arm at baseline and at the 4-month follow-up

	Intervention arm						**Control arm**					
	Baseline (*n* = 15)			**4 months (*n* = 11)**			**Baseline (*n* = 8)**			**4 months (*n* = 7)**		
Questionnaire	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**
BANS-S	15.9 (3.7)	15 (13–19)	10–22	16.2 (4.3)	17 (13–18)	9–23	13.1 (3.8)	13.5 (10–15.5)	8–19	13.9 (4.5)	14 (11–16)	8–22
NPI												
Overall score	28.5 (19.4)	21 (12–48)	4–62	29.9 (17.1)	30 (20–42)	2–52	24.6 (22.6)	22.5 (5–38.5)	0–65	35.3 (28.3)	35 (11–55)	4–84
OD domain	9.7 (9.4)	6 (2–16)	0–28	9.1 (7.6)	12 (2–15)	0–19	8.1 (8.0)	7.5 (0.5–15.5)	0–18	9.1 (12.2)	5 (0–12)	0–35

BANS-S, Bedford Alzheimer Nursing Severity Scale; IQR, interquartile range; OD, occupational distress; SD, standard deviation.

TABLE 43 Summary of numeric outcome measures completed by key informants by intervention arm at the 8- and 12-month follow-ups

	Intervention						**Control**					
	8 months (*n* = 13)			**12 months (*n* = 12)**			**8 months (*n* = 5)**			**12 months (*n* = 5)**		
Questionnaire	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**	**Mean (SD)**	**Median (IQR)**	**Range**
BANS-S	16.9 (3.1)	17 (15–19)	12–23	17.8 (3.7)	18 (15.5–21)	11–23	12 (3.2)	12 (12–13)	7–16	12.6 (4.0)	14 (11–15)	7–17
NPI-NH												
Overall score	24.5 (21.1)	23 (9–29)	1–61	26.7 (26.4)	16.5 (9–40)	0–88	22.6 (24.0)	20 (6–24)	1–62	24 (16.4)	16 (16–21)	14–53
OD domain	6.4 (6.8)	5 (0–10)	0–20	7.5 (9.2)	5.5 (0–10.5)	0–26	4 (3.4)	4 (2–5)	0–9	7.4 (7.7)	6 (3–8)	0–20

BANS-S, Bedford Alzheimer Nursing Severity Scale; IQR, interquartile range; NPI-NH, Neuropsychiatric Inventory-Nursing Home; OD, occupational distress; SD, standard deviation.

TABLE 44 Summary of numeric outcome measures completed by key informants and family carers by intervention arm at baseline and at the 4-month follow-up

	Intervention arm						Control arm					
	Baseline			4 months			Baseline			4 months		
Questionnaire[a]	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range
QUALID	22.0 (9.3)	20.5 (14–28)	11–47	21.8 (8.2)	20 (15–28)	11–37	21.2 (9.4)	18 (13–29)	11–40	22.1 (9.9)	18.0 (15–29)	11–46
SM-EOLD	29.6 (7.8)	27 (24–38)	17–40	32.8 (6.1)	34.5 (29.5–38)	19–40	28.0 (7.7)	29.5 (20.5–35)	13–40	26.0 (9.2)	29.5 (18–32)	7–40
SWC-EOLD	26.3 (3.1)	27 (25–28)	18–32	26.2 (2.7)	26 (25–28)	20–33	26.1 (2.8)	26.5 (24–28)	20–31	25.2 (1.7)	25 (24–26)	20–28

IQR, interquartile range; SD, standard deviation.

a Questionnaires completed by both key informant and family carer, but when there are responses from both for the same item of data, precedence will be given to data from the key informant.

TABLE 45 Summary of numeric outcome measures completed by key informants and family carers by intervention arm at the 8- and 12-month follow-ups

	Intervention arm						Control arm					
	8 months			12 months			8 months			12 months		
Questionnaire[a]	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range
QUALID	22.4 (7.2)	22 (16.5–28.5)	13–38	21.5 (7.8)	19 (16–24.5)	11–39	24.1 (8.8)	20 (19–29)	13–47	24.5 (8.5)	21.5 (18–32)	15–41
SM-EOLD	31.7 (6.3)	32.5 (27–37)	17–40	29.9 (8.5)	30.5 (28–36)	11–40	25.1 (8.1)	24 (21–31)	8–40	28.6 (8.2)	29.5 (21.5–35)	9–40
SWC-EOLD	26.9 (2.0)	27 (26–28)	24–31	25.8 (2.6)	26 (24–28)	20–32	25 (3.2)	26 (24.5–27)	18–28	25.5 (1.5)	26 (24–26)	23–28

IQR, interquartile range; SD, standard deviation.

a Questionnaires completed by both key informant and family carer, but when there are responses from both for the same item of data, precedence will be given to data from the key informant.

TABLE 46 Summary of PAINAD questionnaire scores by intervention arm at baseline and at the 4-month follow-up

	Intervention arm						Control arm					
	Baseline			4 months			Baseline			4 months		
Questionnaire	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range
PAINAD[a] during												
1. Rest	0 (0)	0 (0–0)	0–0	0 (0)	0 (0–0)	0–0	0.1 (0.6)	0 (0–0)	0–3	0.1 (0.7)	0 (0–0)	0–3
2. Movement	0 (0)	0 (0–0)	0–0	0 (0)	0 (0–0)	0–0	0.4 (1.2)	0 (0–0)	0–4	0 (0)	0 (0–0)	0–0

IQR, interquartile range; SD, standard deviation.

[a] Observation by the researcher.

TABLE 47 Summary of PAINAD questionnaire scores by intervention arm at the 8- and 12-month follow-ups

	Intervention arm						Control arm					
	8 months			12 months			8 months			12 months		
Questionnaire	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range	Mean (SD)	Median (IQR)	Range
PAINAD[a] during												
1. Rest	0 (0)	0 (0–0)	0–0	0.1 (0.3)	0 (0–0)	0–1	0 (0)	0 (0–0)	0–0	0.1 (0.3)	0 (0–0)	0–1
2. Movement	0 (0)	0 (0–0)	0–0	0.6 (1.9)	0 (0–0)	0–7	0 (0)	0 (0–0)	0–0	0.3 (0.7)	0 (0–0)	0–2

IQR, interquartile range; SD, standard deviation.

[a] Observation by the researcher.

TABLE 48 People with dementia EQ-5D-5L responses by intervention arm

	Intervention arm (number of respondents)					**Control arm (number of respondents)**				
EQ-5D-5L domain and time point	**No**	**Slight**	**Moderate**	**Severe**	**Unable to do**	**No**	**Slight**	**Moderate**	**Severe**	**Unable to do**
Mobility										
Baseline	11	4	3	2	0	10	3	3	3	1
4 months	10	4	2	2	1	8	1	5	3	0
8 months	12	3	1	1	1	7	3	3	1	0
12 months	8	2	2	2	2	6	3	3	1	0
Self-care										
Baseline	16	2	2	0	0	13	4	1	1	0
4 months	15	3	1	0	1	10	2	2	0	2
8 months	14	1	3	0	0	9	3	1	0	0
12 months	9	3	3	0	1	10	3	1	0	0
Usual activities										
Baseline	12	4	3	0	0	12	3	3	0	0
4 months	12	3	1	0	1	5	3	6	1	1
8 months	14	1	2	0	1	6	5	3	0	0
12 months	9	2	3	0	1	7	2	3	0	0
Pain and discomfort										
Baseline	10	4	5	0	0	13	0	3	2	0
4 months	12	3	3	1	1	10	3	2	2	0
8 months	12	2	5	0	0	8	4	1	1	0
12 months	6	5	4	0	0	8	2	4	0	0
Anxiety and depression										
Baseline	12	3	2	0	0	9	5	4	1	0
4 months	11	6	1	0	0	7	5	1	2	1
8 months	11	4	4	0	0	7	5	1	1	0
12 months	7	4	2	0	0	8	1	4	0	0

TABLE 49 Family carer EQ-5D-5L responses by intervention arm

	Intervention arm (number of respondents)					**Control arm (number of respondents)**				
EQ-5D-5L domain and time point	**No**	**Slight**	**Moderate**	**Severe**	**Unable to do**	**No**	**Slight**	**Moderate**	**Severe**	**Unable to do**
Mobility										
Baseline	12	7	4	2	0	11	2	1	3	0
4 months	12	5	3	2	0	9	4	2	1	0
8 months	13	6	2	1	0	6	3	2	2	0
12 months	13	5	1	1	0	6	3	1	2	0
Follow-up after death	1	0	1	0	0	1	1	1	0	0

continued

TABLE 49 Family carer EQ-5D-5L responses by intervention arm (*continued*)

EQ-5D-5L domain and time point	Intervention arm (number of respondents)					Control arm (number of respondents)				
	No	Slight	Moderate	Severe	Unable to do	No	Slight	Moderate	Severe	Unable to do
Self-care										
Baseline	21	2	1	1	0	15	0	2	0	0
4 months	19	2	0	1	0	15	0	1	0	0
8 months	18	2	1	1	0	11	0	1	1	0
12 months	19	0	0	1	0	10	1	0	1	0
Follow-up after death	2	0	0	0	0	2	1	0	0	0
Usual activities										
Baseline	17	3	4	1	0	13	1	3	0	0
4 months	13	6	2	1	0	10	2	2	2	0
8 months	17	2	2	1	0	8	0	2	3	0
12 months	16	1	2	1	0	7	1	2	2	0
Follow-up after death	2	0	0	0	0	2	0	1	0	0
Pain and discomfort										
Baseline	10	7	5	1	2	5	6	4	2	0
4 months	11	5	4	1	1	7	4	3	2	0
8 months	10	7	3	2	0	3	5	2	3	0
12 months	9	7	2	1	1	5	2	5	0	0
Follow-up after death	1	1	0	0	0	1	0	2	0	0
Anxiety and depression										
Baseline	12	7	4	2	0	8	8	1	0	0
4 months	9	7	6	0	0	7	6	2	1	0
8 months	8	11	3	0	0	3	6	4	0	0
12 months	6	6	7	1	0	3	6	3	0	0
Follow-up after death	1	1	0	0	0	2	1	0	0	0

TABLE 50 Proxy EQ-5D-5L responses by intervention arm[a]

EQ-5D-5L domain and time point	Intervention arm (number of respondents)					Control arm (number of respondents)				
	No	Slight	Moderate	Severe	Unable to do	No	Slight	Moderate	Severe	Unable to do
Mobility										
Baseline	6	9	10	4	7	4	6	5	8	1
4 months	5	4	5	9	6	3	6	7	4	2
8 months	5	7	7	3	8	2	3	6	3	3
12 months	4	5	6	3	10	2	5	5	2	2

TABLE 50 Proxy EQ-5D-5L responses by intervention arm[a] (*continued*)

EQ-5D-5L domain and time point	Intervention arm (number of respondents)					Control arm (number of respondents)				
	No	Slight	Moderate	Severe	Unable to do	No	Slight	Moderate	Severe	Unable to do
Self-care										
Baseline	4	7	7	2	16	3	6	8	5	2
4 months	6	4	4	0	15	4	1	8	4	5
8 months	5	4	4	3	14	2	2	6	2	5
12 months	6	2	3	4	13	0	0	9	5	2
Usual activities										
Baseline	3	8	2	6	17	2	2	6	10	4
4 months	3	3	7	5	11	3	3	2	7	7
8 months	4	4	7	5	10	0	4	4	3	6
12 months	5	1	5	5	12	0	1	3	7	5
Pain and discomfort										
Baseline	12	14	7	2	0	6	6	8	4	0
4 months	14	5	6	2	2	6	5	8	2	1
8 months	11	9	6	3	0	7	2	3	3	1
12 months	10	8	5	4	0	6	2	4	4	0
Anxiety and depression										
Baseline	12	11	9	2	1	4	7	9	3	1
4 months	12	10	5	1	1	6	3	9	2	2
8 months	9	9	11	1	0	1	5	9	2	0
12 months	12	6	6	2	1	4	3	6	2	1

[a] When both the family carer and the key informant completed the proxy response, preference was given to the key informant.

informant responses when both were available. Further analysis could explore whether or not there are systematic differences between the two types of respondent when acting as proxies for the person with dementia. The differences between responses from the person with dementia and responses from the proxy merit further investigation. Typically, responses from the person with dementia would be used in the main analysis, with proxy responses used in a sensitivity analyses, but the differences are so large that further exploration is needed.

Responses to the resource use questionnaire for people with dementia at 12 months are displayed in *Tables 51–61*. (Owing to space limitations, data are not presented for all time points; similarly, because the questionnaire was piloted on only five family carers regarding their own service use, these results are not included.) Several responses are worth noting. Few individuals used inpatient services and, as a group, they were more likely to use outpatient services. Few individuals used day activity services but, as a group, they were much more likely to use community care services, such as the chiropodist, district nurse or GP. None of the patients across the trial was in employment. Carer responses to the questions regarding the patient's source of income were limited.

TABLE 51 Resource use questionnaire for people with dementia at 12 months: patient living arrangements by intervention arm

Living with	Trial arm, *n* (%)	
	Intervention (*N* = 32)	Control (*N* = 17)
Alone	3 (9)	1 (6)
Husband/wife (without children)	6 (19)	4 (24)
Husband/wife (with children)	2 (6)	0 (0)
Partner as a couple or with siblings	0 (0)	0 (0)
Children	2 (6)	3 (18)
Other relatives	1 (3)	0 (0)
Care home	18 (56)	9 (53)

TABLE 52 Resource use questionnaire for people with dementia at 12 months: patient usual accommodation by intervention arm

Usual accommodation	Trial arm, *n* (%)	
	Intervention (*N* = 32)	Control (*N* = 17)
Domestic/family		
Own home/flat	10 (31)	5 (29)
Privately rented home	1 (3)	0 (0)
Housing association rented home	3 (9)	3 (18)
Community (non-hospital)		
Residential/nursing home	4 (13)	8 (47)
Dementia-specific care home	14 (44)	1 (6)
If living in community	***Intervention* (N = *18)***	***Control* (N = *9)***
Care facility organisation		
Local authority social services	1 (6)	0 (0)
NHS	0 (0)	0 (0)
Private organisation	17 (94)	8 (88)
Voluntary organisation	0 (0)	1 (12)

TABLE 53 Resource use questionnaire for people with dementia at 12 months: organisations that contribute towards the costs of the care facility by intervention arm

Organisation	Trial arm, *n* (%)	
	Intervention (*N* = 18)	Control (*N* = 9)
Department of Social Security	1 (6)	0 (0)
NHS	6 (33)	0 (0)
Local authority	8 (44)	1 (13)
Private or voluntary organisation	0 (0)	0 (0)
Patient	7 (39)	1 (13)
Patient's family	1 (6)	0 (7)
Insurance policy	0 (0)	0 (0)
Not known	2 (11)	2 (25)

Note
Placements may be funded by more than one source.

TABLE 54 Resource use questionnaire for people with dementia at 12 months: patient's use of temporary accommodation over the previous 3 months by intervention arm

Use of temporary accommodation over the previous 3 months	Trial arm, *n* (%)	
	Intervention (*N* = 32)	Control (*N* = 17)
No	30 (94)	15 (88)
Yes	2 (6)	1 (6)
Missing	0 (0)	1 (6)
Type of temporary accommodation	***Intervention* (N = 2)**	***Control* (N = 1)**
Nursing home	1 (50)	0 (0)
Hospital	1 (50)	0 (0)
Dementia-specific care home	0 (0)	1 (100)

TABLE 55 Resource use questionnaire for people with dementia at 12 months: use of inpatient services by intervention arm

Use of inpatient services	Trial arm, *n* (%)	
	Intervention (*N* = 32)	Control (*N* = 17)
No	28 (87)	16 (94)
Yes	4 (13)	0 (0)
Missing	0 (0)	1 (6)
Type of inpatient service used	***Intervention* (N = 4)**	***Control* (N = 0)**
Acute medical unit	2 (50)	0 (0)
Accident and emergency	2 (50)	0 (0)
Fracture ward	1 (25)	0 (0)

Note
Individuals can use more than one type of service.

TABLE 56 Resource use questionnaire for people with dementia at 12 months: use of outpatient services by intervention arm

Use of outpatient services	Trial arm, *n* (%)	
	Intervention (*N* = 32)	Control (*N* = 17)
No	26 (81)	14 (82)
Yes	5 (16)	1 (6)
Missing	1 (3)	2 (12)
Type of outpatient service used	***Intervention* (N = 5)**	***Control* (N = 1)**
Psychiatric outpatient visit	1 (20)	0 (0)
Dermatology	1 (20)	0 (0)
Orthopaedic	1 (20)	0 (0)
Scan appointments	1 (20)	0 (0)
Ultrasonography appointment	1 (20)	0 (0)
Urinary and bowel	0 (0)	1 (100)
Vascular	0 (0)	1 (100)

Note
Individuals can use more than one type of service.

TABLE 57 Resource use questionnaire for people with dementia at 12 months: use of day activity services by intervention arm

	Trial arm, *n* (%)	
Use of day activity services	**Intervention (*N* = 32)**	**Control (*N* = 17)**
No	26 (81)	15 (88)
Yes	5 (16)	2 (12)
Missing	1 (3)	0 (0)
Type of day service used	***Intervention* (N = *5*)**	***Control* (N = *2*)**
Voluntary organisation	0 (0)	2 (100)
Lunch club	1 (20)	0 (0)
Gardening group	1 (20)	0 (0)
Private day centre	3 (60)	0 (0)

TABLE 58 Resource use questionnaire for people with dementia at 12 months: use of community services by intervention arm

	Trial arm, *n* (%)	
Use of community services	**Intervention (*N* = 32)**	**Control (*N* = 17)**
No	4 (13)	2 (13)
Yes	25 (78)	12 (75)
Missing	3 (9)	3 (18)
Type of community service used	***Intervention* (N = *25*)**	***Control* (N = *12*)**
Care manager	0 (0)	1 (8)
Chiropodist	13 (52)	0 (0)
Community matron	1 (4)	0 (0)
Community psychiatric nurse	0 (0)	1 (8)
Dentist	5 (20)	0 (0)
District nurse	4 (16)	1 (8)
DoLS assessment	1 (4)	0 (0)
DoLS service	1 (4)	0 (0)
Ear check	0 (0)	1 (8)
GP	20 (80)	10 (83)
General practice nurse	6 (24)	2 (17)
Home care worker	1 (4)	0 (0)
Meals on wheels	1 (4)	0 (0)
Occupational therapist	1 (4)	0 (0)
Optician	7 (28)	1 (8)
Physiotherapist	0 (0)	1 (8)
Podiatrist	0 (0)	2 (17)
Specialist nurse	1 (4)	0 (0)
Social worker	2 (8)	0 (0)

DoLS, deprivation of liberty safeguards.

Note

Individuals can use more than one type of service.

TABLE 59 Resource use questionnaire for people with dementia at 12 months: patient employment status by intervention arm

	Trial arm, *n* (%)	
Employment status	**Intervention (*N* = 32)**	**Control (*N* = 17)**
Paid or self-employed	0 (0)	0 (0)
Voluntary work	0 (0)	0 (0)
Unemployed	0 (0)	0 (0)
Housewife/househusband	0 (0)	0 (0)
Retired	32 (100)	17 (100)
Exempt through disability	0 (0)	0 (0)

TABLE 60 Resource use questionnaire for people with dementia at 12 months: patient income sources by intervention arm

	Trial arm, *n* (%)	
Patient income	**Intervention (*N* = 32)**	**Control (*N* = 17)**
Carer asked about patient's income		
No	18 (56)	13 (76)
Yes	14 (44)	4 (24)
Source of patient's income[a]	***Intervention* (N = *14)***	***Control* (N = *4)***
Wage	0 (0)	0 (0)
State pension	14 (100)	3 (75)
Private pension scheme	6 (43)	2 (50)
Benefits	7 (50)	4 (100)
Income bond	1 (7)	0 (0)
NHS pension	0 (0)	1 (25)
Type of benefits received[b]	***Intervention* (N = *7)***	***Control* (N = *4)***
Council tax benefit	1 (14)	0 (0)
Pension credit guarantee	1 (14)	0 (0)
Pension credit savings	1 (14)	1 (14)
Disability living allowance: care	0 (0)	1 (14)
Disability living allowance: mobility	0 (0)	1 (14)
Severe disability premium	0 (0)	1 (14)
Attendance allowance: low rate	2 (29)	1 (14)
Attendance allowance: high rate	2 (29)	2 (29)
Carer's allowance	2 (29)	1 (14)

a Some respondents reported more than one source of income, although the question asked about the main source only.
b Patients can receive more than one type of benefit.

TABLE 61 Resource use questionnaire for people with dementia at 12 months: patient weekly income by intervention arm

Total patient income (£)	Trial arm, *n* (%)	
	Intervention (*N* = 14)	Control (*N* = 4)
Gross		
≤ 277	2 (14)	2 (50)
278–379	0 (0)	0 (0)
380–518	0 (0)	0 (0)
519–728	0 (0)	0 (0)
> 728	0 (0)	0 (0)
Net		
≤ 277	6 (43)	0 (0)
278–379	3 (21)	2 (50)
380–518	1 (7)	0 (0)
519–728	1 (7)	0 (0)
> 728	0 (0)	0 (0)
Not known	1 (7)	0 (0)

Note
Patients could report their income level in either gross or net terms.

Qualitative data on outcome measures

Stakeholder feedback on the outcome measures used in the pilot trial is summarised below. We also consider the extent to which the measures captured the types of outcomes described by study participants in interviews. Detailed field notes were made by the researchers on the resource use questionnaire and we suggest how this might be adapted to be more suitable for people with dementia and family carers. Five themes were identified from the analysis of data from people with dementia, carers, key informants and researchers regarding the study outcome measures; each is briefly explored in the following sections.

Perceived burden of the outcome measures

Despite our concerns about the burden of the outcome measures, no people with dementia or carers made any negative comments about the duration or frequency of the assessments, and most found them acceptable. Similarly, care home staff reported that participation had not been too onerous, even in homes with a number of study participants:

> *It's been no bother. It hasn't taken long. It's just been ticking things off, me and my dad. It's no problem. It's been fine.*
>
> *Interview, family carer 3014*

> *I was a bit worried about the impact on staff time and resources. But it's been very, very minimal in regard to SEED . . . [Researcher] was very efficient. She would sit with the staff and get the information she needed; didn't have a major impact at all.*
>
> *Interview, care home manager CH2, site 1*

Relevance of some outcome measures

The researchers queried the relevance of some measures to recently diagnosed participants. Self-reported pain was considered more accurate and appropriate than the PAINAD for people recently diagnosed with dementia, most of whom would be able to articulate pain themselves. Similarly, for carers of people recently diagnosed with dementia, questions relating to symptom management and satisfaction with EOLC were considered inappropriate and potentially anxiety-provoking for carers.

Although not explicitly discussed by stakeholders, data from interviews suggest that the outcome measures used may not capture the types of changes resulting from the SEED intervention. One GP felt that the proactive work undertaken by the DNS with people with dementia and carers had resulted in considerable benefits:

> *Some of the patients that [DNS1] had, and especially the social situations and the problems that she has just tackled head-on, before it's reached crisis point, I'm sure, has prevented some people going into care homes. It's prevented some safeguarding issues. It's prevented, even, admissions to hospitals; she's been proactive in picking up medical problems. So she would be speaking to [relatives] . . . and before I know it, [DNS1's] coming back to me, saying 'I wonder whether this person might actually have an underlying physical health problem. We need to do a blood test.' . . . that proactive work, I'm sure, has decreased the burden on secondary care.*
>
> *Interview, GP 1.1, site 1*

This extract highlights the potential impacts of the SEED intervention on service use. Although a resource use questionnaire was used, a number of shortcomings were identified (see below); developing a more robust and user-friendly tool (or alternative ways of collecting data on resource use) will be essential to capture these potential changes.

Perceived reliability of outcome measures

Carers, key informants and the researchers all questioned the reliability of some outcome measures. The extent to which standardised questionnaires captured the reality of living with dementia was disputed:

> *They don't show a true picture of what's going on . . . You just think to yourself 'Well, how can you rate that between 1 and 10 when sometimes that might be a nice 10 for you and other times it's down to a 2, the same question?'.*
>
> *Interview, family carer 1054*

Key informants explicitly commented on the inherent bias in the SWC-EOLD, as they were effectively being asked to rate the quality of their own service:

> *I thought this was a bit biased, because I'm the one looking after her, so I feel she's getting the necessary nursing assistance. I wasn't going to tick 'no . . . I strongly disagree, she's getting rubbish care'.*
>
> *Interview, care home clinical lead, CH2S2, site 1*

Concerns were raised by carers and researchers on the reliability of information provided by people with dementia on the EQ-5D-5L. Carers commented on the discrepancy between self-reported ratings and their knowledge of the difficulties experienced by the person with dementia in their day-to-day life:

> *One of the questions was 'How do you feel physically, your physical things', something like that. '100%', he said . . . 'I'm as fit as a lop'. I said 'Well, you can't walk'. He can't even get out of bed in the morning, never mind walk.*
>
> *Interview, family carer 1054*

The researchers similarly suggested that some people with dementia appeared to overestimate their abilities and QoL rating on the EQ-5L-5D. In addition, they were concerned that carers sometimes minimised problems when completing the NPI.

The low scores on the PAINAD were queried by members of the Trial Oversight Committee, who felt that the scores were inconsistent with the prevalence of pain shown in previous studies. They suggested that more accurate ratings would be obtained from a family carer or key informant who knew the person with dementia well. The researchers acknowledged that their ratings related to a defined, short period of time and that more familiarity with the person with dementia and contact over a longer period of time may have given a different picture (and would probably have decreased the number of missing data relating to pain during movement).

Potential negative emotional impact of some measures on carers

Some carers were distressed by some outcome measures, in particular the NPI and HADS. The researchers were also aware that the NPI could potentially provide new insights into the illness trajectory and the range of symptoms that might be experienced in future. During the post-death interviews, some carers appeared to find the measures focusing on EOLC cathartic, but, for others, the discrepancy between actual and desired EOLC was distressing. The majority of outcome measures used focused on deficits and problems; finding ways to capture positive outcomes may improve the experience of data collection, as well as ensuring a more holistic picture of the impacts of the SEED intervention.

Perceived duplication of items

From the perspectives of the researchers, there was duplication in items across different outcome measures. Although the researchers acknowledged that the wording was not identical and questions on different measures covered different time periods, the process of completing the measures could, nevertheless, feel repetitive. Agitation and aggression were covered in the NPI, the QUALID and the SM-EOLD questionnaires, and anxiety and depression were addressed in the EQ-5D-5L, the NPI, the QUALID and the SM-EOLD questionnaires. Because the NPI includes a series of in-depth questions about different symptom areas, carers and key informants often covered similar items included in subsequent measures.

Suggested modifications to outcome measures

The resource use questionnaire enabled the use of services to be captured, but would not be suitable for use in its current format in a definitive study. The researchers who administered the resource use questionnaire found it unwieldy and onerous for participants and researchers. Currently, the questionnaire asks about contacts with multiple named services (many of which participants struggled to distinguish between). Restructuring the questionnaire, to take a narrative sequential approach to key (health or social care-related) events over the period of interest, may be a more user-friendly way of collecting the data. The researcher could explore each episode of health or social care use in detail. This would enable a narrative, contextualised approach to be used, which is likely to be easier for participants. Other suggested changes to this questionnaire to reduce respondent burden and potentially increase the accuracy of responses include:

- Tailoring response categories so that they are more appropriate for this patient group, for example by –
    - including categories for types of accommodation (e.g. residential/nursing/care homes, sheltered accommodation, extra care facilities, specialist dementia care units)
    - including district nurse in the list of services potentially used
    - removing questions on employment as they are largely irrelevant.

- Removing those questions that few respondents were able to answer and finding alternative ways of collecting the data. For example, many family carers were unsure of the providers of residential/nursing/care homes or sheltered accommodation and of the funding arrangements for such care. However, if they provided basic information (e.g. the name and address of the care home), researchers could be responsible for identifying the provider. Similarly, with appropriate consent, researchers could explore funding arrangements if this information is needed to ascertain who bears the cost.
- Simplifying the questionnaire, for example by asking about the number of hospital outpatient appointments, rather than trying to establish additional details, such as specialty. Similarly, focusing on details such as length of inpatient stays, without collecting additional information on the type of ward and transitions between wards.
- Data on total income help in understanding the impacts of income inequalities. However, some respondents found it easier and more acceptable to provide weekly income. Allowing respondents to give income in the format that is easiest for them (i.e. weekly, monthly or annual income) is suggested.

Appendix 5 Economic modelling study (workstream 5)

Economic modelling summary

As health and social care resources are limited, decision-makers need information about whether or not the benefits that an intervention provides are worth its costs.[144] This information can be provided by an economic evaluation. An economic evaluation involves the comparative analysis of alternative courses of action.[145] In this appendix, the SEED intervention developed in WS3 is compared with alternative ways of providing care, including an example of current practice. The SEED intervention involves a DNS based in a general practice focusing their efforts on seven key components of EOLC.

The potential value of the SEED intervention was assessed using a contingent valuation survey of 1002 members of the general public. These data were used in an economic evaluation decision model. This economic model describes what happens to a person who has been diagnosed with dementia over time and how the SEED intervention might change this. The results of the model were presented in terms of the costs and consequences (e.g. hospitalisations) and, using the contingent valuation data, a cost–benefit analysis.

The contingent valuation showed that the SEED intervention was valued and that a wider package of care was valued more than selected features in isolation. Individuals with experience of dementia placed a higher value on the SEED intervention than those without such experience, but there was no evidence of a difference in the value by gender, household size or health status. The SEED intervention is unlikely to reduce costs, but these may be offset by the value placed on the SEED intervention by the general public. The SEED intervention is expected to improve the well-being of people with dementia and carers, but the impact on services is mixed.

Patient and public involvement perspectives were sought on the economic modelling study, and on the findings of economic modelling and the WTP survey.

Research aim

The aim of WS5 was to estimate the relative efficiency of the SEED intervention. Specific objectives were to:

- Value the consequences of the SEED intervention using contingent valuation methods.
- Develop an economic model of the usual care pathway and new alternative pathways including the SEED intervention developed in WS3.
- Conduct a cost–consequences analysis of the SEED intervention compared with usual care.
- Conduct a cost–benefit analysis of the SEED intervention that compared the scenarios used in the contingent valuation. These scenarios described variations in how the SEED intervention might be provided and they were valued by the contingent valuation.

The next section describes work relating to the first objective; the remaining objectives are addressed in *Economic evaluation of the SEED intervention*.

Valuing the consequences of the SEED intervention

The measures typically used in economic evaluations to quantify the benefits of interventions, such as QALYs, may not adequately capture individual preferences for how services are organised and their associated outcomes.

An alternative approach to determine the benefits an individual derives from an intervention is to determine their maximum WTP for it using a contingent valuation study. Maximum WTP represents the maximum amount, expressed in monetary terms or other goods, an individual is willing to give up (or sacrifice) to gain the benefits of the intervention.[148] In the absence of conventional markets to observe individuals' monetary valuations of the benefits of health-care interventions, it is necessary to directly elicit such values. The contingent valuation method involves setting up a hypothetical market and asking individuals to state their WTP for the interventions in question.[206] The resulting WTP values can then be compared with the cost of providing the intervention in a cost–benefit analysis. This approach was used to estimate a WTP value from members of the general public for the different care packages that could be provided by the SEED intervention using the contingent valuation method.

Methods

Survey development

For the contingent valuation survey, an internet questionnaire was developed. The questionnaire incorporated five WTP scenarios, each of which represent an alternative package of care that could be provided by variations of the SEED intervention. The content of the WTP scenarios was based on the seven key components to support good EOLC identified from WS2 and synthesised into the SEED intervention in WS3.

The main scenario was designed to include all seven key features identified in WS2, but we also recognised that, for many reasons, such as budget or staff availability, there could be situations in which it was not possible to provide a service that would include all seven components. Therefore, it was important to determine if members of the public would value a service that included fewer components and also how these would affect the net benefits estimated in the cost–benefit analysis. The decision on which components to group together to create the four alternative scenarios was based on discussion with the wider SEED team as to what components would be compatible together.

These WTP scenarios were mirrored by comparators used in the economic model (see *Economic evaluation of the SEED intervention*). Prior to the pilot survey, each WTP scenario was tested with the SEED project team and the wording was revised to ensure that the components of the SEED intervention could be understood by members of the public. The final WTP scenarios are presented in *Boxes 7–11* and are summarised, to facilitate comparison, in *Table 62*.

BOX 7 Main scenario

The DNS provides tailored support to enable the provision of high-quality EOLC to people with dementia. The support from the DNS is expected to result in the following:

- Developing confidence in people with dementia, their family and carers, and doctors (GPs) to make timely and early decisions about EOLC and the arrangements after death.
- Documenting the wishes of the person with dementia to help everyone involved in their care to quickly access and understand their preferences and needs.
- Timely co-ordination of care with multiple services to reduce the burden on carers.
- Regular involvement of and visits from the same doctor (GP), nurse or care workers, meaning that the values, medical need and history of the person with dementia are well understood.
- Early recognition of the person nearing the EOL well in advance to help care providers recognise changes indicating that the person with dementia is nearing the EOL so that pain and discomfort are easily detected and managed responsively with the appropriate medication.
- Avoidance of unnecessary hospitalisations but, if admission to the hospital is needed, helps to assist discharge and prevent excessive length of stay.
- Ensuring that health-care workers possess the right skills to provide compassionate care to people with dementia.

BOX 8 Alternative 1

The DNS provides tailored support to enable the provision of high-quality EOLC to people with dementia. The support from a DNS is expected to result in the following:

- Timely co-ordination of care with multiple services to reduce burden on carers.

BOX 9 Alternative 2

The DNS provides tailored support to enable the provision of high-quality EOLC to people with dementia. The support from a DNS is expected to result in the following:

- Developing confidence in people with dementia and their family, carers and doctors (GPs) to make timely and early decisions about EOLC and the arrangements after death.
- Documenting the wishes of the person with dementia to help everyone involved in their care to quickly access and understand their preferences and needs.

BOX 10 Alternative 3

The DNS provides tailored support to enable the provision of high-quality EOLC to people with dementia. The support from the DNS is expected to result in the following:

- Regular involvement of and visits from the same doctor (GP), nurse or care workers, meaning that the values, medical need and history of the person with dementia are well understood.
- Early recognition of the person nearing the EOL well in advance to help care providers recognise changes indicating that the person with dementia is nearing the EOL, so that pain and discomfort are easily detected and managed responsively with the appropriate medication.
- Avoidance of unnecessary hospitalisations but, if admission to the hospital is needed, helps to assist discharge and prevent excessive length of stay.

BOX 11 Alternative 4

The DNS provides tailored support to enable the provision of high-quality EOLC to people with dementia. The support from the DNS is expected to result in the following:

- Ensuring that health-care workers possess the right skills to provide compassionate care to people with dementia.

TABLE 62 Summary description of WTP scenarios used in the contingent valuation survey

Option	Scenario				
	Main	Alternative 1	Alternative 2	Alternative 3	Alternative 4
1. People with dementia and their family, carers and doctors (GPs) are confident to make timely and early decisions about EOLC and the arrangements after death	✓		✓		
2. The wishes of the person with dementia are documented to help everyone involved in their care to quickly access and understand their preferences and needs	✓		✓		
3. A timely co-ordination of care with multiple services will reduce the burden on carers	✓	✓			
4. The values, medical need and history of the person with dementia is well understood because of regular involvement of and visits from the same doctor (GP)	✓			✓	
5. The care providers recognise changes indicating that the person is nearing EOL well in advance, so that pain and discomfort are easily detected and managed responsively with the appropriate medication	✓			✓	
6. Unnecessary hospitalisations are avoided, but, if admission to the hospital is needed, discharge is assisted and excessive length of stay is prevented	✓			✓	
7. It is ensured that health and social care professionals possess the right skills to provide compassionate care	✓				✓

The contingent valuation study took a community perspective, with respondents asked to give their WTP for the SEED intervention to be available in the NHS, even though they would not (necessarily) benefit from it themselves. Given this perspective, respondents were asked their WTP in the form of an additional tax per month that they would pay for the next 10 years. The 10-year duration was chosen as a meaningful time scale for respondents and was also representative of how long a policy intervention might exist before it was redesigned.

The contingent valuation questionnaire comprised three sections. The first section provided a background on current provision of dementia care towards the EOL and the SEED intervention. The second section presented the five hypothetical scenarios described in *Boxes 7–11*, and respondents were asked whether or not they were willing to pay for each of the scenarios. The steps involved in eliciting WTP values were as follows:

1. All respondents were presented with the 'main' WTP scenario and then randomly assigned to receive two of the four remaining WTP scenarios.
2. If they answered 'yes' to a question saying that they would be willing to pay, then they were presented with a series of payment cards selected at random on the screen. For each, they were asked to state their WTP for the proposed scenario with a question 'Would you be willing to pay £X for the scenario described?'.

3. Twelve payment cards with amounts ranging from 50p to £100 were used.
4. Respondents were asked to sort the payment cards by dragging and dropping (using the computer mouse) the WTP amount in the appropriate box ('definitely would pay', 'maybe', 'definitely would not pay'), depending on their answers.
5. The respondents were presented with a summary of the maximum card value that they were definitely willing to pay and the minimum card value that they were definitely not willing to pay and were again asked an open-ended question to state their maximum WTP.

This approach used to present the WTP questions was expected to minimise the potential starting point bias (bidding games) and range bias (payment scales).[207] Respondents answering 'no' to the WTP question on the scenario presented were asked to indicate a reason for not being willing to pay from a set of reasons or using a free-text option. The third section of the survey elicited respondents' socioeconomic and demographic characteristics (age, gender, income, education, etc.). The final questionnaire is available in *Report Supplementary Material 1*.

Survey administration

Pre-piloting of the contingent valuation component of the survey was conducted to test usability and ease of understanding the scenarios. The pre-piloting work was undertaken as 'think-aloud' interviews with seven members of the Institute of Health & Society at Newcastle University.[149]

Piloting of the full web survey was conducted in a subsample of the target general population. For both the pilot and final surveys, the sample of the general population was recruited from the online panel managed by a marketing company (ResearchNow). Respondents were offered a small (£1–2) incentive in the form of shopping vouchers, as per their normal procedures. The pilot sample size ($n = 270$) was considered large enough to conduct preliminary analysis and resulted in small amendments to the response options in the 'No, I am not willing to pay for the scenario'. This study was approved by the Faculty of Medical Sciences REC, part of Newcastle University's REC (approval code number 1410/136).

Data analysis

Data were analysed in statistical programming language R[208] (The R Foundation for Statistical Computing, Vienna, Austria) and reported as the mean and median WTP for each of the five scenarios. Protest responses that indicated that respondents were not willing to pay anything, with a reason 'I don't think I should have to pay for health care' or 'the government should pay', were excluded as per conventional practice in WTP studies.[209] All other reasons for not being willing to pay anything were interpreted as a true zero value and were included in the analysis. To reduce the effect on means of extreme upper-end WTP responses, means and medians were trimmed by excluding responses from the top 1% of WTP values.[150] Given a large proportion of zero WTP values and left-skewed data expected meant that standard regression methods such as ordinary least squares would yield biased and inconsistent estimates. In such a circumstance, a tobit model is the preferred alternative;[210,211] the impact of respondent characteristics (e.g. gender, age, income, education, family size and experience of dementia) on WTP values was investigated using this model for the trimmed sample.

Results

A total of 1002 respondents completed the online survey. *Table 63* presents the number of responses per scenario. The number of protest responses and the reasons for not being willing to pay anything for each of the scenarios are also presented in *Table 63*.

Table 64 reports the mean and median WTP values across the scenarios for both the trimmed and the untrimmed data sets. The mean WTP values computed from the untrimmed data set for the alternative scenarios were much higher than the mean WTP values for the main scenario and the very wide

TABLE 63 Initial sample and protest reasons

	Scenario				
Item	Main	Alternative 1	Alternative 2	Alternative 3	Alternative 4
Initial sample (*N*)	1002	496	506	500	502
Number of yes, positive WTP values, *n* (%)	807 (80.5)	335 (67.5)	327 (64.6)	359 (71.8)	324 (64.5)
Number of no, zero WTP values, *n* (%)	195 (19.5)	161 (32.5)	179 (35.4)	141 (28.2)	178 (35.5)
Number of protest zeros,[a] *n* (%)	104 (10.4)	67 (13.5)	62 (12.3)	57 (11.4)	65 (12.9)
Reasons for not being willing to pay **(n)**					
I do value the improvement in dementia care, but I cannot afford to pay anything for it	62	49	45	54	41
I do not think I should have to pay for health care	94	61	55	54	60
I think the dementia care without the nurse involvement would be satisfactory	19	29	41	19	35
Other	20	22	38	14	42

a Figures include the protest responses from the 'other' category of reasons for not being willing to pay.

TABLE 64 Mean and median WTP (Great British pounds, 2018 values)

	Scenario				
WTP	Main	Alternative 1	Alternative 2	Alternative 3	Alternative 4
Mean (95% CI)	40.13 (26.25 to 54.01)	2357.20 (23 to 14,006)	257.47 (28 to 1391)	810.22 (27 to 4700)	2313.69 (22 to 13,750)
Mean (95% CI)[a]	24.19 (21.85 to 26.52)	18.38 (15.95 to 20.82)	16.18 (13.59 to 18.76)	18.36 (15.72 to 21.00)	16.99 (14.15 to 19.83)
Median (95% CI)	10 (10 to 15)	10 (7.5 to 10)	7.5 (5 to 8)	9.25 (7.5 to 10)	6 (5 to 9)
Median (95% CI)[a]	10 (10 to 12.5)	10 (7.5 to 10)	7.5 (5 to 8)	8 (7.5 to 10)	6 (5 to 8)

a Top 1% of WTP values removed.

Note

Figures expressed are additional monthly taxation over a 10-year period.

95% CIs indicates the presence of very high outlier values. When the top 1% of WTP values were trimmed, the mean WTP was higher for the main scenario than for the alternatives. The medians for both the trimmed and the untrimmed data sets generally remained the same.

Table 65 summarises the mean WTP values by experience of dementia (i.e. who have seen their family, friends or colleagues with dementia). Across all the scenarios, individuals with some experience of dementia were willing to pay more for the improved dementia care service than those with no experience of dementia. However, there is no evidence of a statistically significance difference for alternative 2.

TABLE 65 Subgroup analysis, with and without experience of dementia (Great British pounds, 2018 values)

	Mean WTP (95% CI)				
Subgroup	**Main**	**Alternative 1**	**Alternative 2**	**Alternative 3**	**Alternative 4**
Dementia experience	29.26 (25.72 to 32.79)	21.87 (18.33 to 25.41)	17.21 (13.72 to 20.70)	22.15 (18.14 to 26.16)	19.99 (15.75 to 24.23)
No dementia experience	17.14 (14.67 to 19.60)	13.32 (10.40 to 16.24)	14.79 (10.94 to 18.65)	13.25 (10.33 to 16.17)	12.41 (9.41 to 15.42)
Difference in mean WTP[a]	12.12 (7.81 to 16.42)	8.55 (3.98 to 13.12)	2.42 (–2.76 to 7.60)	9.25 (3.95 to 13.85)	7.58 (2.40 to 12.76)
p-value	0.0000	0.0003	0.36	0.0004	0.0042

a Dementia experience – no dementia experience.

Note

Results based on top 1% of WTP removed from the main data.

The results of the regression analysis of WTP values on selected respondent characteristics for each of the scenarios is presented in *Table 66*. There was no evidence to suggest that respondent characteristics such as age, gender, family size, health utility or education status influenced the WTP values.

Summary of results of the contingent valuation study

Members of the general public do value the care provided by the SEED intervention. Moreover, a higher WTP value for the main scenario indicated that it was valued more than packages with selected features only. The subgroup analysis showed that individuals who have seen their family, friends or colleagues with dementia place a higher value on the tailored support provided by the SEED intervention and the provision of high-quality EOLC to people with dementia than individuals with no experience of dementia.

There was no evidence of a relationship between the WTP value placed on the improvement of dementia care services with age of the respondent, gender, household size or the health utility score. This indicates that the value of quality dementia care towards, and at, the EOL is of importance to all, irrespective of these respondent characteristics.

In line with economic welfare theory, it is expected that individuals with higher ability to pay would give higher WTP values.[212,213] The WTP values were significantly higher for high-income groups than for those on the lowest income level, which corroborates with economic welfare theory; however, there was no evidence of a simple linear relationship with WTP values.

TABLE 66 Regression analysis (based on the top 1% of WTP values trimmed data)

	Coefficient (SE)				
Covariate	**Main**	**Alternative 1**	**Alternative 2**	**Alternative 3**	**Alternative 4**
Age	0.16 (0.09)	–0.08 (0.10)	0.14 (0.11)	0.08 (0.1)	–0.16 (0.13)
Male	4.45 (2.73)	6.16 (3.20)	1.7 (3.31)	4.08 (3.19)	4.56 (4.08)
No dementia experience	–11.65 (2.77)***	–10.71 (3.24)***	1.38 (3.40)	–6.59 (3.25)*	–9.22 (4.11)*
Family size	0.58 (0.96)	–0.50 (0.99)	–0.71 (0.85)	–0.65 (1.0)	–1.0 (1.02)
Health score	0.11 (0.08)	0.26 (0.10)*	0.21 (0.10)*	0.23 (0.1)*	–0.001 (0.123)
Utility	–11.24 (6.95)	–13.28 (8.26)	–10.25 (8.59)	–8.0 (7.66)	–3.90 (10.36)

continued

TABLE 66 Regression analysis (based on the top 1% of WTP values trimmed data) (*continued*)

	Coefficient (SE)				
Covariate	**Main**	**Alternative 1**	**Alternative 2**	**Alternative 3**	**Alternative 4**
Household income (£)					
< 10,000	–	–	–	–	–
10,000–19,999	−1.14 (6.25)	−3.78 (7.32)	11.24 (7.7)	−3.27 (7.02)	4.46 (9.52)
20,000–29,999	3.54 (6.20)	−1.23 (7.23)	11.91 (7.5)	−1.33 (6.81)	9.90 (9.58)
30,000–39,999	3.49 (6.20)	−2.25 (7.25)	6.53 (7.56)	3.92 (6.95)	2.68 (9.46)
40,000–49,999	4.15 (6.50)	−2.02 (7.52)	7.33 (8.11)	−1.94 (7.24)	−5.46 (10.14)
50,000–59,999	9.23 (7.09)	7.96 (8.28)	17.98 (8.6)*	3.73 (8.58)	8.7 (10.38)
60,000–69,999	17.83 (8.24)*	8.51 (9.55)	20.04 (10.06)*	1.59 (8.88)	11.80 (13.58)
70,000–79,999	6.68 (8.66)	0.65 (10.18)	27.69 (10.06)**	6.45 (9.62)	8.29 (13.21)
80,000–89,999	13.67 (8.53)	2.90 (9.85)	23.32 (10.10)*	8.15 (8.36)	25.14 (15.75)
90,000–99,999	19.69 (9.80)*	17.87 (11.20)	7.46 (12.41)	2.18 (11.6)	18.39 (13.77)
100,000–149,999	24.82 (9.03)**	17.48 (9.44)	41.97 (1.77)***	49.10 (11.98)***	16.65 (12.1)
150,000–199,999	7.82 (15.34)	9.63 (16.44)	0.89 (21.07)	−22.97 (25.37)	28.64 (22.88)
200,000–499,999	27.29 (19.41)	13.21 (29.95)	71.49 (19.18)***	50.4 (22.04)*	87.92 (26.99)**
≥ 500,000	44.26 (11.76)***	28.43 (12.15)*	12.19 (17.98)	57.55 (13.59)***	22.28 (17.56)
Prefer not to answer	2.11 (7.12)	−9.87 (8.88)	5.17 (8.53)	−4.18 (7.98)	2.09 (10.94)
Education					
Incomplete secondary education (below GCSE/O level)	–	–	–	–	–
Do not want to disclose	0.16 (18.7)	−25.42 (22.42)	5.20 (27.26)	19.09 (19.39)	2.73 (29.26)
Doctorate, post doctorate or equivalent	12.61 (9.39)	−6.65 (10.83)	8.11 (12.75)	7.34 (11.06)	2.55 (13.86)
Postgraduate education completed (e.g. masters)	0.009 (7.84)	−2.71 (8.79)	19.37 (10.56)	−0.36 (9.39)	3.85 (11.27)
Secondary education completed (A level or equivalent)	−1.0 (7.55)	−5.35 (8.47)	15.29 (10.15)	−2.86 (8.78)	4.27 (10.96)
Secondary education completed (GCSE/O level/CSE or equivalent)	1.82 (7.47)	−2.35 (8.52)	17.10 (9.83)	1.09 (8.58)	−2.54 (10.92)
Some vocational or technical qualifications	8.79 (13.35)	0.1 (13.85)	29.65 (21.48)	−4.34 (19.98)	19.44 (17.44)
University education completed (first degree)	4.72 (7.17)	−3.24 (8.22)	11.28 (9.71)	−4.96 (8.51)	2.83 (10.42)
Vocational or technical qualifications completed (e.g. HND, NVQ)	4.12 (7.38)	1.69 (8.59)	21.25 (9.77)*	1.50 (8.66)	6.04 (10.74)

A level, Advanced level; CSE, Certificate of Secondary Education; GCSE, General Certificate of Secondary Education; HND, Higher National Diploma; NVQ, National Vocational Qualification; O level, Ordinary level; SE, standard error.
$^{*}p < 0.05$, $^{**}p < 0.01$, $^{***}p < 0.001$.

Economic evaluation of the SEED intervention

The economic evaluation aimed to estimate the relative efficiency of the SEED intervention. As the precise form by which this intervention would be implemented is not known at this stage, an early economic model was developed for this purpose.[151] In such models, plausible ranges for model parameters are specified and the impact on a set of specified modelled outcomes (e.g. predicted costs or effectiveness measures) of varying these model parameters over this plausible range is estimated.

During the design stage for the evaluation, and as noted in *Valuing the consequences of the SEED intervention*, there was a concern that QALYs may not capture the full benefit of the SEED intervention. Therefore, the economic evaluation was designed as a cost–consequence analysis, which does not seek to aggregate impacts on patients' and carers' health and well-being into a single measure, such as QALYs. Instead, it reports each impact in units that make sense for that impact (e.g. for hospitalisations, the impact could be reported as number of hospitalisations or days in hospital). The purpose of reporting impacts like this is to highlight choices and trade-offs between costs and impacts. The cost–consequences analysis approach is useful because it can incorporate health and non-health impacts, something that QALYs cannot do.[214]

A cost–consequences analysis can also be thought of as a step along the way to the most comprehensive form of economic evaluation: a cost–benefit analysis.[152,153] In a cost–benefit analysis, costs and benefits are valued in commensurate units, normally money.[145] Following the completion of the cost–consequences analysis, we use cost–benefit analysis approach here, in a novel analysis, to incorporate the results of the contingent valuation into the economic model.

Methods

Cost–consequences analysis

For the cost–consequences analysis, a comparison was drawn between the SEED intervention and usual care. The SEED intervention affects several activities, which directly or indirectly affect the care and well-being of the person with dementia and their family/carers. These activities, service outputs and outcomes are described in detail in *Appendix 6*, *Dementia care services*. The main activities included in this model were as follows:

- regular clinical reviews
- ACP discussions and documentation
- liaison between services before hospitalisation [proxy: use of the situation, background, assessment, recommendation (SBAR)[215] technique]
- liaison between services during hospitalisation (proxy: use of transfer sheets)
- liaison between services after hospitalisation (proxy: discharge planning).

The extent to which the SEED intervention will affect these activities is unknown until a prospective evaluation is conducted. Therefore, a set of exploratory scenarios were produced, whereby:

1. In the SEED intervention arm, the provision of all care activities was set to its expected maximum and was compared with the control arm (usual practice), for which the provision of all care activities was set to its expected minimum. This scenario was named the 'favourable scenario'.
2. In the SEED intervention arm, the provision of all care activities was set to its expected minimum and was compared with the control arm (usual practice), for which the provision of all care activities was set to its expected maximum. This scenario was named the 'conservative scenario'.
3. The expected provision of a single care activity was set to its expected maximum, while the other four activities were set at their average level of provision. This analysis was repeated for each care activity.
4. The expected provision of one care activity only was set to its expected minimum, while the other four activities were set at their average level of provision. This analysis was repeated for each care activity.

Scenarios 1 and 2 allowed the estimation of the boundaries of the plausible cost and consequences associated with the SEED intervention, compared with usual care. Scenarios 3 and 4 provided an estimate of the relative impact of each activity alone, which forms part of the SEED intervention on total costs and consequences compared with usual care. The data for scenarios 3 and 4 can be used to refine the SEED intervention by identifying those activities of the intervention that are likely to be more cost-effective and, hence, more worthwhile in terms of both intervention development and intervention implementation.

Cost–benefit analysis

The contingent valuation study valued five example scenarios (the main scenario and alternative scenarios 1–4; see *Boxes 7–11*) for the SEED intervention, defined in terms of the differing impacts that the SEED intervention may have. For analysis purposes, a sixth scenario was used to provide a common baseline for comparison: a do-nothing option in which no aspects of the SEED intervention were provided. This is in contrast to the cost–consequence analysis, in which usual care was used as a comparator. As noted earlier, this option represents the complete absence of care activities, service outputs and patient outcomes that could be caused by the SEED intervention. The rationale for this change in comparator stems from the way in which the WTP scenarios and questions were formulated in the contingent valuation study. In the contingent valuation, respondents were asked to reveal their WTP for a package of care services that would always be present following the introduction of the SEED intervention, compared with a situation in which these services would be absent.

Development of the model structure

Initial model scoping work

The literature was reviewed to identify existing economic models comparing interventions for dementia (see *Appendix 6*, *Model structure*). No existing economic evaluation model was identified that was suitable for this analysis. Therefore, a new early economic model was needed.

The economic model seeks to describe the key elements of how dementia may develop over time. The model starts at the point when the individual receives a diagnosis of dementia, and then follows them until death. Thus, the model took a lifetime time horizon for a person with dementia and their families; bereavement services shortly after death were also included in the model.

The model is a simplification of a complex situation and it sought to include those changes in services that were deemed most important and that might occur because of the five activities defined in the cost–consequence analysis. Importance was judged based on where the largest impacts on costs and care preferences might occur. This was informed by a review of the literature on cost-effectiveness, epidemiological and cost studies that had been conducted in this area. These studies were selected based on searches of the bibliographic databases and discussion with the project team, along with their relevance to the UK. Further detail is provided in *Appendix 6*, *Model structure* and *Dementia progression*.

The core components of the model are presented in *Figure 14*. In this model, following diagnosis, the disease continues to progress until, eventually, palliative care is considered appropriate, or until the person with dementia dies. The place where care is provided (the care setting) at any point in time could be home, care home or hospital. The model assumes that a person may move between these care settings over time.

Defining model parameters

To use the model in *Figure 14*, data on event probabilities and cost are required; how these were derived is described in the following section.

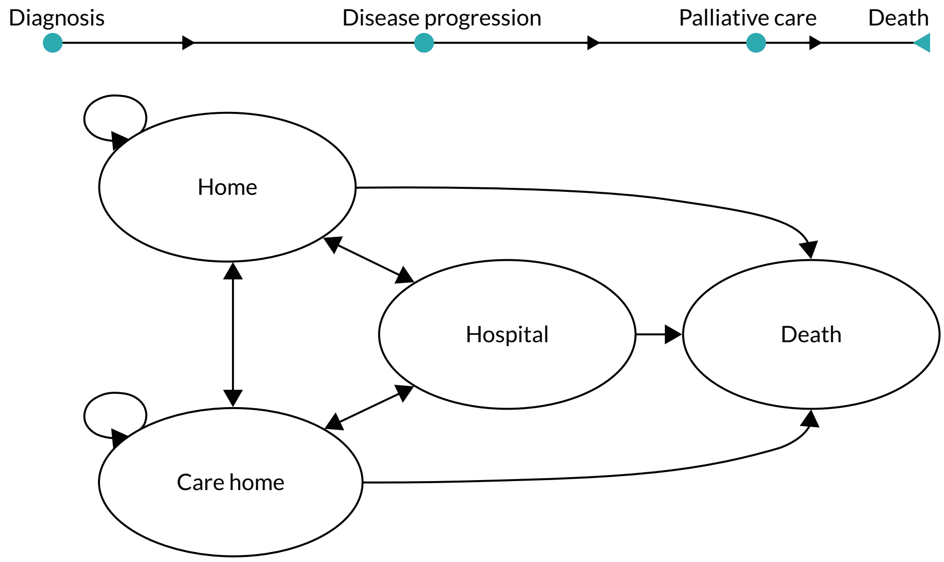


FIGURE 14 Model of disease progression and care setting.

Event probabilities

Dementia progression and transitions between places of care were modelled separately (see *Appendix 6*, *Dementia progression* and *Transition probabilities between care settings*). We reviewed the literature for data on dementia progression and care transitions, for example from home to care home and from care home to hospital (further detail is provided in *Appendix 6*, *Transition probabilities between care settings*). The target population was all dementia subtypes; the aim was to examine the relationship between a change in care setting and disease progression. Selected data had to be relevant to current service delivery in the UK.

No disease progression data for all dementia subtypes suitable for this purpose were identified. There is considerable uncertainty in the disease trajectory;[6] however, a systematic review was identified that provided a framework for the modelling.[216] Data from a health policy model in Alzheimer's disease were used as a proxy for all dementia subtypes and to derive the probability of moving from one severity level to another (called transition probabilities).[217] *Appendix 6*, *Dementia progression*, provides details of how this was done.

Data on movement between setting of care were mainly based on an econometric model that predicted changes in care setting and rate of hospitalisation in the UK.[218] Further details about this model are provided in *Appendix 6*, *Transition probabilities between care settings*.

To use the information on disease progression and on changes in place of care in our model, a mapping exercise was conducted. This mapping exercise ensured that the definitions used for severity of disease in the health policy model[217] (and described in *Appendix 6*, *Transition probabilities between care settings*) were consistent with those used in the setting of care prediction study.[218] Details of the probabilities of disease progression and changes in the place of care and hospitalisation required in the model are described below:

- Change of care setting from home to care home and vice versa (further detail is provided in *Appendix 6*, *Transition probabilities between care settings*).
  The average monthly probability of making the transition from the home of the person with dementia to a care home was estimated as 0.0137.[218] A probability of 0.0005 was assumed, based on expert opinion, for the transition from care home to home.

- Hospital admission and hospital deaths.
  A weighted average of the general and psychiatric hospital probabilities was used for the probability of hospitalisation (further detail is provided in *Appendix 6*, *Transition probabilities between care settings* and *Educational needs assessment for dementia nurse specialist*).
- Discharge from hospital to previous place of care.
  Two predictive logistic models for the probability of discharge to a care home from hospital for patients admitted from home for England and Wales were used; these came from the same study.[219] These models covered two populations with dementia: (1) patients with a primary diagnosis of dementia and (2) patients with dementia, but a primary diagnosis of an ambulatory care sensitive condition,[220] for which hospitalisation may be preventable with timely care (e.g. bacterial pneumonia). A weighted average from these two models was calculated.[219] For all people admitted from home and subsequently discharged, the probability of being discharged to a care home was, on average, 0.149 (further detail is provided in *Appendix 6*, *Transition probabilities between care settings*). We assumed that remaining patients either returned home or died during the index admission. For patients admitted to hospital from a care home, an assumption was made that only 0.5% are discharged to their home.

Mortality

Estimates of mortality rates by age and gender for people with dementia were obtained from the MRC Cognitive Function and Ageing Studies (CFAS) multicentre longitudinal prospective study in the UK.[41] These data may overestimate the risk of death at the earlier stages of dementia and underestimate it for more severe stages. For those people with dementia cared for in hospital, it was assumed that 18% would die during their index admission, regardless of their age and disease severity[221] (see *Appendix 6*, *Mortality and palliative care*).

Palliative care

Based on the GSF,[129] we assumed that a person with dementia would receive dementia-related palliative care only once they had severe cognitive decline. The probability of receiving palliative care in usual practice was estimated by subtracting the time spent on the primary care palliative care register from the individual's time to death following the diagnosis. The distribution of time spent on the palliative care register was based on published data on the proportion of people with dementia and frailty placed on the palliative care register before their death (20%; 32/160 individuals) and their time on the palliative care register prior to death (median 2.42 weeks, interquartile range 0.43–13.14 weeks).[222] How this was done is described in more detail in *Appendix 6*, *Mortality and palliative care*.

Modelled population characteristics

At entry to the model, the characteristics of the hypothetical individuals modelled varied in terms of gender, age, cognitive function, functional ability and behavioural symptoms. With the exception of gender, these characteristics were allowed to change over time as the individual journeyed through the model. The data for these characteristics were for the UK,[2,9] except for the distribution of dementia severity, which was based on data from the USA, as no suitable UK data were available.[217] It was assumed that people with dementia eligible for the intervention would have mild to moderately severe dementia at the time of diagnosis (further detail is provided in *Appendix 6*, *Baseline population*).

Estimation of costs

The estimation of costs has two components. First, the relative impact of the SEED intervention on the use of dementia care services was estimated. Second, information on the use of services was combined with information on the cost of a single use of each service (the unit cost) to generate the overall costs of these dementia care services.

Impact of the SEED intervention on dementia care services

How the introduction of the SEED intervention might influence the use of other services and costs is shown in the influence diagram (*Figure 15*). The influence diagram was informed by the theory of

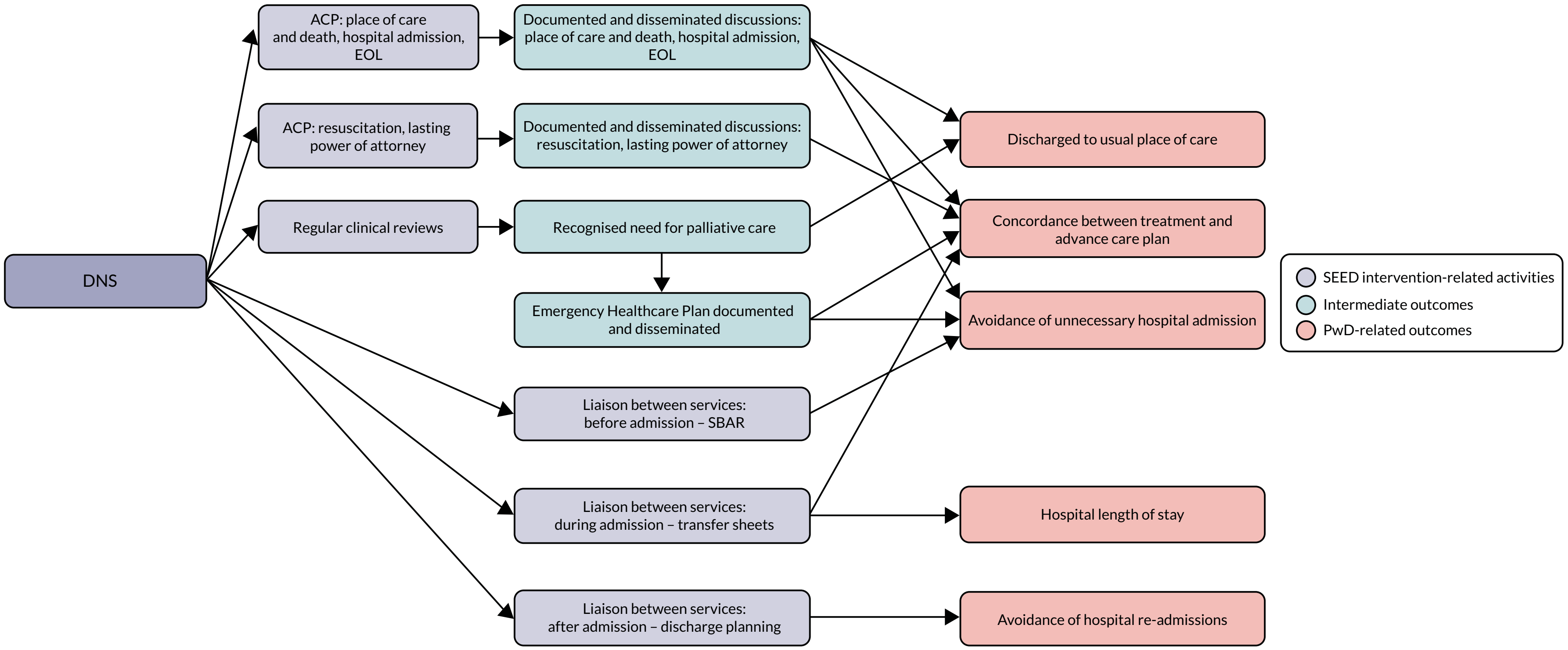


FIGURE 15 Influence diagram of the expected key effects of the SEED intervention components on other services and clinical outcomes. PwD, person with dementia.

change developed in WS3 (see *Box 1*). For example, the SEED intervention is expected to improve the liaison between services before hospitalisation through increased and more effective use of the SBAR technique.[215] Care home staff training and increased use of SBAR (which are part of the activities that form part of the SEED intervention), in turn, help to avoid unnecessary hospitalisations (a potential impact of using the SEED intervention). The cost of staff training and the use of SBAR were taken as the cost of providing the SEED intervention and the reduction in hospitalisation was used to estimate the cost saving that might be produced by the using the SEED intervention.

To estimate a possible range of outcomes associated with the SEED intervention, minimum and maximum values for a care activity were specified. These were informed by relevant data identified from literature searches and on plausible assumptions made about the frequency of individual activities and impacts of services (see *Appendix 6*, *Care services and their effects*).

Costs (see *Appendix 6*, *Cost of the SEED intervention*)

Costs were assessed from a societal perspective, as the SEED intervention could have an impact on costs that fall outside the NHS. The type of costs included in the model relate to the SEED intervention itself, SEED intervention-related activities (e.g. addition of patient's name to palliative care register and more regular clinical reviews) and service outputs (e.g. care-setting costs and hospitalisation).

The SEED intervention costs

The costs associated with the SEED intervention are estimated to be £20.40 per person with dementia, per month. These are associated with the fixed time and cost of the DNS, supervised by clinical specialists. Consequently, the operating cost of the intervention is assumed to be independent of the number and level of care activities the SEED team will be involved in. A detailed breakdown of the SEED intervention operating costs is presented in *Appendix 6*, *Cost of the SEED intervention*.

The SEED intervention-related activities and service outputs

There are costs associated with the care services presented in *Figure 15*. The resource use estimates were based on expert opinion from the project team. Unit costs were obtained from a routine source[223] for each unit of resource use. Family carer time is costed according to the latest government labour force survey, at a median of £11.34 per hour.[224]

Care-setting cost

The cost of care at home or in a care home varied according to the severity of dementia.[2] These costs cover services such as inpatient stays, day-care visits and contacts with GPs and other community-based professionals. Adjustments were made to the care-setting costs to avoid double counting the costs of hospitalisations, regular clinical reviews and ACP (see *Appendix 6*, *People with dementia: care-setting costs*).

Hospitalisation

The cost of a hospitalisation was calculated as a weighted average of the cost of a hospital episode for the four main reasons (hip fracture, kidney or urinary tract infections, pneumonia and stroke) for hospitalisation in this population.[225] The cost per episode came from the *NHS Reference Costs 2015–16*,[226] using the weighted average of relevant health-care resource group codes. The estimated average cost was £282 per day (further detail is provided in *Appendix 6*, *People with dementia: care-setting costs*).

Data analysis (see Appendix 6, Analyses*)*

A patient-level simulation was conducted in R statistical software.[227] In this model, hypothetical cohorts of 380 people with dementia were considered. The size of cohort was a balance between representing heterogeneity between individuals and the computing time needed for analysis. As described above, each individual in this hypothetical cohort was defined in terms of a unique set of characteristics at the time of diagnosis, when they entered the model.[218,219] Some of these individual characteristics changed over an individual's journey through the model, such as the age of an individual, whereas others were fixed, such as gender.

The individual characteristics were used to derive the likelihood that a person with dementia moved between care settings (see *Appendix 6*, *Transition probabilities between care settings*). To capture the uncertainty in the association between the characteristics of an individual and their movement between care setting and disease progression, transition probabilities were randomly sampled for 800 cohorts (with each cohort including 380 people with dementia). Again, the choice of number of cohorts was pragmatic and represented a trade-off between the computing time required for analysis and ensuring that we could capture uncertainty around the model parameters. Average costs and consequences were estimated for each cohort. The model was run for 120 cycles; each cycle represented 1 month (in total 120 cycles represents 10 years). After 10 years, it was expected that 95% of the simulated patients would have died. Costs are reported in 2017 Great British pounds. Costs and benefits were discounted at an annual rate of 3.5%.[154] This process was repeated for each comparator considered in the cost–consequences analysis and for each of the WTP scenarios and which were compared in the cost–benefit analysis.

Cost–consequences analysis (see Appendix 6, Analyses*)*

The primary outcomes in this analysis were total cost, length of stay in hospital, time receiving palliative care, the number of people with dementia discharged to their usual place of care from hospital per 1000 patients and the number of avoided hospitalisations per 1000 possible hospitalisations. The total cost is the sum of the discounted costs over the 10-year duration of the model.

Cost–benefit analysis (see Appendix 6, Analyses*)*

The net benefit of providing a SEED intervention to new incident cohorts over a 5-year period was estimated for each of the scenarios described in *Valuing the consequences of the SEED intervention*. In the cost–benefit analysis, the WTP scenario with the highest net benefit is the most efficient. By modelling 800 cohorts, a distribution of net benefits was produced for each WTP scenario, and, from this, the mean net benefit and 95% CIs were produced for each scenario. The probability that any given scenario would be most efficient compared with the other scenarios was also estimated.

For the cost–benefit analysis, it was assumed that the intervention would be made available to people diagnosed with early to mild dementia over an illustrative 5-year period. This means that these people receive the intervention (or relevant components) for the rest of their lives, but that anyone diagnosed with early to mild dementia outside this 5-year window would not be offered the SEED intervention. This approach was taken because the implementation would affect the costs and outcomes of those who receive it over their entire lifetime (through the upskilling of community staff), but patients beyond this 5-year period might receive a different intervention as the SEED intervention itself may be replaced after a period of time. However, possible changes in the delivery of health care beyond this 5 years is out of the scope of this analysis and does not influence the results of the cost–benefit analysis. Five years was chosen as this is consistent with the minimum likely time scale before the NICE guidelines might be revised. This is a shorter period than was considered in the contingent valuation work, and so the analysis may overestimate benefits, but, by the same token, total cost for 5 years is likely to be lower than total costs estimated over 10 years.

The contingent valuation work, reported in *Valuing the consequences of the SEED intervention*, expressed WTP as monthly tax contributions by individual tax payers for all or some components of the SEED intervention to be delivered nationally. Therefore, to make the modelled cost and the WTP data comparable, the cumulative costs and benefits were estimated at the national level. Further details of how this was conducted are described in *Appendix 6*, *Analyses*.

Results

Cost–consequence analysis

Table 67 reports the results for two scenarios: scenario one describes a situation in which the data and assumptions used are all more favourable to the SEED intervention (favourable SEED scenario) than to usual care. The second scenario is one in which the data and assumptions are less favourable to the

TABLE 67 Mean estimates and 95% CIs of the difference between the favourable and conservative interventions, compared with usual practice

Analysis	Mean (95% CI)				
	Cost (£) per patient[a]	Length of hospital stay[a] (days)	Duration of palliative care[a] (months)	Discharge from hospital to usual place per 1000 discharges[a]	Avoided hospitalisations per 1000 hospitalisations[a]
Favourable SEED scenario	9930 (−3174 to 23,553)	−1.4 (−2.8 to 0)	1.91 (1.07 to 2.86)	25 (−31 to 75)	161 (119 to 201)
Conservative SEED scenario	2007 (−10,701 to 14,189)	−1.3 (−2.8 to 0.1)	0.46 (0.09 to 0.9)	0 (−50 to 44)	81 (57 to 109)

[a] Mean incremental outcome compared with usual practice.

SEED intervention (conservative SEED scenario). For each scenario, the mean difference for each outcome between the SEED intervention and a do-nothing option is presented.

As *Table 67* shows, the SEED intervention had, on average, reduced rates of hospitalisation, a reduced length of hospital stay and an increased number who were discharged from hospital to usual place of care. There was also increased access to, and duration of, palliative care. However, there was an increased cost. There is considerable uncertainty surrounding these values, with CIs including zero for all outcomes except for duration of palliative care and number of hospitalisations avoided. The CIs for costs, and discharge to usual place of care, are sufficiently wide to include clinically and economically important differences that could favour either the SEED intervention or usual practice.

The SEED conservative scenario is, on average, less costly than the SEED favourable scenario (but still, on average, more costly than usual practice). This is because the SEED favourable scenario increases service use, and hence costs, but is also expected to improve outcomes for people with dementia. These increased costs for the SEED favourable scenario are not fully offset by the reduced need for other services such as hospitalisations.

Further analysis explored the impact of high and low levels of provision of individual SEED intervention-related activities (*Table 68*). The ACP component was treated as one service in this analysis. As *Table 68* illustrates, the individual components of the SEED intervention are not assumed to be additive. Furthermore, some components have no expected impact on some outcomes; for example, there is little to no impact of ACP service provision on length of stay.

Cost–benefit analysis

The cost–benefit analysis compares the different variants of the SEED intervention (main scenario and alternative scenarios 1–4). Every WTP scenario is associated with a positive net benefit (column D in *Table 9*). The scenarios in *Table 9* are ordered from lowest to highest net benefits. The main scenario, which incorporates all the activities of the SEED intervention, has the greatest net benefit; alternative scenario 4 has the lowest net benefit. Although there is considerable uncertainty in the net benefit estimates, the 95% CI includes zero for only one scenario (alternative 4). These net benefits are all relative to the provision of no SEED intervention, that is an absence of care activities and service outputs.

Column E in *Table 9* shows the incremental net benefit. This illustrates the gain from moving to a scenario that provides more benefits. Column F shows the probability that each scenario provides the greatest net benefit, namely that it is the most efficient. The main scenario has the highest probability of being the most efficient (30%) out of the five compared. However, no scenario clearly stands out because of the considerable uncertainty in the cost and WTP estimates.

TABLE 68 Mean estimates and 95% CIs of the difference between individual SEED intervention component and the usual care groups

		Mean (95% CI)				
SEED intervention component	**Intervention level**	**Cost (£) per patient[a]**	**Length of hospital stay[a] (days)**	**Duration of palliative care[a] (months)**	**Discharge from hospital to usual place per 1000 discharges[a]**	**Avoided hospitalisations per 1000 hospitalisations[a]**
Reviews	Minimum	5833 (–7946 to 18,342)	–1.35 (–2.8 to –0.1)	1.17 (0.52 to 1.91)	13 (–38 to 61)	120 (82 to 164)
	Maximum	6669 (–6512 to 19,907)	–1.36 (–2.7 to 0)	1.87 (0.99 to 2.94)	13 (–40 to 63)	121 (84 to 165)
ACP	Minimum	4590 (–8362 to 17,295)	–1.32 (–2.8 to 0)	1.83 (0.96 to 2.95)	3 (–47 to 51)	103 (73 to 136)
	Maximum	8481 (–4339 to 21,854)	–1.33 (–2.8 to 0)	1.84 (1.01 to 2.97)	22 (–30 to 73)	138 (99 to 180)
SBAR	Minimum	6067 (–6552 to 19,160)	–1.3 (–2.8 to 0)	1.85 (1.01 to 2.96)	13 (–39 to 61)	106 (72 to 142)
	Maximum	7202 (–6176 to 19,945)	–1.32 (–2.8 to 0)	1.89 (1.04 to 3)	13 (–39 to 64)	135 (96 to 177)
Transfer sheets	Minimum	6553 (–6392 to 19,493)	–1.35 (–2.8 to 0)	1.85 (0.99 to 2.93)	13 (–42 to 65)	121 (84 to 164)
	Maximum	6586 (–6222 to 19,496)	–1.43 (–3.1 to 0)	1.87 (0.98 to 2.97)	13 (–42 to 65)	121 (84 to 164)
Discharge planning	Minimum	6475 (–6102 to 19,756)	–1.32 (–2.9 to 0)	1.87 (0.96 to 2.98)	7 (–48 to 57)	121 (84 to 164)
	Maximum	6788 (–5321 to 20,159)	–1.32 (–2.9 to 0)	1.87 (1.01 to 2.94)	13 (–42 to 66)	121 (84 to 166)

a Mean incremental outcome compared with usual care.

Appendix 6 Economic modelling study (workstream 5): additional explanatory text

This appendix provides further details of the methods and results of the economic evaluation.

Dementia care services

The activities of the SEED intervention, the service outputs and the outcomes related to people with dementia are described in detail in *Table 69*.

TABLE 69 Descriptions of the SEED intervention activities, service outputs and patient-related outcomes

Services and outcomes	Description
SEED intervention activities	
Regular clinical reviews to support recognition of the need for palliative care input towards the EOL (short name: regular clinical reviews)	Regular clinical review by GP or care home nurse to identify changes in activities of daily living, physical health and cognitive functioning that indicate an increase in care needs as the person with dementia approaches the EOL, and may suggest that they should be added to the primary care palliative care register. The process could be facilitated by the use of formal assessment tools, GSF criteria or the 'surprise question'. This may improve the recognition of patients approaching the EOL and help to ensure that appropriate care plans are in place
Planning discussions offered	The provision of opportunities for timely discussions involving the person with dementia and/or key family members about future care preferences, including EOLC. Systems are in place to prompt primary care and care home staff to prompt the process and to review at specified trigger points (e.g. annual dementia review) Discussions can be around the preferred place of care and death, hospitalisation, DNACPR, tube-feeding, lasting power of attorney and/or preferred decision-maker, and EHCPs Planning discussions outcome is categorised in two different categories because each category is anticipated to affect different groups of outcomes, and, in some discussion sessions, some topics might not be covered
EHCP documented and disseminated	Ensuring that family carers and professionals are aware of the care plan for the person with dementia, which includes contact details for the most appropriate service to contact in case of an emergency or change in condition. Information is accessible via the EHCP to services potentially involved (e.g. out-of-hours services, paramedics). It is expected that this will result in appropriate care being provided by the most appropriate person, rather than by generic services. Additional information on how to deal with expected acute events that might arise is provided in the EHCP document

continued

TABLE 69 Descriptions of the SEED intervention activities, service outputs and patient-related outcomes (*continued*)

Services and outcomes	Description
ACP discussions documented and disseminated	Documentation is completed to an appropriate standard and is relevant to the person with dementia's current clinical needs. This outcome has been split into the following categories: preferred place of care and death, hospitalisation, DNACPR, tube-feeding, lasting power of attorney and/or preferred decision-maker and EHCPs Each of these refers to the documentation of the corresponding discussion topics (mentioned in planning discussions offered) that reflect the preferences of the patient with respect to each of these topics ACP documents are expected to have also been flagged and disseminated to all key stakeholders (i.e. care home, out-of-hours services, ambulance service)
Liaison between hospitals, community services and families before admission (short name: SBAR)	Documentation of reasons for referral (e.g. by using a structured tool such as SBAR) to clarify the purpose of the referral and desired outcomes and to prompt staff to consider the referral in the broader context of the patient's overall condition and where they are on the illness trajectory Improving communication through the use of structured documents might facilitate decision-making. The approach may also help professionals to identify alternative ways of achieving the desired outcomes, which could help to avoid a potential hospitalisation
Liaison between hospitals, community services and families during admission (short name: transfer sheets)	Accessible information provided to hospital staff in the event of hospitalisation to facilitate person-centred care towards, and at, and at the EOL (e.g. through documents such as 'TOP 5' or 'this is me')
Liaison between hospitals, community services and families after discharge (short name: discharge planning)	Transparent communication between hospitals, community services and families to develop a shared understanding of the patient's needs and how best to meet them and facilitate timely discharge
Service outputs and patient-related outcomes	
Recognised as being in need of palliative care (proxy: entering patient in palliative care register)	This is a state that there is an anticipated change in care type. The major care transition that happens at the point of palliative care recognition is to stop regular/preventative medication (e.g. statins), and to even stop the dementia-modifying drugs when condition deteriorates significantly. The approach to care in this state is palliative. To capture the palliative care state, we are using the palliative care register as a proxy
Practical and emotional support offered to carers prior to and after patient's death (proxy: bereavement services)	Information is given to families prior to or at the time of death containing practical advice and listing legal requirements (e.g. details of local undertakers, how to register a death), emotional support is offered to families in the period around the death and practical support is offered with immediate tasks (e.g. contacting other relatives). This outcome captures both emotional and practical support before death
Meeting the needs of the person with dementia for comfort at the EOL	Comfort at the EOL is promoted through comfort care planning and review. This encompasses physical, emotional and spiritual comfort. Comfort may be promoted through the use of pain assessment scales, which help both in identifying pain and in evaluating the response to pain-relieving medications This is expected to improve care and the QoL and death of individuals by tailoring care to their individual preferences, but is not captured in the model

TABLE 69 Descriptions of the SEED intervention activities, service outputs and patient-related outcomes (*continued*)

Services and outcomes	Description
Concordance between treatment and advance care plan	There is agreement between the patient's preferences (when recorded in an ACP document) and the actual treatment received. Because ACP is separated in different components now in the interactions table, concordance applies to different categories. One is concordance for aggressive treatments, such as CPR and feeding tube, and the other is for hospitalisations This outcome also describes avoiding overly aggressive, burdensome or futile treatment when a person with dementia is considered to be in a palliative care state. The unwanted interventions or treatments in our case include CPR, tube-feeding and hospitalisations. This is expected to improve the QoL and death of individuals by tailoring care to their preferences, but it is not an outcome captured in the model
Length of hospital stay	Length of inpatient hospital stay which might vary according to the presence or absence of other outcomes
Reduced unnecessary hospitalisations and re-admissions	Reduction of hospitalisations for conditions that could have been effectively treated or managed in the community by utilising existing alternative care services (e.g. district nurse). This applies for ambulatory care-sensitive conditions, but not for hospitalisations that are necessary
Discharged to usual place of care	The individual patient is discharged to the place of care from which he/she was admitted to the hospital
Deaths in preferred place of care	Individual patient dies in the preferred place of care/death
Time spent in preferred place of care	Duration for which individuals are being cared in their preferred place of care
Hospital deaths	Number of deaths in hospital

CPR, cardiopulmonary resuscitation; EHCP, Emergency Healthcare Plan.

Model structure

The literature was reviewed for cost-effectiveness, epidemiological and cost studies, preferably relevant to the UK. A focused search (*Table 70*) was run in the MEDLINE database to identify reviews of studies that model Alzheimer's disease or dementia progression and economic impacts. A review of studies by Green *et al.*[216] was identified, which described the analytical approach and health outcomes of previously published model-based economic evaluations in Alzheimer's disease. Using pearl-growing techniques[228] to search for more recent evidence, an update of this review was identified.[229] The search strategy used by this review[216] was replicated to explore further evidence not captured in the review from 2013 to 2016. The search strategy can be found in Green and Zhang.[217]

The SEED intervention is not expected to slow down the progression of dementia, but rather to support the continuity of care and transitions between settings of care. Therefore, a model structure to account for transitions between settings of care, rather than clinical outcomes, was considered most appropriate. In the identified review, the Assessment of Health Economics in Alzheimer's Disease model[230] and the McDonnell model[231] had adopted this approach. Many studies have applied these two models, or modified them, to conduct economic evaluations in Alzheimer's disease and dementia.[216,217]

Our economic model sought to incorporate the costs and benefits to the people with dementia, their family and their carers, as well as to the NHS and Personal Social Services. It sought to describe the key elements of the 'typical' illness trajectory of an individual with dementia from the point of

TABLE 70 Search strategy to identify studies modelling progression in dementia and Alzheimer's disease

#	Searches: MEDLINE® In-Process & Other Non-Indexed Citations (via Ovid)	Results
1	Alzheimer Disease/di, ec [Diagnosis, Economics]	14,297
2	Dementia/di, ec, ep [Diagnosis, Economics, Epidemiology]	16,096
3	Cost-Benefit Analysis/	74,599
4	"Costs and Cost Analysis"/or "Cost of Illness"/	69,980
5	Decision Support Techniques/or Decision Making, Computer-Assisted/	20,509
6	Health Care Costs/	35,880
7	models, economic/	9029
8	Models, Statistical/	85,192
9	1 or 2	28,123
10	3 or 4 or 5 or 6 or 7 or 8	267,740
11	9 and 10	1316
12	"review"/	2,421,662
13	11 and 12	200

diagnosis through progression until death, this being the period during which the effects of SEED intervention are anticipated to occur. Consequently, the model took a lifetime time horizon for a person with dementia. The model structure was selected to provide the best estimates of the most significant cost and care preference consequences of an improvement in the provision of a selection of dementia care services.

The core components of the model are presented in *Figure 14*. In this model, following diagnosis, the disease continues to progress until eventually palliative care is considered appropriate, or until the person with dementia dies. The care setting at any point in time could be at home, in a care home or in hospital. The model assumes that a person may move between these care settings over time. The structure enables the estimation of the key costs and consequences of dementia care services.

Dementia progression

A focused search was conducted in January 2017 to identify studies that model disease progression in dementia or Alzheimer's disease. This was required to inform the change in severity of the individual in the model over time, which is a known predictor of changing between settings of care.[218,219,231–236] The search was conducted in MEDLINE® In-Process & Other Non-Indexed Citations, via Ovid, and is presented in *Table 71*.

Of the 36 studies identified from the search strategy, a systematic review and a multidomain health policy model by the same author were used to identify further relevant studies.[216,217] Several methods of modelling disease progression were identified in this focused review of evidence.[217,237–239] Our criteria for the selection of method to model progression in dementia were relevance to current UK treatment and care practice, size of the analysis data set and the use of multiple disease domains (e.g. functional capacity) that enable disease progression to be linked to change of care setting and risk of hospitalisation.

Data from Green and Zhang[217] were used to model disease progression. Although patients included in this study were diagnosed with Alzheimer's dementia subtype, the choice was based on the size of the

TABLE 71 Focused search strategy to model disease progression in dementia

#	Searches	Results (*n*)
1	disease progression/	143,345
2	Humans/	17,379,680
3	DEMENTIA/	45,912
4	Alzheimer Disease/di [Diagnosis]	13,680
5	3 or 4	57,213
6	2 and 3 and 5	45,327
7	models, statistical/	85,143
8	1 and 2 and 5 and 7	36

cohort ($n = 3009$), the recent (2016) publication date of the study and the ability to map the dementia severity characteristics to the characteristics used in Knapp *et al.*[218] The relatively recent date of the study was considered an important factor in the disease progression model, as it ensures that the cohort is receiving care that is contemporaneous with current practice. Furthermore, in this study, dementia was described using three severity domains: cognitive capacity, behavioural symptoms and functional ability. Each domain had three severity levels: cognition (mild, moderate and severe), behaviour (no problem/mild, moderate and severe) and functional ability (no problem, mild and severe). The definitions are provided in *Table 72*.

Although more methodologically sophisticated models of disease progression were available in the literature,[216] such as the Getsios *et al.*[237] microsimulation model or the Peninsula Technology Assessment Group (PenTAG) model,[233] these were based on cohorts of patients recruited before 2000, when the disease-modifying acetylcholinesterase inhibitors were not yet adopted into current practice.[240]

In addition, in a more modern cohort, the type of care received is also expected to be more representative. Other studies, such as the one by Stallard *et al.*,[239] that modelled disease progression in Alzheimer's were considered; however, to model disease progression according to their suggested

TABLE 72 Dementia severity domains and levels used in Green and Zhang[217]

Domain	Severity level	Definition
Cognitive function	Mild	$21 \geq \text{MMSE} \geq 26$
	Moderate	$10 \geq \text{MMSE} \geq 20$
	Severe	$0 \geq \text{MMSE} \geq 9$
Behaviour and mood	No problem/mild	NPI-Q: each item ≥ 1
	Moderate	NPI-Q: each item ≥ 2, with at least one item equal to 2
	Severe	NPI-Q: at least one item equal to 3
Functional ability	No problem	$0 \geq \text{FAQ total} \geq 8$
	Moderate	$9 \geq \text{FAQ total} \geq 23$
	Severe	$24 \geq \text{FAQ total} \geq 30$

FAQ, Functional Activities Questionnaire; MMSE, Mini Mental State Examination; NPI-Q, Neuropsychiatric Inventory Questionnaire.

methodology would be computationally burdensome, and would be technically challenging to use when secondary data are the main type of data available.

As described previously, in Green and Zhang,[217] which was used to model disease progression, the severity of the condition was described using three severity domains: cognitive capacity, functional ability and behavioural symptoms. These three domains were measured using the Mini Mental State Examination (MMSE), the Functional Activities Questionnaire (FAQ) and the Neuropsychiatric Inventory Questionnaire (NPI-Q), respectively. These instruments are presented in *Table 72*.

The MMSE is a 30-question questionnaire, widely used in clinical settings to measure the global cognitive ability of an individual.[241] To measure the progression in behavioural symptoms, data collected using the NPI-Q were used. The NPI-Q is a self-administered questionnaire that identifies the presence and measures the severity of neuropsychiatric symptoms in patients with dementia and their informants.[242] Functional abilities were measured using the FAQ. The FAQ measures the activities of daily living and can accurately discriminate individuals according to their functional levels.[243]

The transition probabilities from each severity level to the other severity levels for each severity domain are reported in *Table 73*. These were derived from the transition matrix reported in Green and Zhang.[217] These probabilities are a simplified version of the Green and Zhang[217] disease progression model which estimates the probability of multidomain severity transitions over 1 year. Green and Zhang[217] defined a severity state as the combined severity in cognition, functional ability and behavioural symptoms, resulting in a 20-state disease progression model. For example, if an individual had mild cognitive decline, mild functional impairment and mild behavioural symptoms, then this individual is in state '1–1–1'. If an individual had the same characteristics but severe cognitive decline instead, then the individual would be in state '3–1–1', where '1' stands for mild, '2' for moderate and '3' for severe.

In contrast to Green and Zhang,[217] it was assumed in our model that progression within a severity domain was independent from the severity stage in other domains. Consequently, the 20-state model reported by Green and Zhang[217] was reduced to a three-state model for all domains. To estimate the probabilities of progressing to the next severity stage for each severity domain in our model, the number of patients in a specific severity level at the beginning of the study was multiplied by the sum of the transition probabilities to the next severity levels. This resulted in a 3 × 3 transition matrix for each severity domain. Finally, it was assumed that the probability of the next transition between severity levels does not depend on how much time had already elapsed. This means that the probability of progression to the next severity level was the same for someone who had spent 1 month at the current

TABLE 73 Transition probabilities between severity levels for each dementia severity domain

Dementia severity	Cognitive function	Functional ability	Behavioural symptoms
Mild to mild	0.96	0.9699	0.9359
Mild to moderate	0.0349	0.0233	0.0598
Mild to severe	0.0011	0.0068	0.0043
Moderate to mild	0.011	0.0386	0.0032
Moderate to moderate	0.9726	0.9421	0.9631
Moderate to severe	0.0164	0.0194	0.0336
Severe to mild	0	0	0
Severe to moderate	0.0067	0.0411	0.00702
Severe to severe	0.9933	0.96	0.9929

severity level as someone who had spent 12 months at that same level. As the model allowed transitions between severity levels on a monthly basis, annual probabilities of disease progression were transformed into monthly probabilities.

Transition probabilities between care settings

A predictive logistic model for the probability of making the transition from the home of the person with dementia to a care home for the UK setting estimated by Knapp *et al.*[218] was used. The precise coefficient values and the CIs were provided to us directly by personal communication with the authors (Professor Martin Knapp, London School of Economics and Political Science, London, 17 November 2017, personal communication; Kia–Chong Chua, King's College London, London, 17 November 2017, personal communication); these are reported in *Table 74* (reported to two decimal places only; more precise estimates can be found elsewhere). The results of this model were used to estimate the probability of a patient being admitted to a care home within a 6-month period.

TABLE 74 Logistic regression coefficients for transition from home to care home

Coefficients	OR	CI
MMSE	1.08	1.00 to 1.16
MMSE (squared)	1	0.99 to 0.99
Year (reference: 2006 or earlier)		
2007	1.00	0.69 to 1.46
2008	1.27	0.89 to 1.81
2009	1.08	0.75 to 1.55
2010 or later	1.00	0.71 to 1.41
Prior 12 months: general hospital inpatient care (reference: no history)	1.54	1.22 to 1.94
Prior 12 months: mental health inpatient care (reference: no history)	2.59	1.42 to 4.74
Age	1.04	1.02 to 1.06
Gender (0 = female, 1 = male)	1.11	0.86 to 1.44
Ethnicity (reference: white)		
Caribbean/African	0.57	0.38 to 0.86
East/South Asian	0.57	0.24 to 1.34
Mixed/unknown	0.30	0.12 to 0.74
Partner (reference: no partner)	0.60	0.45 to 0.80
Living alone (reference: not)	1.29	0.99 to 1.67
Living conditions (HoNOS11)		
Minor problems only	1.59	1.19 to 2.12
Significant problems	1.65	1.18 to 2.32
Activities of daily living (HoNOS10)		
Minor problems only	1.17	0.72 to 1.91
Significant problems	1.87	1.21 to 2.90

continued

TABLE 74 Logistic regression coefficients for transition from home to care home (*continued*)

Coefficients	OR	CI
Physical illness (HoNOS5)		
Minor problems only	1.10	0.81 to 1.51
Significant problems	1.23	0.91 to 1.68
Agitated (HoNOS1)		
Minor problems only	1.41	1.05 to 1.89
Significant problems	1.98	1.45 to 2.70
Depression (HoNOS7)		
Minor problems only	0.94	0.72 to 1.24
Significant problems	1.13	0.79 to 1.60
Relationship (HoNOS9)		
Minor problems only	1.10	0.82 to 1.48
Significant problems	1.22	0.88 to 1.69
Constant term	0.002	< 0.01 to < 0.01

HoNOS, Health of the Nation Outcome Scales; OR, odds ratio.

To transform the 6-month probabilities derived by the logistic regression to the monthly probabilities required in our model, it was assumed that the rate of moving from home to a care home is constant over the 6-month period. Therefore, for the monthly probability of moving to a care home, first, the rate (r) was calculated by:

$$r = -[\ln(1 - Pr)]/6. \tag{1}$$

This rate was used to derive the monthly probability (p):

$$p = 1 - e^{(-r*1)}. \tag{2}$$

The probability of a care home admission differed between patients according to a patient's characteristics (e.g. gender, ethnicity). Moreover, the probability of a patient being moved to a care home varied over time, as some of the patient's characteristics (e.g. age, severity) were updated in every cycle of the model. For patient characteristics, the average value of the covariates were assigned to each patient. The average monthly probability of moving from the home of the person with dementia to a care home was estimated to be 0.0137.

When additional effects on the probability of admission to a care home were available in the literature, we applied these on the probability estimated from the logistic regression model. For example, a hazard ratio of 1.12 (from Cepoiu-Martin *et al.*[244]) of having a different dementia subtype to Alzheimer's disease was applied to the logistic regression before the probability of moving from the home of the person with dementia to a care home was estimated. An assumption was made that the probability of moving from a care home to the person's own home was 0.0005 per month, as experts from the project team suggested that this event is rare.

As described in *Table 74*, disease severity in terms of cognitive capacity, functional ability and behavioural symptoms is expected to have an impact on the likelihood of moving between settings of care. In the logistic regressions used to estimate the likelihood of moving between settings of care (see *Table 74*), dementia severity in these three domains is captured by MMSE scores (for cognitive capacity), activities of daily living [Health of the Nation Outcome Scales (HoNOS 10)] (for functional ability), and agitation (HoNOS 1) and depression (HoNOs 7) (for behavioural symptoms). However, in our model, severity in these three domains is assumed to change over time, and this will have an impact on the probability of moving between settings of care. Because different instruments are used by Green and Zhang,[217] whose data we are using to model disease progression, and Knapp *et al.*,[218] whose data we are using to model transitions between settings of care, the severity levels used in Green and Zhang[217] were mapped onto severity levels in Knapp *et al.*,[218] as outlined below, for the three domains: cognitive decline, functional ability and behavioural symptoms.

Cognitive decline was measured in both studies using the MMSE instrument. Green and Zhang[217] classified patients in three discrete MMSE severity categories (*Table 75*). However, in the logistic regression models estimated by Knapp *et al.*,[218] the MMSE was analysed as a continuous measure. In our economic evaluation model, it was assumed that patients who had mild, moderate or severe cognitive decline were assigned a MMSE value of 24, 15 and 5, respectively.

Progression in functional ability was modelled in Green and Zhang[217] using the FAQ. This questionnaire measures instrumental activities of daily living (IADLs). Knapp *et al.*[218] use the 10th item from the HoNOS[245] to measure functional ability. The HoNOS describes problems with both basic activities of daily living and more complex activities implicitly (IADLs), and is categorised in three severity levels, as described in *Table 76*. In the logistic regression, reported by Knapp *et al.*,[218] functional ability was reported by three discrete categories: 'no problems', 'minor problems' and 'significant problems' (see *Table 76*). An assumption was made that the 'minor problems' category in the HoNOS reflects moderate severity of functional impairment, according to the FAQ, and that the 'significant problems' category in the HoNOS10 reflects severe impairment in function, according to the FAQ (see *Table 76*).

Behavioural symptoms in Green and Zhang[217] are captured by the NPI-Q, whereas, in the logistic regression by Knapp *et al.*,[218] behavioural symptoms are captured by HoNOS1 (agitation) and HoNOS7 (depression). In the logistic regression, Knapp *et al.*[218] categorise the HoNOS1 (agitation) and HoNOS7 (depression) in three discrete categories ('no problems', 'minor problems' and 'significant problems'), as shown in *Table 77*. The behavioural disturbance categories were mapped between Knapp *et al.*[218] and Green and Zhang,[217] as described in *Table 77*. In our model, if a patient is considered to have mild

TABLE 75 Mapping the cognitive decline severity between Green and Zhang[217] and Knapp *et al.*[218]

	MMSE score		
Cognitive decline (MMSE severity)	**Green and Zhang[217]**	**Knapp *et al.*[218]**	**Model**
Mild	21–26	21–30	24
Moderate	10–20	11–20	15
Severe	0–9	0–10	5

TABLE 76 Mapping functional ability between Green and Zhang[217] and Knapp *et al.*[218]

Green and Zhang[217]	**Knapp *et al.*[218]**
No problems, $0 \le FAQ \le 8$	Baseline, (HoNOS10) = 0
Moderate, $9 \le FAQ \le 23$	Minor problems, (HoNOS10) = 1
Severe, $24 \le FAQ \le 30$	Significant problems, (HoNOS10) = 2, 3 and 4

TABLE 77 Mapping behavioural disturbances

	Knapp *et al.*[218]	
Green and Zhang[217] (NPI-Q)	**HoNOS1 (agitation)**	**HoNOS7 (depression)**
No problem/mild NPI-Q: each item ≤ 1	Baseline, (Honos1) = 0	Baseline, (HoNOS7) = 0
Moderate NPI-Q: each item ≤ 2, with at least one item = 2	Minor problems, (HoNOS 1) = 1	Minor problems, (HoNOS7) = 1
Severe NPI-Q: at least one item = 3	Significant problems, (HoNOS 1) = 2, 3 and 4	Significant problems, (HoNOS7) = 2, 3 and 4

behavioural symptoms by the NPI-Q, then this would match to ‘no HoNOS1 agitation problems’ and ‘no HoNOS7 depression problems’. Moderate behavioural symptoms as measured by the NPI-Q would match to ‘minor HoNOS1 agitation problems’ and ‘minor HoNOS7 depression problems’ in the logistic regression used by Knapp *et al.*[218]

Hospitalisation

The predictive logistic model for the probability of hospitalisation was based on a UK population.[218] The precise coefficient values and the CIs were provided to us directly by personal communication with the authors (Professor Martin Knapp, London School of Economics and Political Science, London, 17 November 2017, personal communication; Kia–Chong Chua, King’s College London, London, 17 November 2017, personal communication), and are reported to two decimal places in *Table 78* (more precise estimates are reported elsewhere).[218]

TABLE 78 Logistic regression coefficients for hospitalisation by Knapp *et al.*[218]

	General hospital admission		Psychiatric hospital admission	
Coefficient	**OR**	**CI**	**OR**	**CI**
MMSE	0.93	0.88 to 0.97	0.94	0.86 to 1.02
MMSE (squared)	1.00	0.10 to 1.00	1.00	0.99 to 1.00
Year (reference: 2006 or earlier)				
2007	1.05	0.83 to 1.33	0.86	0.55 to 1.36
2008	1.33	1.07 to 1.67	0.90	0.58 to 1.39
2009	1.23	0.98 to 1.54	0.50	0.31 to 0.83
2010 or later	1.16	0.93 to 1.43	0.36	0.22 to 0.58
Prior 12 months: general hospital inpatient care (reference: no history)	2.21	1.92 to 2.55	2.40	1.75 to 3.29
Prior 12 months: mental health inpatient care (reference: no history)	0.83	0.48 to 1.42	7.73	4.47 to 13.35
Age	1.04	1.03 to 1.05	0.96	0.94 to 0.98
Gender (0 = female, 1 = male)	1.37	1.16 to 1.61	1.16	0.83 to 1.63
Ethnicity (reference: white)				
Caribbean/African	0.68	0.53 to 0.88	0.89	0.54 to 1.47
East/South Asian	0.43	0.25 to 0.79	1.21	0.53 to 2.75
Mixed/unknown	1.35	0.93 to 1.96	0.87	0.36 to 2.09

TABLE 78 Logistic regression coefficients for hospitalisation by Knapp *et al.*[218] (*continued*)

	General hospital admission		Psychiatric hospital admission	
Coefficient	**OR**	**CI**	**OR**	**CI**
Partner (reference: no partner)	0.77	0.65 to 0.93	1.63	1.11 to 2.39
Living alone (reference: not)	1.25	1.05 to 1.49	2.56	1.76 to 3.71
Living conditions (HoNOS11)				
Minor problems only	1.48	1.22 to 1.79	1.90	1.28 to 2.82
Significant problems	1.75	1.37 to 2.22	2.06	1.32 to 3.21
Activities of daily living (HoNOS10)				
Minor problems only	1.15	0.91 to 1.46	1.23	0.69 to 2.19
Significant problems	1.25	0.99 to 1.57	0.97	0.56 to 1.68
Physical illness (HoNOS5)				
Minor problems only	1.30	1.07 to 1.57	1.76	1.13 to 2.73
Significant problems	2.15	1.78 to 2.60	1.70	1.10 to 2.64
Agitated (HoNOS1)				
Minor problems only	1.11	0.92 to 1.35	1.86	1.23 to 2.82
Significant problems	1.50	1.21 to 1.88	3.56	2.36 to 5.45
Depression (HoNOS7)				
Minor problems only	0.96	0.81 to 1.14	0.92	0.63 to 1.34
Significant problems	1.49	1.18 to 1.88	2.04	1.35 to 3.09
Relationship (HoNOS9)				
Minor problems only	1.01	0.84 to 1.22	1.20	0.80 to 1.81
Significant problems	0.98	0.78 to 1.24	1.71	1.13 to 2.60
Constant term	0.01	< 0.01 to 0.03	0.42	0.07 to 2.67

A logistic regression of general inpatient hospitalisations and a logistic regression for mental care hospitals were available. To estimate the probability of any type of hospitalisation, we used a weighted average of the probabilities of these logistic regressions. The proportion of patients admitted to a mental care hospital and the proportion of patients admitted to a general care hospital in Knapp *et al.*[218] were applied as weights as:

$$P(admission) = \frac{1140 \times \text{P(general hospital)} + 195 \times \text{P(psychiatric hospital)}}{1335}. \tag{3}$$

An assumption was made that the probability of being hospitalised from home and from a care home is derived from the same predictive logistic model. This predictive regression model provided the probability of a patient being admitted to a care home within a 6-month period. To transform the 6-month probabilities derived by the logistic regression to monthly probabilities, the same approach described above for transition between home and care home was used. Logistic regressions of a general hospital admission from any care setting produced an average monthly probability of 0.0331 for general hospitals and 0.00121 for psychiatric hospital admissions.

Hospital length of stay

Length of stay in hospital was estimated by combining two different sources. A median of 11 days in hospital for patients with dementia has been reported in a previous study.[221] However, a non-parametric distribution of length of stay in hospitals was provided directly to us by personal communication with Sampson and colleagues (Professor Elizabeth Sampson and Dr Victoria Vickerstaff, University College London, London, 14 November 2017, personal communication). These data reported the length of stay of 805 patients with dementia admitted to an acute general hospital in London, for > 2 days. Because we wanted to capture all acute inpatient hospitalisations, the proportion of patients with dementia being admitted overnight, but for < 2 days, was used to update the probability distribution of length of stays. This was carried out by estimating the proportion of patients with dementia admitted for 1 day and those admitted for > 1 day. These figures were available in a report based on Hospital Episode Statistics for 2010–11.[225] According to this report,[225] 16.9% of inpatient non-elective hospitalisations were admitted to hospital for 1 day, whereas 88.1% of patients were admitted for > 1 day. The distribution of length of stay can be seen in *Figure 16*.

In contrast to settings-of-care states, the 'hospital state' in the model varied according to the length of time individuals spend in hospital. A length of stay for each patient who was hospitalised was sampled from the distribution reported in *Figure 16*. Progression in age and disease severity in the 'hospital state' were automatically adjusted in the model to account for different length of stay.

To transform the monthly probabilities of progressing to a different severity level for cognition to probabilities considering a different duration of hospitalisation, it was assumed that the rate of progressing to a different severity level was constant over time. Therefore, to estimate the probability of progressing to a different severity level for different length of stay, the rate was calculated by:

$$r = -[\ln(1 - Pr)]/1. \tag{4}$$

This rate was used to derive the probability that is conditional on different lengths of stay in the model:

$$p = 1 - e^{(-r \times LoS/30)}, \tag{5}$$

where 'LoS' is length of stay.

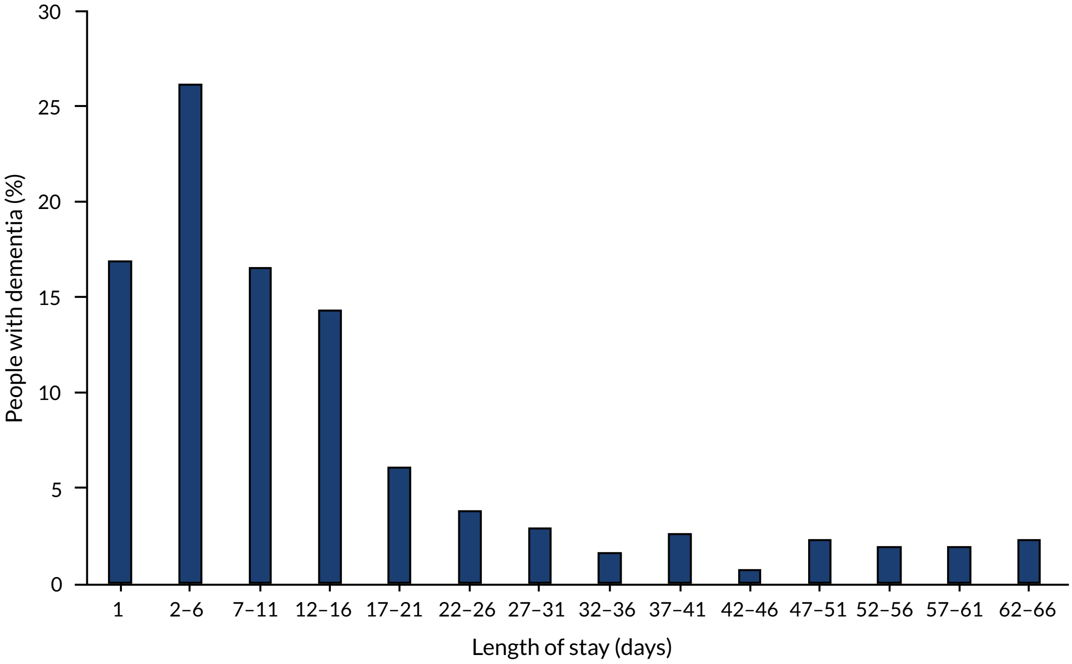


FIGURE 16 Distribution of days in hospital for non-elective hospitalisations of people with dementia (length of stay for unplanned admissions of > 1 day).

Probability of discharge from hospital

A probability of discharge to the previous place of care was assigned to patients who were admitted to hospital. Two predictive logistic models for the probability of discharge to a care home from hospital for patients admitted from home for the England/Wales setting were used (*Table 79*).[219] The precise coefficient values and the CIs were provided to us directly by the author (Dr Panos Kasteridis and Mrs Anne Mason, University of York, York, 14 November 2017, personal communication). However, only two decimal places for the estimates are reported in *Table 79*. The more precise values can be found elsewhere.[218] These models differed by their populations: patients with a primary diagnosis of dementia and patients with dementia with a primary diagnosis of ambulatory care sensitive condition.[220] Using a weighted average, for patients admitted from home, the probability of being discharged to a care home was, on average, 0.149. It was then assumed that the rest of the patients returned home or died during the index admission.

TABLE 79 Predictive logistic model for the probability of being discharged to a care home when admitted from home, by Kasteridis *et al.*[219]

	Admissions for dementia		Admissions for ambulatory care sensitive condition	
Explanatory variable	**OR**	**CI**	**OR**	**CI**
QOF dementia score (%)	1.0	0.998 to 1.00	0.99	0.99 to 1
Age	1.0	1.02 to 1.03	1.03	1.02 to 1.03
Male	0.86	0.80 to 0.91	0.88	0.84 to 0.91
White ethnicity	0.99	0.91 to 1.09	1.09	1.04 to 1.15
Alzheimer's disease	1.19	1.11 to 1.28	1.04	0.99 to 1.09
Vascular dementia	1.19	1.11 to 1.28	1.10	1.05 to 1.15
Urinary incontinence	1.24	1.07 to 1.44	1.23	1.13 to 1.34
Faecal incontinence	1.28	1.05 to 1.56	1.32	1.19 to 1.48
Fall (excludes hip fracture cases)	1.16	1.05 to 1.30	1.20	1.13 to 1.27
Hip fracture (excludes falls)	1.48	1.00 to 2.17	1.44	1.28 to 1.63
Cancer	1.38	1.15 to 1.65	1.05	0.96 to 1.15
Myocardial infarction	0.99	0.76 to 1.27	1.11	0.99 to 1.23
Peripheral vascular disease	0.85	0.68 to 1.06	0.87	0.79 to 0.95
Cerebrovascular disease	1.10	1.01 to 1.20	1.25	1.19 to 1.32
Delirium	1.04	0.91 to 1.19	1.22	1.04 to 1.42
Senility	1.30	1.17 to 1.45	1.20	1.13 to 1.28
Total diagnoses (count)	1.13	1.11 to 1.14	1.11	1.10 to 1.11
ACSC: acute (reference)				
ACSC: chronic d			0.71	0.68 to 0.74
ACSC: vaccine			1.09	1.04 to 1.14
Carer 1: % of LSOA population providing 1–19 hours per week of unpaid care	1.04	1.01 to 1.06	1.02	1.00 to 1.03
Carer 2: % of LSOA population providing 20–49 hours per week of unpaid care	0.92	0.84 to 1.00	0.96	0.91 to 1.00
Carer 3: % of LSOA population providing ≥ 50 hours per week of unpaid care	0.93	0.89 to 0.98	0.90	0.88 to 0.93

continued

TABLE 79 Predictive logistic model for the probability of being discharged to a care home when admitted from home, by Kasteridis *et al.*[219] (*continued*)

	Admissions for dementia		Admissions for ambulatory care sensitive condition	
Explanatory variable	**OR**	**CI**	**OR**	**CI**
Living alone: % of LSOA population aged ≥ 60 years living alone	0.99	0.99 to 1.00	0.99	0.99 to 0.99
Deprivation 1: % of LSOA population aged ≥ 60 years claiming guarantee credit	0.99	0.98 to 0.99	0.99	0.99 to 0.99
Deprivation 2: % of LSOA population aged ≥ 60 years claiming savings credit	1.02	1.00 to 1.04	1.02	1.00 to 1.03
Deprivation 3: % of LSOA population aged ≥ 60 years claiming both types of pension credit	1.02	1.01 to 1.03	1.03	1.02 to 1.03
Care home beds: beds per 100 population aged ≥ 60 years within 10 km of LSOA centroid	1.01	0.99 to 1.04	1	0.98 to 1.02
Urban residential area (population of > 10,000)	1.06	0.97 to 1.16	1.10	1.04 to 1.16
Year = 2006/7			1	0.90 to 1.01
Year = 2007/8	0.95	0.86 to 1.05	0.95	
Year = 2008/9	0.93	0.84 to 1.03	0.91	0.86 to 0.96
Year = 2009/10	0.85	0.78 to 0.94	0.73	0.69 to 0.77
Year = 2010/11	0.67	0.61 to 0.74	0.61	0.58 to 0.65
Constant	< 0.01	< 0.01 to < 0.01	< 0.01	< 0.01 to < 0.01

ACSC, ambulatory care sensitive condition; LSOA, lower super output area; QOF, Quality and Outcomes Framework.

The probability of returning to home if a patient was admitted from home is a joint probability, calculated as:

$$P = P(alive) \times (1 - 0.149). \quad (6)$$

For patients admitted from a care home, an assumption was made that only 0.5% are discharged to their home.

Mortality and palliative care

Estimates of mortality rates, conditional on age and gender, for people with dementia were obtained from a study based on the MRC CFAS multicentre longitudinal prospective study in the UK.[41] These are reported in *Table 80*. Because the risk of mortality is not conditional on stage of dementia, the mortality risk may be overestimated at the earlier stages of dementia and underestimated at the later stages of dementia. Based on the mean time to death, we fitted exponential distributions to derive the monthly probability of death for each age group and gender.

According to the World Health Organization, palliative care is a care approach that focuses on improving the QoL of patients with a life-threatening disease such as dementia, by preventing and relieving suffering by assessing timely care, assessing and treating pain and other psychosocial and spiritual problems.[28] Although an individual is expected to receive well-co-ordinated, high-quality care,[246] there is no clear time point at which palliative care should replace curative treatment.[247]

TABLE 80 Monthly probability of mortality by age and gender, and probability of entering palliative care register

			Probability of entering the register			
	Mortality		**Control**		**SEED**	
Age group (years)	**Women**	**Men**	**Women**	**Men**	**Women**	**Men**
65–69	0.00716	0.00488	0.0075	0.0051	0.0082	0.0053
70–79	0.0096	0.01070	0.0103	0.0115	0.0116	0.0131
80–89	0.01202	0.01369	0.0131	0.0151	0.0152	0.0179
≥ 90	0.01468	0.01682	0.0161	0.0191	0.0197	0.0237

This should vary from patient to patient, but it is important to identify people nearing the EOL to ensure that they are entered in a register to facilitate better planning and care co-ordination.[246] According to the GSF, individuals are approaching the EOL when they are likely to die in the next 12 months.[248] To be in line with the GSF criteria for providing EOLC, it was assumed that a person with dementia would receive dementia-related palliative care only once they had a level of dementia severity defined by severe cognitive decline.

No good evidence on time to palliative care or the probability of receiving palliative care was identified. The probability of receiving palliative care in current practice was derived using simulation methods by subtracting the time spent on the palliative care register from the time to death for age and gender categories. The distribution of time spent on the palliative care register was provided by Zheng *et al.*,[222] who reported the proportion of patients with dementia and frailty who are placed in the palliative care register before their death. The median time on the palliative care register for older people with dementia and frailty was reported to be 2.42 weeks (interquartile range 0.43–13.14 weeks).

According to Zheng *et al.*,[222] 20% (32/160) of those diagnosed with frailty and dementia spent some time on the palliative care register. In our model, we assumed that individuals would be at a different risk of dying according to whether or not they are entering palliative care. The 20% of patients who were expected to spend some time in palliative care were assigned the general age- and gender-specific mortality risk until they had the dementia severity level of severe cognition. From that point, they were assigned a probability of entering palliative care. Once they were receiving palliative care, they were assigned a time to death from the distribution of time spent on the palliative care register before death. The 80% of people who never spent any time in palliative care were assumed to have a mortality risk associated with their age and gender based on data from Xie *et al.*[41] The probabilities of entering the palliative care register in each cycle for the control arm and the SEED intervention arm are provided in *Table 80*.

In-hospital mortality

The probability of dying in the hospital was taken from a study by Sampson *et al.*;[221] it was 18.1% for patients with dementia. When patients with dementia were in the 'hospital state', they were subject to dying with a probability of 0.18, rather than a probability presented in *Table 80*. This may lead to an overestimation of mortality in the early stages of dementia.

Baseline population

When entering the model, each patient was assigned multiple characteristics that would influence disease progression, the transition between settings of care and the time to death. The population characteristics that are used as covariates in the predictive logistic models to estimate the likelihood of changing setting of care are reported in *Tables 81* and *82*. These patient characteristics are also used to estimate the time to death of each individual entering the model.

TABLE 81 General patient characteristics 1

Characteristic	Probability or %	
Age (years)	*Female*	*Male*
65–69	8.7	10.7
70–74	11.2	16.3
75–79	20.1	21.4
80–84	27.8	28.7
≥ 85	32.2	22.9
Cognitive capacity severity (%)	*Incident cohort*	*Prevalent cohort*
Mild	80	58.8
Moderate	15	36.8
Severe	5	4.4
Functional ability severity (%)	*Incident cohort*	*Prevalent cohort*
Mild	75	57.9
Moderate	20	31.3
Severe	5	10.8
Behavioural symptoms severity (%)	*Incident cohort*	*Prevalent cohort*
Mild	65	22.7
Moderate	25	54.8
Severe	10	22.5

TABLE 82 General patient characteristics 2

Characteristic	%
Dementia subtype	
Alzheimer’s disease	62
Vascular	17
Mixed	10
Lewy bodies	4
Frontotemporal	2
Parkinson’s disease	2
Other	3
Ethnicity	
White	83
Caribbean/African	10
East/South Asian	3
Mixed/unknown	4

The proportion of incident cases of people with dementia belonging to different age groups was derived from Matthews *et al.*[8] This study provided separate estimates by gender. Information on the severity of patients at the time of diagnosis was also sought. However, evidence was not available to inform the baseline severity of all three severity domains (cognitive decline, functional ability and behavioural symptoms) for patients at the point of diagnosis. The baseline severity of a prevalent cohort for the three different severity domains was derived by Green and Zhang.[217] To reflect a milder severity profile of patients at the point of diagnosis, an assumption was made that almost half of the patients in the severe and moderate stages in each severity domain would be in the mild stage at the point of diagnosis. Information on dementia subtype and the ethnicity of people with dementia was derived from the 2014 dementia report by the Alzheimer's Society[2] and Knapp *et al.*,[218] respectively.

Additional patient characteristics were also assigned to patients in the model. These characteristics were required to inform the covariates in the logistic regression used to estimate transitions between settings of care. The characteristics of patients required to estimate the probability of moving to a care home, and being admitted to hospital, are reported in *Table 83*.[218] To estimate the probability of being discharged back to home after a hospitalisation, patient characteristics from Kasteridis *et al.*[219] were used to inform the covariates in the logistic regression for discharge back home. These patient characteristics, reported in *Table 84*, were the weighted average of the four groups of patients described in the study.[219]

TABLE 83 Patient characteristics used in logistic regressions by Knapp *et al.*[218]

Patient characteristic	Percentage of individuals (%)
Partner	36
Living alone	74
Living conditions	
Minor problems only	15
Significant problems	10
Activities of daily living	
Minor problems only	25
Significant problems	52
Physical illness	
Minor problems only	30
Significant problems	37
Agitated	
Minor problems only	19
Significant problems	15
Depression	
Minor problems only	26
Significant problems	11
Relationship	
Minor problems only	20
Significant problems	15

TABLE 84 Patient characteristics used in logistic regression by Kasteridis *et al.*[219]

Patient characteristic	Percentage of individuals (%)
QOF dementia score	73.6
Urinary incontinence	5
Faecal incontinence	3.1
Fall	7.6
Hip fracture	1.1
Cancer	3
Myocardial infarction	2.1
Peripheral vascular disease	3
Cerebrovascular disease	10.6
Delirium	1
Senility	7.4
Total diagnoses (count)	6.3
ACSC: acute	0.566
ACSC: chronic disease related	0.279
ACSC: vaccine	0.156
Enabling factors	
Carer 1: % of LSOA population providing 1–19 hours per week of unpaid care	6.97
Carer 2: % of LSOA population providing 20–49 hours per week of unpaid care	1.12
Carer 3: % of LSOA population providing ≥ 50 hours per week of unpaid care	2.1
Living alone: % of LSOA population aged ≥ 60 years living alone	7.1
Deprivation 1: % of LSOA population aged ≥ 60 years claiming guarantee credit	10.1
Deprivation 2: % of LSOA population aged ≥ 60 years claiming savings credit	5.5
Deprivation 3: % of LSOA population aged ≥ 60 years claiming both types of pension credit	11.9
Care home beds: beds per 100 population aged ≥ 60 years within 10 km of LSOA centroid	84
Urban residential area (population of > 10,000)	84.3
Year = 2006/7	0
Year = 2007/8	0
Year = 2008/9	0
Year = 2009/10	0
Year = 2010/11	1

ACSC, ambulatory care sensitive condition; LSOA, lower super output area; QOF, Quality and Outcomes Framework.

Care services and their effects

The first set of analyses compare the SEED intervention with current practice. Current practice comparator describes the pattern of dementia care services provided at the time of writing. These are described by recently published dementia care guidance.[249] This supersedes earlier guidance,[32] the implementation of which was suboptimal.[158] The expected effect of SEED intervention on service outputs and outcomes in many cases is an increase in the prevalence of care services described as good practice by the dementia care guidance.[158]

The model parameters associated with the prevalence of services in the current practice, and the effects described in *Figure 15*, were too many to allow the use of systematic review methodology to identify evidence to inform them. Therefore, ranges of plausible values for model-effect parameters were specified so that we could estimate a possible range of outcomes associated with the SEED intervention. This involved defining maximum and minimum values for model parameters, with uniform distributions used to characterise the uncertainty in the value of these parameters. The potential minimum and maximum values of these parameters were informed by relevant data identified from focused literature searches for individual activities and service outputs. When evidence was not available, assumptions were made on the possible values that these parameters could be. Uncertainty in parameters associated with the prevalence of services are described in *Table 85*. (See *Table 86* for the uncertainty in parameters' associated effects.)

The values presented in *Table 85* show the proportion of patients receiving a particular service. For instance, in current practice, 13–39% of patients are expected to be offered the opportunity for ACP discussions regarding their preferences on hospitalisations, place of care, and death. The equivalent value in the presence of the SEED intervention is expected to be between 46% and 100%. Some of these care services were conditional on other aspects of care; for example, Emergency Healthcare Plans were available only to people who were in the palliative care register. For instance, 70–90% of the people in the control group in the model would be eligible to have an Emergency Healthcare Plan once they entered palliative care register. The equivalent proportion of patients eligible for an emergency health-care plan once on the palliative care register for the SEED arm was 80–100%.

TABLE 85 Assumptions on the prevalence and frequency of service components in current practice and with the SEED intervention

Prevalence and frequency of service components	Current practice	SEED intervention
Prevalence of ACP discussions: hospitalisation, preferred place of care and death, and EOL	13%[250] to 39%[250]	46%[250] to 100%
Prevalence of ACP discussions: resuscitation, tube-feeding, lasting power of attorney	13%[250] to 39%[250]	46% to 100%
Prevalence of liaison between services: before admission (SBAR) per admission	10% to 40%	60% to 100%
Prevalence of liaison between services: during admission (transfer sheets) per admission	10% to 40%	60% to 100%
Prevalence of liaison between services: after admission (discharge planning) per discharge	10% to 40%	60% to 100%
Likelihood of documenting an ACP discussion	70% to 90%	80% to 100%
Likelihood of having an EHCP in place if a patient enters the palliative care register	70% to 90%	80% to 100%
Likelihood of concordance between treatment and advance care plans	50% to 82%[251]	100%
Prevalence of bereavement services offered to carers if SEED intervention is present	30% to 60%	60% to 100%
Number of clinical reviews per year to identify need for palliative care	1 review	2–6 reviews
Proportion of patients entering palliative care register	0.2 (IQR 0.5–13)[222]	1
Duration on palliative care register	2.4 weeks[222]	1 year

EHCP, Emergency Healthcare Plan; IQR, interquartile range.
Note
Most values are assumptions.

It was assumed that people in current practice have one clinical review by a GP per year, whereas, in the SEED intervention, this would vary from two to six reviews annually. In addition, in current practice, 20% of patients enter the palliative care register before they die, whereas, with the SEED intervention, it was assumed that all people having severe dementia would enter the palliative care register. The time spent on the palliative care register in current practice is considered to be 2.4 weeks,[222] whereas it was assumed that, with SEED intervention, people should be entered in the palliative care register 1 year before death.

For the parameters reported in *Table 85*, when sources were listed, these same sources informed the choice of the minimum and maximum values of these parameters.

Table 86 presents the assumptions around the effects of the service outputs on patient-related outcomes. These effects, presented as relative risks, were applied to the probabilities of the associated patient outcomes. For instance, improved liaison between hospitals and care services through the provision of transfer sheets was expected to reduce the length of stay of a person with dementia by 8%. Similarly, being on the palliative care register was assumed to increase the likelihood of being discharged to the previous place of care by 5% to 10%.

In the model, we sought to capture the main impact of the SEED intervention on the care service outputs, and on the outcomes for people with dementia (see *Figure 15*). The process of exploring how the introduction of the SEED intervention might influence the use of other services was an iterative process in which the SEED project team was involved. The SEED project team was presented with all the possible interactions between the SEED intervention's activities, service outputs and patient outcomes. These were presented in a form of an interaction table. The team members were then asked which service outputs would be influenced by each of the SEED intervention's main activities. The service outputs and effects were then reduced according to (1) the magnitude of the impact on costs and patient outcomes, and (2) when a service output was indicated as affecting final outcomes directly and indirectly via another care service, only the indirect links were retained, as described in *Figure 17*.

Following this methodology, in a stepwise approach, the influence diagram in *Figure 15* was developed jointly with the SEED project team. The diagram illustrates the SEED intervention activities, service outputs, where a priori there would be a clear direct effect on costs and patient-related outcomes. An example of how the model works is as follows: the SEED intervention is expected to improve the

TABLE 86 Assumptions on the effects of service components on clinical and care preference outcomes

Effects of service components and other effects	Possible range of relative risks (RR)
Relative effect of transfer sheets on length of hospital stay	0.92[229]
Relative effect of liaison between services before an admission (SBAR) on the likelihood of a hospital admission	0.85 to 0.95
Relative effect of an advance care plan regarding preferences on place of care and hospitalisation on the likelihood of a hospital admission if an advance care plan is documented	0.85 to 0.95
Relative effect of EHCP on likelihood of a hospital admission during palliative care stage	0.85 to 0.95
Relative maximum effect of liaison between services after admission (discharge planning) on the likelihood of a re-admission in the next 3 months	0.46 to 0.79[229]
Relative effect of being on the palliative care register on the likelihood of being discharged to the previous place of care (home)	1.05 to 1.10
Relative effect of an ACP document on the preferred place of care and death and hospital admission on the likelihood of being discharged to the previous place of care (home)	1.05 to 1.10

EHCP, Emergency Healthcare Plan.

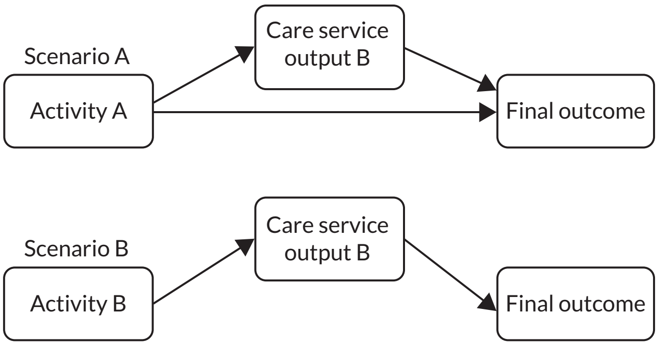


FIGURE 17 Indirect and direct effects. Scenario B was retained; scenario A was not retained.

liaison between services' activity through increased use of the SBAR technique. The liaison between services affects the avoidance of unnecessary hospitalisations outcome. The effect of SEED is accounted for in the model by assuming that the effective use of the SBAR technique is increased through training, and that the increased use of the SBAR technique increases the avoidance of unnecessary hospitalisations. There is a cost attached to the SEED intervention and the use of the SBAR technique, and there is an impact on cost associated with avoiding hospitalisation.

Cost of the SEED intervention

Cost parameters in the model included costs associated with the SEED intervention, SEED intervention-related activities, service outputs, care-setting costs and hospitalisation. The SEED intervention is expected to occur an additional £20.40 for each patient per month. The intervention is designed to consist of nurse specialists trained in dementia care with a team consisting of two band 3 nurses, one band 5 nurse and one band 7 nurse working full time on training staff and operating care activities that improve the care service outputs and patient-related outcomes. This team will be led and supervised by the band-7 nurse, with additional supervision provided by an old-age psychiatrist who is expected to spend 2 hours per month on the SEED intervention. The band 7 nurse is expected to also supervise the rest of the team. This team is expected cover, on average, four registered practices. We have assumed that, on average, the estimated 773,502 patients with dementia[2] in the UK will be distributed evenly between the 7271 registered practices. Therefore, a SEED intervention team is expected to cover, on average, 106 patients per practice, or 424 dementia patients in total (*Table 87*).

People with dementia: care-setting costs

These costs included costs for home care, care home care and hospitalisation. The cost of care at home or in a care home varied according dementia severity (mild, moderate or severe).[2] The instrument used in this study to categorise the severity of dementia was the Cambridge Mental Disorders of the Elderly

TABLE 87 Cost breakdown of the SEED intervention

Cost of SEED intervention (per patient per month)	Resource use per four practices	Unit cost (£)	Total monthly cost (£)
Band 3 nurses	Two nurses full time	18,333 per annum	7.20
Band 5 nurse	One nurse full time	26,038 per annum	5.10
Band 7 nurse	One nurse full time	38,801 per annum	7.60
Old-age psychiatrist	2 hours per month	108 per hour	0.50
773,502 dementia patients aged > 65 years,[2] distributed equally over 7271 practices[252] (424 patients per four practices)			20.40

Examination (CAMDEX),[253] which, according to a review of assessment scales in dementia,[254] performs well against the MMSE used in the present analysis. Therefore, these costs were linked in the model to the cognitive capacity severity domain (MMSE) of each individual (*Table 88*).

The costs of home and care home services that are presented in *Table 88* and include costs associated with health care, social care, unpaid care, and other costs. This is presented in *Box 12*.

The breakdown of costs for community care at home and at a care home were taken from the 2014 Alzheimer's Society report.[2] These included costs associated with health care, social care, unpaid care and other costs. To account for hospital admissions and to avoid double counting, a table from this report was used to estimate the proportion of health-care costs that are attributed to hospitalisations. We estimated that 32.8–80.1% of the health-care costs are due to hospitalisations. Therefore, we estimated the minimum and maximum societal costs associated with being cared for at home and in a care home, as shown in *Table 89*. Then the average of these costs, reported in *Table 88*, were used in the model. It is worth noticing that the total cost at home are driven by the unpaid care costs.

Adjustments were made to avoid double counting the costs of hospitalisations from the summary estimates of state costs in *Table 88*. A distribution of costs of care between services was provided by the 2014 Alzheimer's Society report.[2] Information on the proportion of costs associated with hospital

TABLE 88 Monthly costs of home care and care home care

	Care cost (£)		
Dementia severity	**Home**	**Care home**	**Hospital**
Mild	2183	2615	282
Moderate	3829	3168	
Severe	4818	3067	

BOX 12 Services captured in the summary cost estimates according to the 2014 Alzheimer's Society report[2]

Inpatient hospitalisations and outpatient attendances

- Day hospital treatment.
- Social club visits.
- Day-care visits.
- Time spent with community-based professionals.
- Community psychologists.
- Community psychiatrists.
- GPs.

Community psychiatrists

- Practice nurses.
- District nurses.
- Social workers.
- Occupational therapist.
- Home care workers.
- Physiotherapists.

TABLE 89 Monthly costs breakdown for patients living in the community and in care homes[2]

	Cost (£)				Societal cost minus hospital cost (£)	
Dementia severity	**Health care**	**Social care**	**Unpaid care**	**Other**	**Minimum**	**Maximum**
People with dementia living in the community (average cost)						
Mild	248	282	1780	12	2124	2241
Moderate	243	702	2911	12	3789	3869
Severe	1017	932	3024	12	4651	4985
People with dementia living in residential care homes (average cost)						
Mild	407	2234	96	12	2423	2616
Moderate	852	2322	262	12	2765	3169
Severe	785	2337	191	12	2696	3067

services out of total health-care costs was available from this distribution. It was estimated that, on average, 57% of the health-care costs were attributed to hospital services. Therefore, the health-care costs for each severity and setting of care were reduced by 57% to exclude the cost of hospital services from the state costs.

Finally, the costs reported in the study[2] were reported in 2012/13 prices. To estimate the value of these costs in 2017, an inflation index of 0.020198 was used from the Bank of England.[255] The final costs were therefore increased by z, where:

$$z = (2017\ \text{cost} - 2012\ \text{cost}) \times 0.020918. \tag{7}$$

Care service costs

In addition to the state costs, the model accounts for costs associated with the care services reported. The resource use estimates were obtained by expert opinion from the project team. The unit costs associated with formal care were obtained from Curtis and Burns,[223] and those associated with informal care were informed by the Department for Business, Energy and Industrial Strategy.[224] The costs of SEED intervention activities and service outputs are reported in *Table 90*.

Despite the adjustments made to avoid double counting, costs associated with the care settings may be slightly overestimated as it is possible that low-cost activities, such as the use of transfer sheets, may be captured in the care-setting costs. To further avoid double counting, the expected prevalence of a care activity and resource output on a monthly basis was multiplied by its cost and was subtracted by the costs associated with the setting of care.

Cost of hospitalisation

To estimate the cost of hospitalisation, the most common reasons for hospitalisation for people with dementia were first identified. According to Curtis and Burns,[223,225] these were hip fracture, kidney or urinary tract infections, pneumonia and stroke. The cost of an episode was identified from *NHS Reference Costs 2015–16*[226] using the weighted average of relevant HRG codes. *Table 91* shows the data from the NHS reference costs used to estimate the daily cost of a hospitalisation. To estimate the value of each cost in 2017 prices, an inflation index of 0.017 was used from the Bank of England.[255]

The daily cost of a patient with a hip fracture or injury was, on average, £291. For urinary tract infections, pneumonia and stroke, the daily costs were £257, £263 and £295, respectively. The weighted average according to the activity of these estimates was used to derive the pooled average daily cost in hospital of £282 per day.

TABLE 90 Cost assumptions and calculations for SEED-related health and care service

Service delivery factors	Resource use	Unit cost (£)	Total cost (£)
Cost of regular clinical reviews for EOLC (per review)	30 minutes of GP time	4 per minute	120
Cost of ACP discussions (per year)	30–60 minutes GP time	4 per minute	146.67–393.34
	30–60 minutes of nurse time	42 per hour	
	30–60 minutes of carer time	11.34 per hour	
Documentation of ACP discussions	30 minutes of nurse time per year	42 per hour	21
Liaison between services before admission (SBAR)	10 minutes of care home staff time per admission	59 per hour	9.83
Liaison between services during admission (transfer sheets)	15 minutes of care home staff time per admission	59 per hour	14.75
Recognised need for palliative care (inclusion in the palliative care register)	Direction of the cost unknown. The extra cost associated with palliative care drugs is considered insignificant compared with the scale of the rest of the costs		
EHCP documented and disseminated (per EHCP)	30 minutes of GP time per plan	4 per minute	120
Bereavement services offered (per service)	30 minutes of home care manager time	39 per hour	19.5
Avoided hospital admission (per admission avoided)	Supervision: 10 minutes per hour for 5 days of district nurse (band 6)	44 per hour	1212
	2 visits of 30 minutes of GP time	4 per hour	
	2 hours of Macmillan nurse time (band 7)	53 per hour	
	2 hours of Admiral nurse time (band 7)	53 per hour	

EHCP, Emergency Healthcare Plan.

TABLE 91 Healthcare Resource Group (HRG) codes used to estimate cost of index hospitalisation for patients with dementia

Healthcare Resource Group code	Code description
HD39	Pathological fractures
HE11	Hip fracture with multiple interventions
HE12	Other injury of hip with interventions
HT12	Very major hip procedures for trauma
HT13	Major hip procedures for trauma
HT14	Intermediate hip procedures for trauma
HT15Z	Minor hip procedures for trauma
HT81	Complex hip or knee procedures for trauma, with CC score
LA04	Kidney or urinary tract infections, with interventions and without interventions
DZ22	Unspecified acute lower respiratory infection, with and without interventions
DZ23	Bronchopneumonia without, with single and with multiple interventions
AA22	Cerebrovascular accident, nervous system infections or encephalopathy
AA23	Haemorrhagic cerebrovascular disorders
AA29	Transient ischaemic attack
AA35	Stroke
WD11Z	All patients aged ≥ 70 years with a mental health primary diagnosis, treated by a non-specialist mental health service provider

CC, complexity and comorbidity.

Analyses

Two sets of comparisons were made:

1. A DNS who facilitates the provision of services aimed at improving the quality of care of a person with dementia and their carers (i.e. the SEED intervention) compared with current practice.
2. Comparison of the different care scenarios valued in the contingent valuation study.

Comparison 1

For this comparison, a cost–consequences analysis was conducted.[145]

The comparator: a DNS who facilitates the provision of services aimed at improving the QoL of a person with dementia and their carer(s) is hereafter called the SEED intervention for brevity. The potential cost–consequences of the SEED intervention were evaluated by conducting two scenario analyses: (1) the 'favourable analysis' utilising the maximum parameter estimates for SEED intervention and the minimum for the control, and (2) the 'conservative analysis' utilising the minimum parameter estimates for SEED intervention and the maximum for the control.

The cost–consequences of individual care service outputs of the SEED intervention were also included in the analysis. The individual service outputs considered were as follows:

- regular clinical reviews
- ACP discussions and documentation
- liaison between services before admission (proxy: use of the SBAR technique)
- liaison between services during admission (proxy: use of transfer sheets)
- liaison between services after admission (proxy: discharge planning).

For each of these service outputs, the analysis considered two alternative situations: one for which there was the maximum expected provision of the care service and one for which there was the minimum expected provision of the care service. When the effect of one of these care services was explored, the other services were assumed to have a level of provision in between the maximum and minimum values. It was assumed that it was equally probable that the level of provision of these services could take any value between (and including) the maximum and minimum value (i.e. the level of provision for these services was sampled from uniform distributions, with an upper and lower value given by the maximum and minimum value).

In addition, the 2018 NICE guidance for care services[158] for dementia was reviewed to identify which care services included in the model were recommended in the guidance. All the SEED intervention care activities, and service outputs, appeared to feature in the NICE guidance (*Table 92*); consequently, no further analysis was conducted to evaluate the cost–consequences of the NICE guidance recommendations, as this analysis is reflected in the scenario of maximum provision of the care services under evaluation.

Comparison 2

An analysis was conducted for each of the five scenarios valued in the contingent valuation study (see *Boxes 7–11*) and a control scenario where none of the services included in the contingent valuation scenarios are provided. These scenarios are referred to as control, scenario 1, scenario 2, scenario 3, scenario 4 and main scenario.

Analysis methods

A patient-level simulation was conducted in R statistical software.[227] Discrete-event simulations can be more computationally efficient, but some of the transition probabilities utilised in the model are based on logistic regressions with covariates that change over time. Despite the computationally intense approach, discrete time periods were retained. This allowed us to keep track of previous events that occurred in the model that would affect the likelihood of future events occurring. For instance, prior hospitalisations are a predictor of a future hospital admission, according to predictive logistic models.[218]

TABLE 92 The SEED services recommended in the 2018 NICE guidance[249]

SEED service/outcomes	NICE guidance[249] corresponding section
Facilitator and team of DNSs	1.3 Care co-ordination
	1.13 Staff training and education
Regular reviews	1.3 Care co-ordination
ACP discussions and documentation	1.1 Involving people living with dementia in decisions about their care
Liaison between services to avoid hospital admission: SBAR	1.9 Risks during hospital admission
Liaison between services: transfer sheets	1.3 Care co-ordination
	1.12 Moving to different care settings
Liaison between services: discharge planning	1.12 Moving to different care settings
Emergency Healthcare Plan completed	1.10 Palliative care
Bereavement support	1.10 Palliative care

In this model, hypothetical cohorts of people with dementia were considered. Each individual in this hypothetical cohort was defined in terms of a unique set of characteristics at the time of diagnosis, when they entered the model. Some of these characteristics changed over the course of the model, for example the age of the individual, whereas others were fixed, such as gender. These patient characteristics, among others that were assumed to be constant over time, were used as inputs in logistic regressions to derive the likelihood that a patient moves between settings of care.

Each cohort consisted of 380 people with dementia and a total of 800 cohorts were run through the model with different sampled values of parameter distributions representing uncertainty in the mean estimate. The simulation sample size is small for a patient-level simulation,[256] but was adopted as this is an early economic model that aims to provide guidance on relative efficiency, rather than obtain precise estimates. To improve comparability between the analyses of the different service packages and the assumptions, the same random number seed was used in each analysis. The model was run for 120 cycles; each cycle was 1 month long. At the end of 120 cycles, it was estimated that 95% of the simulated patients would have died. Costs and benefits were discounted at an annual rate of 3.5% according to NICE guidelines.[154]

Analysis for comparison 1, the analyses of the SEED dementia services

A patient-level simulation was conducted in R statistical software using the RStudio interface.[227] A cohort of people with dementia had different characteristics at diagnosis. These characteristics were sampled from distribution characteristics for patients with dementia. The characteristics that were allowed to change over time in the model were age, cognitive function, functional ability and behavioural symptoms.

The patient characteristics were characteristics that changed over the course of the model plus the gender of the person with dementia. For each modelled patient, the other patient characteristics included in logistic regressions in the model were assigned the average value reported in the source publication. One cohort consisted of 380 people with dementia; 800 cohorts of this size were run through the model with different sampled values of parameter distributions representing uncertainty in the mean estimate. A probabilistic analysis accounted for any non-linearity in the model design.

The simulation sample size adopted in our analysis is small for a patient-level simulation. This was done to minimise computation time, and, as this is an early economic model, the model is not estimating precise cost-effectiveness estimates. To improve comparability between the analyses of the different service packages and the assumptions, the same random number seed was used in each analysis.

As described above, the model was run for 120 cycles of monthly length. Costs and benefits were discounted at an annual rate of 3.5%.

In the analyses of the SEED dementia services, the primary outcomes were total cost, length of stay in hospital, time receiving palliative care, the number of people with dementia discharged to the usual place of care from hospital per 1000 patients and the number of avoided admissions per 1000 potential admissions. The total cost is the sum of the discounted costs over the duration of the model.

Analysis for comparison 2, comparison of scenarios used in the contingent valuation survey

To conduct the analysis for comparison of the scenarios valued in the contingent valuation survey, we first had to determine how these scenarios would be represented in the model by the existing model structure and outcomes. To achieve this, a mapping exercise between care activities and service outputs captured in our model and those that were broadly described in each scenario were identified. This mapping exercise was undertaken by three members from the project team independently. These were provided with the descriptions of care activities, service outputs and outcomes related to people with dementia (see *Table 69*), the description of WTP scenarios and a table to checkmark which care activities were described by each WTP scenario (*Table 93*). Overall, the results of this exercise between

TABLE 93 Mapping WTP scenario elements to model outcomes

	Alternative scenario			
Elements appearing in the scenarios	**1**	**2**	**3**	**4**
Care activities				
Regular clinical reviews to identify need for palliative care			✓	✓
ACP discussions offered		✓	✓	
Improved liaison between services: before admission (SBAR)	✓		✓	
Improved liaison between services: during admission (transfer sheets)	✓			
Improved liaison between services: on discharge (discharge planning)	✓		✓	
Care service outputs				
ACP documented and disseminated		✓	✓	
Recognised need for palliative care			✓	✓
EHCP documented and disseminated			✓	
Bereavement services offered		✓		✓
Outcomes related to people with dementia				
Length of hospital stay			✓	
Reduced unnecessary/avoidable hospital admissions and re-admissions			✓	
Discharged to the usual place of care after hospitalisation				
Other outcomes (not included in the model)				
Dying in preferred place of care		✓	✓	
Time spent in preferred place of care			✓	
Hospital deaths			✓	
Meeting needs for comfort at the EOL				✓
Concordance between treatment and advance care plan		✓		

EHCP, Emergency Healthcare Plan.

the three individuals were similar. For elements of *Table 93* for which there was no agreement, the majority view of the three individuals was considered as the result.

The main scenario, which assumes perfect prevalence of care activities, care service outputs and outcomes related to people with dementia, and the scenario for which none of these was provided were not included in the exercise. For care activities, services outputs and outcomes related to people with dementia in *Table 93* that are checkmarked for a scenario, perfect provision was assumed in the model. When a WTP scenario was not describing one of these elements, complete absence was assumed in the model.

The net benefit of providing a dementia service package to new incident cohorts over a 5-year programme was estimated for each of the scenarios. Incident cohorts were selected for the estimation of the net benefit rather than prevalent cohorts because the service package may affect costs in later years. The model was used to calculate a distribution of present values of the costs of a 5-year programme for the cumulative dementia cohort by year.

The average cost per person with dementia of the model in year 1 is denoted as C_{M1}. The cost of the national programme in year 1 is denoted as C_{P1}. For an incident cohort N, the costs for each year of a programme delivered to new incident annual cohorts, when the cumulative cohort increases each year of the 5 years, is as follows:

$$C_{P1} = NC_{M1}. \tag{8}$$

$$C_{P2} = NC_{M1} + NC_{M2}. \tag{9}$$

$$CC_{Pn} = N\textstyle\sum_{i=1}^{n} C_{Mi}. \tag{10}$$

The present value of the costs over a 5-year course is the sum of the annual discounted programme costs.

The WTP estimates are monthly tax contributions made by individual taxpayers for a programme delivered nationally, that is to all people living with dementia. If b is the average WTP estimate for a service package, y is the total number of taxpayers, n_i is the size of the cumulative cohort in year i, and x is the number of people living with dementia in a given year (prevalent cases), then the aggregate WTP estimate across all taxpayers for each year (B_i) is as follows:

$$B_1 = \frac{12 \times b \times y \times n_1}{x}. \tag{11}$$

$$B_2 = \frac{12 \times b \times y \times (n_1 + n_2)}{x}. \tag{12}$$

$$B_n = \frac{12 \times b \times y \times \sum_{i=1}^{n} n_i}{x}. \tag{13}$$

The total numbers of people with dementia alive each year were obtained from the economic model. The parameters of a log-normal distribution were calculated from the WTP median and mean estimates. A distribution of the present value of the aggregate WTP estimates for each year of the 5-year programme was simulated.

The net benefit of a service package is the total value of the benefit B minus the cost of the service package C. The cost of a service package is the cost of the dementia services with the package C_{d+p} minus the cost of dementia services without the package C_d. The net benefit (NB) was calculated as:

$$NB = B - (C_{d+p} - C_d). \tag{14}$$

For 800 samples, 800 net benefit estimates were derived and the mean and 95% CIs were produced.

A WTP scenario model was run to estimate C_{d+p} and a control model was run to estimate C_d.

For each WTP scenario, the included services were assumed to be delivered to every person with dementia. It is therefore assumed that the prevalence of a care service described in a WTP scenario exceeds the one that is expected to be accomplished by the SEED intervention. When an activity or service output was absent from a WTP scenario, then the complete absence of this service was assumed.

The incident dementia cases N, the prevalent dementia cases x, and the number of eligible taxpayers y are presented in *Table 94*.

Summary for economic evaluation

The results of the cost–consequence analysis suggest that the SEED intervention is unlikely to reduce costs, but that it may result in changes in the use of services expected to improve the well-being of people with dementia and family carers. These findings are reinforced by the cost–benefit analysis, which suggest that the SEED intervention is likely to be more efficient than not implementing any aspect of the SEED intervention.

However, the results are imprecise (the CIs are wide); further research is needed to obtain more precise estimates of the probabilities, and to ensure that all clinically and economically important costs and outcomes are included.

Overall workstream 5 conclusions

This WS (in *Appendices 5* and *6*) describes several innovative economic components, namely the first contingent valuation of a specialist dementia service, the first detailed economic model for a non-pharmacological intervention in dementia from diagnosis to EOL and the first economic evaluation model that incorporates the results of a contingent valuation into a probabilistic economic model. Its methodology, as a minimum, meets internationally accepted best-practice recommendations for contingent valuation, economic evaluation and economic modelling.[146,154]

A key finding is that the SEED intervention is perceived by the general population as having real value in economic terms, in particular by individuals with some experience of dementia in their close family members, colleagues or relatives and by those with higher income levels.

TABLE 94 Incident cases, prevalent cases and eligible taxpayers

Parameter	Notation	Number of people
Incident cases of dementia per year[8]	N	209,600
Prevalent cases of dementia per year in 2015[2]	x	850,000
Number of eligible taxpayers in 2017[257]	y	30,800,000

Despite the high value of the SEED intervention to the general public, it is unlikely to reduce costs, but it may change service use in ways that improve the well-being of people with dementia and their families. These changes may relieve pressure on some NHS services, for example hospital beds, but may increase demand on others that are overstretched, for example palliative care services.

Reflections on workstream 5

The results of the contingent valuation study are based on a large sample thought to represent the UK general population, but the validity of the responses could have been affected by biases arising out of the construction of the WTP survey or by the interpretation and understanding of the scenarios by the respondents. Using the internet survey panels could have introduced bias by failing to include major consumers of health-care services who are not internet users.

The economic analyses are based on an early economic model; therefore, there is considerable uncertainty surrounding both the model inputs and the underlying structure of the model. The effect of this is that estimates for model outputs may be imprecise (i.e. CIs are wide) and important costs and benefits may not be accurately captured. Nevertheless, rigorous approaches were undertaken to use the best evidence available at the time to ensure that the model captured key aspects.

The economic evaluation allowed us to explore the contribution of each component of the SEED intervention to relative efficiency. The reliability of these estimates is directly related to the trustworthiness of the structural assumptions of the model. The individual components of the SEED intervention do not change outcomes in an additive way; rather, there appear to be diminishing returns from adding each component. This phenomenon has been observed in many studies investigating complex multicomponent interventions.[155,156] However, the precise nature of correlation between components is unclear. Should new data and understanding become available, consideration should be given to refining the model and the data inputs.

Appendix 7 Commissioning good-quality, community-based end-of-life care in dementia (workstream 6)

TABLE 95 Academic papers included in the updated narrative review (unpublished data)

Study	Title	Aims/objectives	Participants	Method	Results/conclusions
Addicott[258]	Challenges of commissioning and contracting for integrated care in the NHS in England	Explore challenges in developing, commissioning and contracting models to stimulate greater integration between providers of NHS care	*n* = 31, of which 14 providers and 17 commissioners	• Case studies and semistructured interviews • Thematic analysis	• Three contractual models identified: i. Prime contract ii. Prime provider contract iii. Alliance contract • Independent of contractual process commissioners spent time and resources on it • Contracts do not solve problems or contribute to integration or restore poor relationships • Contractual methodologies mainly depend on procurement and supply chain management • Integrated and co-ordinated care lost in the technicalities of the contractual models
Checkland *et al.*[166]	Complexity in the new NHS: longitudinal case studies of CCGs in England	How CCGs are set up, structured and what is the role of the GP in a CCG	Phase 1: • CCG leaders • *n* = 104 and 118 (for survey) • *n* = 96 (refers to number of participants) Phase 2: • Senior CCG staff (focus on GPs and managers) • *n* = 42 (refers to number of interviews)	Longitudinal design ongoing study, eight case studies/ interviews, meeting observations, and two online surveys	• CCG structures are very complex • CCGs differ in: size (very large vs. small), structure and on how functions are distributed between different bodies and GPs

Study	Title	Aims/objectives	Participants	Method	Results/conclusions
Jones *et al.*[259]	Development of a model for integrated care at the EOL in advanced dementia: a whole-systems UK-wide approach	Develop an evidence-based intervention (COMPASSION) in order to improve EOLC for patients with advanced dementia and their carers	Dementia patients, carers and social care professionals (actual sample sizes not mentioned)	Realistic method: qualitative and quantitative, literature review, RAND/UCLA appropriateness method	Relevant qualitative results: • Continuing changes in commissioning for health care are disruptive and limit service planning • Health-care budget varies depending on the local priorities
Kupeli *et al.*[67]	What are the barriers to care integration for those at the advanced stages of dementia living in care homes in the UK? Health-care professional perspective	To identify barriers to providing integrated dementia care	*n* = 14 health professionals, including two commissioners working in dementia care	Qualitative interviews, thematic analysis	Relevant qualitative results: • Commissioners are more focused on early intervention and diagnosis than on EOLC • Social care system reorganisation to reduce costs affects timely and co-ordinated care
Kupeli *et al.*[68]	Context, mechanisms and outcomes in EOLC for people with advanced dementia	To explore the context, mechanisms and outcomes for providing good palliative care to people with advanced dementia residing in UK care homes	*n* = 14 health social care, nursing staff, home managers and commissioners for older adult services	Realistic evaluation framework/qualitative interviews	Relevant results: CCGs not certain whether or not dementia-specific palliative care is required (beliefs that palliative care may not need to differentiate for dementia patients)
Lancaster *et al.*[260]	Commissioning of specialist palliative care services in England	Explore variation in commissioning of palliative care in England	*n* = 176 CCGs	Freedom of information 3-wave survey	• CCGs do not have standardised information about their population • Population palliative care needs not consistently linked to budget allocation for palliative care

continued

TABLE 95 Academic papers included in the updated narrative review (unpublished data) (*continued*)

Study	**Title**	**Aims/objectives**	**Participants**	**Method**	**Results/conclusions**
McDermott *et al.*[261]	Engaging GPs in commissioning: realist evaluation of the early experiences of CCGs in the English NHS	Explore development of CCGs and what GPs add to the CCG process and in what ways they add value to the CCG	• Clinicians and managers, $n = 42$ • $n = 48$ meetings and 111 hours of observations	Realist evaluation: longitudinal qualitative interviews/seven case study sites/theories were compared with observational data	• CCGs are very complex in terms of their structure and they differ; therefore, comparisons are difficult • GPs' involvement in CCGs/commissioning is perceived to be valuable • Perceptions about the GP role/value, however, were broad, not concrete and could not be contextualised within existing CCGs/commissioning
Moran *et al.*[262]	GPs' views of clinically led commissioning: cross-sectional survey in England	To explore GP attitudes to involvement in commissioning and future intentions for engagement	National sample of GPs, $n = 2611$	Survey	GPs believe that they can contribute to commissioning; however, the majority do perceive it to be important part of their role. Current leaders consider quitting their commissioning role in the next 5 years. Few would consider taking up commissioning responsibilities in the future

UCLA, University of California, Los Angeles.
All papers were concerned with data relating to England, with the exception of Jones *et al.*,[259] which was UK based.

EME
HS&DR
HTA
PGfAR
PHR

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