
Example 8: Supporting Excellence in End of life care in Dementia – SEED programme

About the research

Lead researcher: Professor Louise Robinson, Institute for Health and Society / Institute for Ageing and Health, Newcastle University.

Funder: National Institute for Health Research (NIHR) Programme Grants for Applied Research (PGfAR).

Project aim: The overall aim is to support professionals to deliver good quality, community-based end of life care in dementia. This will involve identifying which aspects of existing end of life care in dementia are effective and efficient, developing and evaluating an evidence-based integrated care pathway and determining how community-based end of life care in dementia should be organised and commissioned.

Type of research: Wide ranging programme of research.

Duration: Starts October 2013 – five years duration.

Who we spoke to

We interviewed the lead researcher Louise Robinson. Her comments are in blue below.

About the involvement

How patients influenced the research question

Louise is the Lead and Chair of the Primary Care Group (PCG) in the Dementia and Neurodegenerative Diseases Research Network (DeNDRoN). A few years ago the Alzheimer's Society approached the PCG, because they wanted to work with the Group to develop a project that would address one of the Society's research priorities. The Alzheimer's Society had previously asked patients and carers about their [priorities for research](#). One of the top five topics was end-of-life care for people with dementia. The PCG were enthusiastic about taking this work forward as end of life care for people with dementia is often provided within the community setting.

Patient / carer involvement prior to applying for funding

The PCG and The Alzheimer's Society worked together to develop the proposal and write the funding application. They jointly funded this development work and the Alzheimer's Society helped find patients and carers to be involved.

“ We decided to start with a one-day workshop bringing together patients, carers and researchers. We invited people already doing research in this area as well as some of the carers and people with dementia who had been involved in the priority setting exercise. In the morning we had a few presentations from researchers about what was currently happening and what they thought the potential research questions might be. Then in the afternoon we split into small mixed groups, where researchers, carers and patients could share their views. We asked patients and carers about their thoughts and experiences of end-of-life care. We had bereaved carers there. So we used the small groups to bring out the personal experiences and to bring the two together. ” Louise

The findings from the workshop were reviewed by a group of academics. This group included members of the PCG and the researcher presenters from the workshop, but no patients or carers. They met for a joint writing day, funded by DeNDRoN, to develop the research proposal. It was agreed that they would apply for an NIHR Programme Grant as the discussions at the workshop had shown that little was known about the current state of end of life care and much research needed to be done.

“ We got the proposal to a point where we could send it back to the Alzheimer's Society. They had a workshop with patients and carers to discuss it and fed back to us. On the whole they were very supportive. They felt we had addressed some of the key issues that had come up from the initial priority-setting exercise. They also volunteered to become part of a PPI group if the grant was successful. One of the carers became a co-applicant and worked with us on writing up the rest of the bid. The whole process has taken us years - we started this work in 2011. ” Louise

Impact of the early involvement

The involvement of patients and carers helped to keep the researchers' thinking **grounded in reality**. Most of the previous research in this area had been carried out in other countries and suggested that end-of-life care for dementia was sub-optimal. The carers reported that their experience hadn't all been bad.

“ Some of the carers said the nurses had been very good in looking after their loved one but that 'Nobody looked after me'. The carers don't seem to get enough follow-up support. So we realised it would be important for us to observe actual care and to identify local initiatives around the country where there is good practice, which people knew about, but which hadn't been properly evaluated. ” Louise

The patients and carers also stated their wish to be involved in **developing outcome measures** for the quality of care.

“The carers said ‘You’ve got to talk to us about what are the important outcomes’. So that became another area of research work. We’re planning to look at current literature and policy around outcomes, to talk to people with early dementia and carers about the outcomes they would want services to achieve and compare their views to what’s currently advocated. ” Louise

Continuation of involvement following funding

The original patients and carers have joined the programme oversight board, which meets once a year to review progress.

“ We felt we had to broaden the input because we needed to get some fresh ideas – to have people take a new critical look at the proposed research. Also with a five year programme, we thought not everyone would want to commit to that length of time. So DeNDRoN North-East is holding an event with their regional PPI group to see if we can find any additional patients / carers. We’re trying to find people who can work with their local research group to give direct and immediate feedback. ” Louise

Lessons learnt

“ Involvement helps to ground your thoughts in reality. A lot of the researchers on our team didn’t have experience of clinical practice – so it’s about making sure we keep a balance and remember the impact on patients and carers, and what’s important to them. ” Louise

“ It requires investment of time and resources. When we got feedback we got absolutely superb feedback on the PPI section of the programme grant. We scored really highly because we had invested in it. ” Louise

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[INVOLVE Briefing note five: How to involve members of the public in research](#)

planning a meeting of members of the public see

[INVOLVE Briefing note eight: Getting started](#)

Budgeting for public involvement in your study

www.invo.org.uk/resource-centre/involvement-cost-calculator/

Alzheimer's Society Dementia Research Priority Setting

http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=1804

Dementia and Neurodegenerative Diseases Research Network (DeNDRon) North East

www.northeastdendron.org.uk/

your local **Research Design Service**

<http://www.invo.org.uk/find-out-more/information-for-researchers/research-design-services-information/>

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