

SEED Newsletter

Supporting Excellence in End of life care in Dementia (SEED programme) November 2017

The SEED programme, which began in 2013, aims to support professionals to deliver better quality, community-based end of life (EoL) care to people with dementia and their families. We are looking for examples of local good practice and how to expand into the real world. We hope to influence both professionals who provide care and also those who commission care.

We continue to make good progress and would like to share our achievements since the January 2017 newsletter.

Workstream 3: Development of a new intervention to support good quality end of life care for people with dementia

What we have achieved:

Based on workstream 2 findings, this workstream has primarily focused on developing a Care Plan Guide for people with dementia and their families, providing an introduction and guidance to key plans required at end of life. The Care Plan Guide has been developed as a booklet and a prototype app.

In addition, other ideas requiring further development include:

- a set of filmed/animated scenarios for end of life care to inform and assist people with dementia, their families and carers
- a web portal for accessing current resources, which would provide separate interfaces for healthcare professionals, people with dementia and their families and carers.

Workstream 4: Development of a new intervention to support good quality end of life care for people with dementia

Pilot study to test the SEED intervention

Since our last update, the project has:

- Successfully recruited 62 people with dementia; our target was 66. Baseline interviews have been carried out over the summer, and four month follow-up visits are completed in two GP practices
- We have trained two Dementia Nurse Specialists, based in the two intervention GP practices to work with patients and carers recruited to the trial. They are also:
 - developing a summary of local services for the GP practices involved
 - delivering training to care home staff
 - and establishing working relationships with existing practitioners involved in the participants' care
- Dementia Nurse Specialists have ongoing intervention supervision sessions with project team researchers.



Julie Young
Dementia Nurse
Specialist



Clare O'Toole
Dementia Nurse
Specialist

Workstream 5: Economic modelling/willingness to pay exercise

What we have achieved:

- An early economic model has been developed to reflect the costs of good quality end of life care
- A further mathematical economic model is currently being developed to further evaluate the costs and of alternative care pathways to the SEED intervention.

Members of the general public will also participate in a Willingness to Pay (WTP) survey, asking what their maximum WTP would be for scenarios describing different care pathways for end of life care in dementia. A sample of people with early dementia and their family carers will also be surveyed and asked to state their WTP.

Willingness to pay is a method for measuring strength of preference. By presenting different scenarios and asking participants how much they would hypothetically be willing to pay for each, we can find out which options are preferred. If a low willingness to pay is obtained (or if participants are not willing to pay more for the preferred option), then this indicates only a weak preference for the preferred option; in contrast, if participants are willing to pay considerably more for the preferred option, this suggests a strong preference.

Workstream 6: Understanding of how services are commissioned and development of new guidance

Due to the delay in publication of the new NICE guidance on dementia, WS6 work has been paused. Following discussions with the External Steering Committee, we have used this time to conduct additional interviews with commissioners and vanguard sites.

Presentations & Publications

Conference presentations:

- Royal College of Psychiatrists' Conference, Bristol, March 2017
- End of Life Research Showcase and Networking event, Glasgow, April 2017
- AAIC Conference, London, July 2017
- IAGG Conference, San Francisco, July 2017
- Alzheimer Europe Conference, Berlin, October 2017
- Glasgow School of Art Symposium Health and Wellbeing, October 2017

Journal papers:

Lee, Bamford, Poole, McLellan, Exley, Robinson. End of life care for people with dementia: The views of health professionals, social care service managers and frontline staff on key requirements for good practice. *PLOS ONE* 12(6): June 2017 e0179355. <https://doi.org/10.1371/journal.pone.0179355>

Poole, Bamford, McLellan, Lee, Exley, Hughes, Harrison-Denning, Robinson. End-of-life care: A qualitative study comparing the views of people with dementia and family carers. *Palliative Medicine* 2017 <http://journals.sagepub.com/doi/pdf/10.1177/0269216317736033>

Macdonald, Neves, McLellan, Poole, Harrison-Denning, Tucker, Bamford, Robinson. Co-designing new resources to support better quality end of life care with people with dementia and family carers. *Journal of Dementia Care*, 2017, In Press



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