

SEED Newsletter

January 2017

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

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. 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.

Each workstream has a different start date and duration. Workstream 1 is complete, 2 nearing completion, 3 and 6 ongoing. We continue to make good progress and would like to share with you our achievements since the April 2016 newsletter.

Workstream 1: Mapping current guidance and identifying how good quality care is measured (complete)

What we have achieved:

- Review of guidance and EoL care
- Survey of palliative care services, working with National Council for Palliative Care (NCPC), to which 15 services responded
- Q-sort and analysis with 58 participants including people with dementia, bereaved carers and current carers
- Paper in press in *BMJ Supportive and Palliative Care*, another in preparation for submission to *Palliative Medicine*

Workstream 2: Exploring how care is currently provided to people with dementia at the end of life

What we have achieved:

- Interviews with 30 national policy and practice experts
- Interviews with 33 service managers delivering EoL care in dementia
- Conducted 10 focus groups with 54 frontline staff from 8 services

- Interviewed 11 people with mild dementia and 25 family carers of people with dementia (either currently caring and recently bereaved)
- 241 hours of observations in 3 care home sites to further explore end of life care

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

We have achieved conceptualisation of the intervention as follows:

- The WHO – a Dementia Care Facilitator
- The WHAT – focused on 7 key themes/areas:
 - Timely planning discussions
 - Co-ordination of care
 - Effective working relationships with primary care
 - Managing hospitalisations
 - Recognition of end of life and provision of supportive care
 - Continuing care after death
 - Valuing staff and ongoing learning
- And the HOW – a 'care resources toolkit' to support people with dementia, families and carers and to upskill care staff, GPs and nurses

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

This began in August 2016 and so far we have:

- Translated the theoretical intervention outline into a real world intervention, including a job description and practical educational resources
- Completed the pilot trial protocol and submitted the ethical review application
- Successfully recruited GP practices in Alnwick, Hexham, North Shields and Newcastle to trial the intervention
- Recruited a Dementia Care Facilitator
- Started recruiting members for the trial steering committee

Workstream 5:

The Workstream 5 team is developing an economic model of care pathways, and has produced a protocol for a proposed willingness to pay exercise and cost benefit analysis.

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

What we have achieved:

- 30 interviews with experts in commissioning dementia care and/or palliative care in England
- 4 key factors identified, which influence good practice in EoL care for people with dementia:
 - Leadership & management of care
 - Integrating clinical expertise
 - Continuity of care
 - Use of guidelines
- Key findings to be published in two papers

Presentations & Publications

Conference presentations:

- 21st WONCA Europe conference, Copenhagen, June 2016
- SAPC annual conference, Dublin, July 2016

Journal papers:

Gotts ZM, Baur N, McLellan E, Goodman C, Robinson L, Lee RP. Commissioning care for people with dementia at the end of life: a mixed-methods study. *BMJ Open* 2016 6, (12) pp. e013554

Amador S, Goodman C, Robinson L, Sampson E. UK end-of-life care services in dementia, initiatives and sustainability: results of a national online survey. *BMJ Supportive and Palliative care* 2016 doi: 10.1136/bmjspcare-2016-001138.

Hill S, Mason H, Poole M, Vale, L, Robinson L, on behalf of the SEED team. What is important at the end of life for people with dementia? The views of people with dementia and their carers. *International Journal of Geriatric Psychiatry* 2016, doi: 10.1002/gps.4564

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