Supporting shared decision-making for older people with multiple health and social care needs: a realist synthesis

Frances Bunn, 1* Claire Goodman, 1 Bridget Russell, 1 Patricia Wilson, 2 Jill Manthorpe, 3 Greta Rait, 4 Isabel Hodkinson 5 and Marie-Anne Durand 6

Declared competing interests of authors: Greta Rait is a member of the Health Technology Assessment (HTA) Commissioning Board and HTA Mental Health Panel and Methods Group. Claire Goodman is a National Institute for Health Research (NIHR) senior investigator and a trustee of The Orders of St John Care Trust. Marie-Anne Durand reports personal fees from EBSCO Health and the ACCESS Community Health Network outside the submitted work. There are no other financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years.

Published August 2018 DOI: 10.3310/hsdr06280

Plain English summary

Shared decision-making for older people with multiple care needs

Health Services and Delivery Research 2018; Vol. 6: No. 28

DOI: 10.3310/hsdr06280

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

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

²Centre for Health Service Studies, University of Kent, Canterbury, UK

³Social Care Workforce Research Unit, King's College London, London, UK

⁴Research Department of Primary Care and Population Health, University College London Medical School (Royal Free Campus), London, UK

⁵Tower Hamlets Clinical Commissioning Group, The Tredegar Practice, London, UK ⁶The Preference Laboratory, The Dartmouth Institute for Health Policy & Clinical Practice, Lebanon, NH, USA

^{*}Corresponding author f.bunn@herts.ac.uk

Plain English summary

In this study we reviewed the evidence to find out how to improve the way we involve older people with multiple conditions, and their family carers, in decisions about their health and social care. We call this approach 'shared decision-making' (SDM). In particular, we wanted to find out how SDM can work in community settings where many different health and social care workers (such as general practitioners, nurses and social carers) may be involved in caring for the older person.

Engaging with stakeholders, such as professionals, patients and carers, we developed an initial 'theory' about how interventions to support SDM for older people should work. This was then tested and developed through a structured search for evidence. We then went back to the stakeholders to test the findings of the review and refine them further.

The findings indicate that, for older people with multiple conditions, SDM should not just be thought of as one conversation between a patient and a doctor. Rather, it should be thought of in terms of a series of conversations that patients, and their family carers, may have with a variety of health and care professionals. Some of the things we know are important for older people are face-to-face consultations, ongoing relationships with trusted professionals and time and space to consider the available options. These help older people to talk about what is important to them and give them the confidence to be involved in decision-making. SDM works best when all the professionals involved understand SDM and think that it is important.

We need more research to tell us how we can best support older people who find engaging in SDM difficult and increased consideration of how workers other than doctors can be involved in SDM.

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 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 15/77/25. The contractual start date was in July 2016. The final report began editorial review in August 2017 and was accepted for publication in January 2018. 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 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 2018. This work was produced by Bunn 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).

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 and EME Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

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

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

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 Director of the NIHR Dissemination Centre, University of Southampton, UK

Ms Tara Lamont Scientific Advisor, NETSCC, 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 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 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 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 editors: www.journalslibrary.nihr.ac.uk/about/editors

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