

This is a repository copy of *Improving Care for People with Dementia : development and initial feasibility study for evaluation of life story work in dementia care (final report)*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/104193/>

Version: Published Version

---

**Article:**

Gridley, Kate [orcid.org/0000-0003-1488-4516](https://orcid.org/0000-0003-1488-4516), Brooks, Jennifer Carole [orcid.org/0000-0001-7735-3718](https://orcid.org/0000-0001-7735-3718), Birks, Yvonne Frances [orcid.org/0000-0002-4235-5307](https://orcid.org/0000-0002-4235-5307) et al. (2 more authors) (2016) *Improving Care for People with Dementia : development and initial feasibility study for evaluation of life story work in dementia care (final report)*. Health Services and Delivery Research. i-300. ISSN 2050-4357

<https://doi.org/10.3310/hsdr04230>

---

**Reuse**

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

**Takedown**

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing [eprints@whiterose.ac.uk](mailto:eprints@whiterose.ac.uk) including the URL of the record and the reason for the withdrawal request.

# Improving care for people with dementia: development and initial feasibility study for evaluation of life story work in dementia care

Kate Gridley, Jenni Brooks, Yvonne Birks, Kate Baxter and Gillian Parker\*

Social Policy Research Unit, University of York, York, UK

\*Corresponding author

**Declared competing interests of authors:** none

**Disclaimer:** This report contains transcripts of interviews conducted in the course of the research and contains language that may offend some readers.

Published August 2016

DOI: 10.3310/hsdr04230

## Plain English summary

### Improving care for people with dementia

Health Services and Delivery Research 2016; Vol. 4: No. 23

DOI: 10.3310/hsdr04230

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

## Plain English summary

Life story work (LSW) is used to support people with dementia to communicate their life stories. Until now there have been no large-scale, rigorous studies of LSW to see whether or not it works and why.

This research involved:

1. searching for existing evidence
2. asking people with dementia, their carers and professionals about LSW and how to do it well
3. two surveys (of service providers and family carers) to find out where LSW is being done and how
4. two small studies to measure the costs and outcomes of LSW, and to see how feasible LSW is to introduce.

We involved people with dementia on our advisory group and worked with partner organisations to make sure we included as many people with dementia as possible in the research.

We identified what good practice might look like and found that many services now use LSW, but not always to inform care. We found some improvements in staff attitudes towards people with dementia in care homes and some improvements in quality of life for some people with dementia, although we had only small numbers in the study.

The cost of delivering LSW was relatively small, and staff felt that doing LSW encouraged interactions with family and helped staff to get to know the person with dementia.

We therefore think that LSW has potential to help people with dementia and that a full study is needed to judge whether or not this is really so.

# Health Services and Delivery Research

ISSN 2050-4349 (Print)

ISSN 2050-4357 (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: [nihredit@southampton.ac.uk](mailto:nihredit@southampton.ac.uk)

The full HS&DR archive is freely available to view online at [www.journalslibrary.nihr.ac.uk/hsdr](http://www.journalslibrary.nihr.ac.uk/hsdr). 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 *Health Services and Delivery Research* journal

Reports are published in *Health Services and Delivery Research* (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

## HS&DR programme

The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: <http://www.nets.nihr.ac.uk/programmes/hsdr>

## This report

The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 11/2000/11. The contractual start date was in July 2012. The final report began editorial review in April 2015 and was accepted for publication in October 2015. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR 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, NETSCC, the HS&DR programme or the Department of Health. 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 HS&DR programme or the Department of Health.

**© Queen's Printer and Controller of HMSO 2016. This work was produced by Gridley et al. under the terms of a commissioning contract issued by the Secretary of State for Health. 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)).

## **Health Services and Delivery Research Editor-in-Chief**

**Professor Jo Rycroft-Malone** Professor of Health Services and Implementation Research, Bangor University, UK

## **NIHR Journals Library Editor-in-Chief**

**Professor Tom Walley** Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

## **NIHR Journals Library Editors**

**Professor Ken Stein** Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

**Professor Andree Le May** Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

**Dr Martin Ashton-Key** Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

**Professor Matthias Beck** Chair in Public Sector Management and Subject Leader (Management Group), Queen's University Management School, Queen's University Belfast, UK

**Professor Aileen Clarke** Professor of Public Health and Health Services Research, Warwick Medical School, University of Warwick, UK

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

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

**Ms Tara Lamont** Scientific Advisor, NETSCC, UK

**Professor Elaine McColl** Director, Newcastle Clinical Trials Unit, Institute of Health and Society, Newcastle University, UK

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

**Professor Geoffrey Meads** Professor of Health Sciences Research, Health and Wellbeing Research and Development Group, University of Winchester, UK

**Professor John Norrie** Health Services Research Unit, University of Aberdeen, UK

**Professor John Powell** Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), 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 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 Jim Thornton** Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

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

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

**Editorial contact:** [nihredit@southampton.ac.uk](mailto:nihredit@southampton.ac.uk)