Comorbidity and dementia: a mixed-method study on improving health care for people with dementia (CoDem)

Frances Bunn,^{1*} Anne-Marie Burn,¹ Claire Goodman,¹ Louise Robinson,² Greta Rait,³ Sam Norton,⁴ Holly Bennett,⁵ Marie Poole,² Johan Schoeman⁶ and Carol Brayne⁵

¹Centre for Research in Primary and Community Care, University of Hertfordshire, Hatfield, UK

- ²Institute for Health and Society, Newcastle University, Newcastle upon Tyne, UK ³PRIMENT Clinical Trials Unit, Research Department of Primary Care and
- Population Health, University College London Medical School, London, UK ⁴Department of Psychology, Institute of Psychiatry, King's College London, London, UK
- ⁵Department of Public Health and Primary Care, University of Cambridge, Cambridge, UK
- ⁶East London Foundation Trust, London, UK

*Corresponding author

Declared competing interests of authors: Professor Goodman reports grants from the National Institute for Health Research (NIHR) during the course of the study. Dr Norton reports grants from the NIHR Health Services and Delivery Research programme during the course of the study and grants from the NIHR Research for Patient Benefit programme and the Multiple Sclerosis Society, outside the submitted work.

Published February 2016 DOI: 10.3310/hsdr04080

Plain English summary

Improving health care for people with dementia

Health Services and Delivery Research 2016; Vol. 4: No. 8 DOI: 10.3310/hsdr04080

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

Plain English summary

n the UK people living with dementia (PLWD) have an average of 4.6 long-term medical conditions in addition to their dementia. Despite this, health-care services are generally organised around single conditions rather than caring for the person as a whole. The aim of this study was to explore how having dementia alongside diabetes, stroke or vision impairment affects access to care and to identify ways in which services might be improved for this group.

We undertook (1) a review of the literature, (2) a statistical analysis of differences in service use between people with and people without dementia, (3) interviews and group discussions with 28 PLWD, 33 family carers and 56 health-care professionals (HCPs) and (4) a conference in which HCPs, members of the public and representatives from the voluntary sector generated priorities for research and practice.

We found that PLWD may have poorer access to health services than those without dementia. Systems are not designed to involve family carers in decision-making and there is a lack of guidance for HCPs when they are making decisions about care, for example when weighing up the risks and benefits of treatment.

Key elements of good care for PLWD and other medical conditions include having the PLWD and family carer at the centre, flexibility around processes and good communication, which ensures that all services are aware when someone has a diagnosis of dementia. Guidance for HCPs needs to take into account the impact of a diagnosis of dementia on pre-existing conditions such as diabetes.

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: nihredit@southampton.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 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 11/1017/07. The contractual start date was in September 2012. The final report began editorial review in June 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 Bunn *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), produced by Prepress Projects Ltd, Perth, Scotland (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 HTA 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 Peter Davidson Director of NETSCC, HTA, 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

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

Editorial contact: nihredit@southampton.ac.uk