

# Supporting good quality, community-based end-of-life care for people living with dementia: the SEED research programme including feasibility RCT

Louise Robinson,<sup>1\*</sup> Marie Poole,<sup>1</sup> Emma McLellan,<sup>1</sup> Richard Lee,<sup>2</sup> Sarah Amador,<sup>3</sup> Nawaraj Bhattarai,<sup>1</sup> Andrew Bryant,<sup>1</sup> Dorothy Coe,<sup>4</sup> Anne Corbett,<sup>5</sup> Catherine Exley,<sup>1</sup> Claire Goodman,<sup>6</sup> Zoe Gotts,<sup>7</sup> Karen Harrison-Dening,<sup>8</sup> Sarah Hill,<sup>1</sup> Denise Howel,<sup>1</sup> Susan Hrisos,<sup>1</sup> Julian Hughes,<sup>9</sup> Ashleigh Kernohan,<sup>1</sup> Alastair Macdonald,<sup>10</sup> Helen Mason,<sup>11</sup> Christopher Massey,<sup>7</sup> Sandra Neves,<sup>10</sup> Paul Paes,<sup>12</sup> Katherine Rennie,<sup>13</sup> Stephen Rice,<sup>1</sup> Tomos Robinson,<sup>1</sup> Elizabeth Sampson,<sup>14</sup> Susan Tucker,<sup>15</sup> Dimitrios Tzelis,<sup>1</sup> Luke Vale<sup>1</sup> and Claire Bamford<sup>1</sup>

<sup>1</sup>Population Health Sciences Institute, Newcastle University, Newcastle upon Tyne, UK

<sup>2</sup>Social Work, Education and Community Wellbeing, Northumbria University, Newcastle upon Tyne, UK

<sup>3</sup>Division of Psychiatry, University College London, London, UK

<sup>4</sup>North East and North Cumbria Local Clinical Research Network, Newcastle upon Tyne, UK

<sup>5</sup>College of Medicine and Health, University of Exeter, Exeter, UK

<sup>6</sup>School of Health and Social Work, University of Hertfordshire, Hatfield, UK

<sup>7</sup>Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust, Newcastle upon Tyne, UK

<sup>8</sup>Dementia UK, London, UK

<sup>9</sup>Medical School, University of Bristol, Bristol, UK

<sup>10</sup>The Glasgow School of Art, Glasgow, UK

<sup>11</sup>Yunus Centre for Social Business and Health, Glasgow Caledonian University, Glasgow, UK

<sup>12</sup>Northumbria Healthcare NHS Foundation Trust, Newcastle upon Tyne, UK

<sup>13</sup>Faculty of Medical Sciences, Professional Services, Newcastle University, Newcastle upon Tyne, UK

<sup>14</sup>Marie Curie Palliative Care Research Department, University College London, London, UK

<sup>15</sup>Patient and Public Involvement Representative

\*Corresponding author [a.l.robinson@newcastle.ac.uk](mailto:a.l.robinson@newcastle.ac.uk)

**Declared competing interests of authors:** Louise Robinson was a member of the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Programme primary care themed call board from 1 October 2012 to 18 February 2014. Claire Goodman was a trustee of the Order of St John Care Trust from 2016 to 2019, a NIHR Health Services and Delivery Research (HSDR) Programme Commissioning Board member from February 2012 to 30 June 2015 and a NHS Service Delivery and Organisation (SDO) Commissioning Board member from 1 April 2009 to 1 January 2012; she is currently a NIHR senior investigator (since 2016). Denise Howel was a member of the NIHR SDO Commissioning Board from April 2009 to December 2011, a member of the NIHR HSDR Programme Commissioning Board from January 2012 to November 2015 and a member of the NIHR Programme Grants for Applied Research (PGfAR) Programme funding subpanel from February 2016 to present. Luke Vale was a member of the NIHR HTA Clinical Evaluation and Trials funding panel from 2014 to 2018 and a member of the NIHR PGfAR Programme funding subpanel from 2008 to 2016.

Published September 2020

DOI: 10.3310/pgfar08080

## Plain English summary

The SEED research programme including feasibility RCT

Programme Grants for Applied Research 2020; Vol. 8: No. 8

DOI: 10.3310/pgfar08080

NIHR Journals Library [www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)

## Plain English summary

In the UK, two-thirds of people with dementia die in the community. Compared with people with cancer, the end-of-life care for people with dementia is relatively poor. The aim of this programme was to support professionals to deliver better community-based care towards, and at, the end of life for people with dementia and their families.

First, we looked at current care by reviewing existing guidance and research. We also looked at the commissioning of dementia and end-of-life care. Second, we worked with people with dementia, their families, service providers and commissioners to identify good end-of-life care in dementia, challenges to service delivery and possible solutions. Seven components of end-of-life care were key:

1. timely planning discussions
2. recognising end of life and providing supportive care
3. co-ordinating care
4. effective working with primary care
5. managing hospitalisation
6. continuing care after death
7. valuing staff and ongoing learning.

These informed the intervention, which was a primary care-based dementia nurse specialist and associated resources. The dementia nurse specialist provided direct care to people with dementia and their families, while also supporting professionals to make system changes.

The intervention was piloted in two general practices in North East England, and two other practices acted as controls, providing usual care. We achieved the recruitment target of 11 people with dementia per practice; 12 people with dementia died over the 12-month follow-up period. One-year outcome data were successfully collected for 41 (66%) people with dementia.

The dementia nurse specialist intervention was feasible, acceptable and highly valued by all participants. Key components of the role were providing proactive care, continuity and co-ordination. Unfortunately, it is unlikely to reduce care costs. It is a possible solution to delivering the single, named care co-ordinator role recommended in the recent National Institute for Health and Care Excellence dementia guidance.



# Programme Grants for Applied Research

ISSN 2050-4322 (Print)

ISSN 2050-4330 (Online)

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) ([www.publicationethics.org/](http://www.publicationethics.org/)).

Editorial contact: [journals.library@nihr.ac.uk](mailto:journals.library@nihr.ac.uk)

The full PGfAR archive is freely available to view online at [www.journalslibrary.nihr.ac.uk/pgfar](http://www.journalslibrary.nihr.ac.uk/pgfar). Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: [www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)

## Criteria for inclusion in the *Programme Grants for Applied Research* journal

Reports are published in *Programme Grants for Applied Research* (PGfAR) if (1) they have resulted from work for the PGfAR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

## Programme Grants for Applied Research programme

The Programme Grants for Applied Research (PGfAR) programme, part of the National Institute for Health Research (NIHR), was established in 2006 to fund collaborative, multidisciplinary programmes of applied research to solve health and social care challenges. Findings are expected to provide evidence that lead to clear and identifiable patient benefits, in the relatively near future.

PGfAR is researcher led and does not specify topics for research; however, the research must be in an area of priority or need for the NHS and the social care sector of the Department of Health and Social Care, with particular emphasis on health and social care areas that cause significant burden, where other research funders may not be focused, or where insufficient funding is available.

The programme is managed by the NIHR Central Commissioning Facility (CCF) with strategic input from the Programme Director. For more information about the PGfAR programme please visit the website: <https://www.nihr.ac.uk/explore-nihr/funding-programmes/programme-grants-for-applied-research.htm>

## This report

The research reported in this issue of the journal was funded by PGfAR as project number RP-PG-0611-20005. The contractual start date was in October 2013. The final report began editorial review in May 2019 and was accepted for publication in May 2020. As the funder, the PGfAR programme agreed the research questions and study designs in advance with the investigators. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The PGfAR editors and production house have tried to ensure the accuracy of the authors' report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, CCF, NETSCC, PGfAR or the Department of Health and Social Care. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the PGfAR programme or the Department of Health and Social Care.

© Queen's Printer and Controller of HMSO 2020. This work was produced by Robinson *et al.* under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library ([www.journalslibrary.nihr.ac.uk](http://www.journalslibrary.nihr.ac.uk)), produced by Prepress Projects Ltd, Perth, Scotland ([www.prepress-projects.co.uk](http://www.prepress-projects.co.uk)).

## Editor-in-Chief of *Programme Grants for Applied Research* and NIHR Journals Library

---

**Professor Ken Stein** Professor of Public Health, University of Exeter Medical School, UK

### NIHR Journals Library Editors

---

**Professor John Powell** Chair of HTA and EME Editorial Board and Editor-in-Chief of HTA and EME journals. Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK, and Senior Clinical Researcher, Nuffield Department of Primary Care Health Sciences, University of Oxford, UK

**Professor Andrée Le May** Chair of NIHR Journals Library Editorial Group (HS&DR, PGfAR, PHR journals) and Editor-in-Chief of HS&DR, PGfAR, PHR journals

**Professor Matthias Beck** Professor of Management, Cork University Business School, Department of Management and Marketing, University College Cork, Ireland

**Dr Tessa Crilly** Director, Crystal Blue Consulting Ltd, UK

**Dr Eugenia Cronin** Senior Scientific Advisor, Wessex Institute, UK

**Dr Peter Davidson** Consultant Advisor, Wessex Institute, University of Southampton, UK

**Ms Tara Lamont** Senior Scientific Adviser (Evidence Use), Wessex Institute, University of Southampton, UK

**Dr Catriona McDaid** Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

**Professor William McGuire** Professor of Child Health, Hull York Medical School, University of York, UK

**Professor Geoffrey Meads** Professor of Wellbeing Research, University of Winchester, UK

**Professor John Norrie** Chair in Medical Statistics, University of Edinburgh, UK

**Professor James Raftery** Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

**Dr Rob Riemsma** Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

**Professor Helen Roberts** Professor of Child Health Research, UCL Great Ormond Street Institute of Child Health, UK

**Professor Jonathan Ross** Professor of Sexual Health and HIV, University Hospital Birmingham, UK

**Professor Helen Snooks** Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

**Professor Ken Stein** Professor of Public Health, University of Exeter Medical School, UK

**Professor Jim Thornton** Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

**Professor Martin Underwood** Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of editors: [www.journalslibrary.nihr.ac.uk/about/editors](http://www.journalslibrary.nihr.ac.uk/about/editors)

**Editorial contact:** [journals.library@nihr.ac.uk](mailto:journals.library@nihr.ac.uk)