

SEED Newsletter

March 2015

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

The SEED programme aims to support professionals to deliver better quality, community-based end of life care to people with dementia and their families. Our ultimate goal is to look for examples of good practice and see how we can translate these on a wider scale into the real world. We hope to influence both professionals who provide hands on care and also those who commission care.

We have had strong patient and public involvement (PPI) both in developing the research and also in helping us carry it out; the SEED programme has been named as an example of best practice for PPI in research <http://www.invo.org.uk/resource-centre/examples/exploring-public-involvement-in-nihr-research-funding-applications/>.

SEED began in October 2013. The programme is made up of 6 related streams of work which have separate aims;

1. Mapping current guidance and identifying how good quality care is measured.
2. Exploring how care is currently provided to people with dementia at the end of life.
3. Development of a new Integrated Care Pathway (ICP) to support good quality care.
4. Trial of the new ICP.
5. Evaluation of the ICP.
6. Understanding of how services are commissioned and development of new guidance.

The workstreams start at different times, with 1, 2 and 6 currently underway. We would like to tell you about our progress to date now that the research has been going for over a year.

Workstream 1

In this workstream we are looking for existing guidance for good practice in end of life care in dementia, and specific examples of services delivering good end of life care. We are also looking at how to measure 'good' quality care, especially what people with dementia and their families think are the priorities for this aspect of care. For the latter we are using a novel method called *Q-sort*, where participants are asked to rank a list of statements on the topic according to their individual priorities.

What we have achieved

- A thorough search of existing care pathways for end of life care in dementia and identified indicators that have been used to measure the quality of this care.

- We have been working with the National Council for Palliative Care (NCPC) to carry out a survey of palliative care services for dementia.
- We have developed and pilot tested an appropriate *Q-sort* tool.

Workstream 2

This workstream is focused on how care towards and at the end of life for people with dementia is provided; we are specifically looking for examples of good practice. We have spoken with national experts to seek their views on good practice, and have also talked to service managers and frontline staff who care for people. In some of these services we will spend time observing care work and talk to family carers, people with advanced dementia, staff and other health professionals.

What we have achieved

- We have interviewed 30 national experts.
- We have carried out 9 group discussions with frontline staff in 7 different services.
- We have begun to interview carers of people with dementia to find out their experience of services.

Workstream 6

Building on workstream 2, this aspect of the programme is concerned with how end of life care services for people with dementia are commissioned. We will be looking at national guidance and then speaking to commissioners to find out what happens in actual practice. This piece of work has just started and we will be able to provide more information in later newsletters.

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Further Information

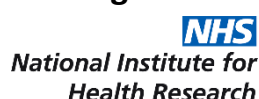
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