Understanding and improving experiences of care in hospital for people living with dementia, their carers and staff: three systematic reviews

Ruth Gwernan-Jones,¹ Ilianna Lourida,¹ Rebecca A Abbott,¹ Morwenna Rogers,¹ Colin Green,² Susan Ball,³ Anthony Hemsley,⁴ Debbie Cheeseman,⁴ Linda Clare,⁵ Darren Moore,⁶ Julia Burton,⁷ Sue Lawrence,⁷ Martyn Rogers,⁸ Chrissy Hussey,⁹ George Coxon,¹⁰ David J Llewellyn,^{11,12} Tina Naldrett⁹ and Jo Thompson Coon^{1*}

- ¹Evidence Synthesis Team, PenCLAHRC, University of Exeter Medical School, College of Medicine and Health, University of Exeter, Exeter, UK
- ²Health Economics Group, University of Exeter Medical School, College of Medicine and Health, University of Exeter, Exeter, UK
- ³Health Statistics Group, PenCLAHRC, University of Exeter Medical School, College of Medicine and Health, University of Exeter, Exeter, UK
- ⁴Royal Devon and Exeter NHS Foundation Trust, Exeter, UK
- ⁵Centre for Research in Ageing and Cognitive Health, University of Exeter Medical School, College of Medicine and Health, University of Exeter, Exeter, UK
- ⁶Graduate School of Education, College of Social Sciences and International Studies, University of Exeter, Exeter, UK
- ⁷Alzheimer's Society Research Network Volunteers, c/o University of Exeter Medical School, College of Medicine and Health, University of Exeter, Exeter, UK
- ⁸Age UK Exeter, Exeter, UK
- ⁹Hospiscare, Exeter, UK
- ¹⁰Devon Care Kitemark, Exeter, UK
- ¹¹Mental Health Research Group, University of Exeter Medical School, College of Medicine and Health, University of Exeter, Exeter, UK
- ¹²The Alan Turing Institute, London, UK

*Corresponding author J.Thompson-Coon@exeter.ac.uk

Declared competing interests of authors: Colin Green is a member of the National Institute for Health Research (NIHR) Health Technology Assessment (HTA) Funding Panel (General) from 2019 to present. David J Llewellyn is a member of the Alzheimer's Research UK grant review board and has provided peer reviewing for the NIHR Dementia Themed Call Committee. Jo Thompson Coon is a member of the HTA General Committee.

Published November 2020 DOI: 10.3310/hsdr08430

Plain English summary

Improving hospital care for people with dementia Health Services and Delivery Research 2020; Vol. 8: No. 43 DOI: 10.3310/hsdr08430

NIHR Journals Library www.journalslibrary.nihr.ac.uk

Plain English summary

F or people living with dementia, being in hospital can be confusing, challenging and overwhelming. This can have a lasting effect on their health and well-being. There is a need to improve the experience of care in hospital of people living with dementia.

This report assessed the research that has already been carried out on this topic and explored:

- 1. what the experiences of care are for people living with dementia in hospital, their families and the staff caring for them
- 2. whether or not approaches to improve the experience of hospital care for people living with dementia work, and how much they cost
- 3. what people who have been involved in such approaches think about them.

We found 96 studies describing experience of care or approaches to improve it. These studies found that people living with dementia, and their families, feel that care does not always meet their needs, which can heighten their distress. Hospital staff are aware that people living with dementia will benefit from a more person-centred approach to care, but they feel that they cannot always provide this because of lack of time, pressures of ward routines, and hospital targets.

Some approaches designed to improve experience of care have had positive results. For example, activity programmes such as music or art-making on wards have helped improve the mood of people living with dementia. Training has helped staff feel more confident in providing more person-centred care. Many studies, however, were not very well designed or were carried out very differently, which meant that it was hard to compare studies.

Overall, this report shows that the more staff can be supported to deliver person-centred care, and the more routine it becomes, the better the experience of care for everyone. Twelve areas of changes to practice to improve experience of care are proposed.

© Queen's Printer and Controller of HMSO 2020. This work was produced by Gwernan-Jones *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 SC16 7NS, UK.

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/).

Editorial contact: journals.library@nihr.ac.uk

The full HS&DR archive is freely available to view online at 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

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, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme

The HS&DR programme funds research to produce evidence to impact on the quality, accessibility and organisation of health and social care services. This includes evaluations of how the NHS and social care might improve delivery of services.

For more information about the HS&DR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/ health-services-and-delivery-research.htm

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 16/52/52. The contractual start date was in February 2018. The final report began editorial review in September 2019 and was accepted for publication in March 2020. 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 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 NHS, the NIHR, NETSCC, the HS&DR programme 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 HS&DR programme or the Department of Health and Social Care.

© Queen's Printer and Controller of HMSO 2020. This work was produced by Gwernan-Jones *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), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).

Editor-in-Chief of Health Services and Delivery 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 Professor of Digital Health Care, 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 Emeritus 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

Editorial contact: journals.library@nihr.ac.uk