

# Supporting Excellence in End of life care in Dementia (SEED programme)

<https://www.neurodegenerationresearch.eu/survey/supporting-excellence-in-end-of-life-care-in-dementia-seed-programme/>

## Principal Investigators

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## Institution

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### Country

United Kingdom

## Title of project or programme

Supporting Excellence in End of life care in Dementia (SEED programme)

## Source of funding information

NIHR (PGfAR Competition 11 Stage 2 Panel A)

## Total sum awarded (Euro)

€ 2,628,059

## Start date of award

14/10/2013

## Total duration of award in years

5.0

## The project/programme is most relevant to:

Alzheimer's disease & other dementias

## Keywords

Research Abstract

Aims and objectives

The overall aim of the programme is to support professionals, both commissioners and providers, to deliver good quality, community-based end of life care in dementia. Our three objectives are:

1. To identify which aspects of existing end of life care in dementia are effective and efficient.
2. To develop, implement and evaluate an evidence-based integrated care pathway (ICP), and associated educational resources, to support the provision of good quality end of life care in dementia.
3. To determine how community-based end of life care in dementia should be organised and commissioned.

## **Background and rationale**

Our ageing population will mean more people with long term illnesses like dementia leading to an increased need for community-based end of life care for those with complex needs. People with dementia already receive poorer quality end of life care compared to those with cancer, with more hospital admissions and worse symptom control.

NICE commissioning guidance has developed a framework for an integrated care pathway (ICP) for end of life care in dementia, and identified best practice examples, but a lack of empirical UK research in this area is limiting wider implementation. An ongoing research programme, The Marie Curie Dementia Programme (MCDP), aims to determine the health/social care needs and costs of providing end of life care to people with advanced dementia, through a prospective cohort study, and then develop, and pilot, a complex specialist intervention to address these needs.

## **Research environment**

The multi-disciplinary team are from centres of excellence in dementia and palliative care research; Newcastle University, the academic host, is internationally recognised for dementia research and Marie Curie for end of life research. We will seek programme adoption by NIHR DeNDRoN.

## **Research plan**

Our programme will build upon and complement quantitative data from the MCDP by exploring, in-depth, how end of life care in dementia is currently organised and delivered in community settings and whether existing end of life tools support the provision of good quality care in dementia. Though six related and interlinked workstreams (WSs), we will develop an ICP, following MRC guidance on complex interventions, to support professionals to deliver good quality care and also produce evidence-based guidance for commissioners.

We will begin in WS1 with a series of systematic reviews mapping existing guidance, care pathways and national best practice and identification of person-centred outcomes, via a Q-sort study, to measure this care (objectives1,3). In WS2 we will explore the delivery of good quality care in practice via an in depth qualitative study (objectives1,3). Using data from WS1,2 and

MCDP, we will develop an evidence-based ICP (WS3) and educational resources to support its use in practice and then in WS4, undertake a pilot study of the ICP, with process evaluation and nested qualitative study, to determine acceptability and feasibility (objective 2). To ascertain the relative efficiency of the developed ICP compared with alternative care pathways, we will undertake in WS5, economic modelling using evidence from earlier WSs and MCDP; we will also carry out a Willingness to Pay exercise to explore the cost-consequences of aspects of the ICP (objectives 1,3). Finally in WS6 we will explore how care is currently commissioned, and using data from WS1,2,3,5 and MCDP, develop and disseminate evidence-based guidance for commissioners (objectives 1,3).

### **Project outputs and dissemination plans**

The NHS will be presented with tools to support the organisation/delivery of better quality care: evidence-based commissioning guidance, a care pathway with accompanying educational resources to facilitate use in practice, and person-centred outcomes to measure their impact. Dissemination will be co-ordinated via Alzheimer's Society, Marie Curie and RCGP.

### **Relevant expertise of the team**

Robinson has extensive expertise in leading/managing multi-disciplinary, community-based dementia research, confirmed by NIHR translational professorship award. Sampson is co-applicant on MCDP and recognised as an international expert in this area. Clinicians and academics, with expertise in mixed methods research, statistics and health economics, complete the team; co-applicants have already collaborated to produce high quality research in this area.

### **Management, governance and ethical implications**

This research presents considerable ethical issues; involvement of people with impaired capacity and the sensitivity of conducting research at the end of life. A Programme Management Board (all co-applicants) will meet every 3 months; external oversight of programme management will be via an External Steering Committee and a Patient Programme Advisory Board.

### **Patient/Public Involvement**

This research began in carer groups from the Alzheimer's Society Research Network and progressed through ongoing work between these groups and tNIHR DeNDRoN. The original carer group will form the Patient Programme Advisory Board, providing specific advice on individual WSs.

### **Justification of costs**

The project involves inter-related research studies; a programmatic approach is essential to facilitate this work and create a critical mass of national expertise. The qualitative work, especially ethnographic approaches, is costly and time-consuming but allows a deeper understanding of current challenges and possible solutions.

### **Lay Summary**

**Further information available at:**

**Types:**

Investments > €500k

**Member States:**

United Kingdom

**Diseases:**

Alzheimer's disease & other dementias

**Years:**

2016

**Database Categories:**

N/A

**Database Tags:**

N/A