# Optimum models of hospice at home services for end-of-life care in England: a realist-informed mixed-methods evaluation

Claire Butler,<sup>1\*</sup> Patricia Wilson,<sup>1</sup> Vanessa Abrahamson,<sup>1</sup> Rasa Mikelyte,<sup>1</sup> Heather Gage,<sup>2</sup> Peter Williams,<sup>3</sup> Charlotte Brigden,<sup>1,4</sup> Brooke Swash,<sup>5</sup> Melanie Rees-Roberts,<sup>1</sup> Graham Silsbury,<sup>6</sup> Mary Goodwin,<sup>6</sup> Kay Greene,<sup>7,8</sup> Bee Wee<sup>9</sup> and Stephen Barclay<sup>5</sup>

Declared competing interests of authors: Vanessa Abrahamson has declared employment as a research associate at the University of Kent for the duration of this project and has received funding from the OPtimum hospice at home services for End of Life care (OPEL) project to attend and present OPEL findings at the (online) 2021 International Conference for Realist Research, Evaluation and Synthesis (February 2021). Charlotte Brigden has declared facilitating a support group for clinicians and academics involved in palliative care research projects (the Kent and Medway Palliative Care Research Group). Brooke Swash has declared research funding for other projects from Macmillan Cancer Support (London, UK) and Marie Curie (London, UK) and additional employment as senior lecturer at the University of Chester. Bee Wee has declared that her employer (Oxford University Hospitals NHS Foundation Trust) is reimbursed for her time as National Clinical Director for End of Life Care, NHS England and NHS Improvement.

Published August 2022 DOI: 10.3310/MSAY4464

<sup>&</sup>lt;sup>1</sup>Centre for Health Services Studies, University of Kent, Canterbury, UK

<sup>&</sup>lt;sup>2</sup>School of Biosciences and Medicine, University of Surrey, Guildford, UK

<sup>&</sup>lt;sup>3</sup>School of Mathematics, University of Surrey, Guildford, UK

<sup>&</sup>lt;sup>4</sup>Pilgrims Hospices, Canterbury, UK

<sup>&</sup>lt;sup>5</sup>School of Clinical Medicine, University of Cambridge, Cambridge, UK

<sup>&</sup>lt;sup>6</sup>Lay author (member of the public), University of Kent, Canterbury, UK

<sup>&</sup>lt;sup>7</sup>Mary Ann Evans Hospice, Nuneaton, UK

<sup>&</sup>lt;sup>8</sup>National Association for Hospice at Home, Fareham, UK

<sup>&</sup>lt;sup>9</sup>NHS England, London, UK

<sup>\*</sup>Corresponding author c.butler-779@kent.ac.uk

## **Plain English summary**

Optimum hospice at home services for end-of-life care Health and Social Care Delivery Research 2022; Vol. 10: No. 24 DOI: 10.3310/MSAY4464

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

## **Plain English summary**

ospice at home services have been developed to support people to live at home for as long as possible, and to die at home if that is their preference.

A survey of 70 hospice at home services across England found considerable variation in how services were set up, funded and run. We selected 12 hospice at home services that represent the range of services and recruited 339 patients and their informal carers at home. We interviewed hospice at home staff, local commissioners and bereaved carers. Using a research method called realist evaluation, we used all of the data to understand the key factors that need to come together in each hospice at home service to provide the best possible care. The findings were then presented to a range of people at workshops to confirm them.

We found that hospice at home services support most of their patients to achieve a 'good death' and to die in their preferred place. What people most valued about hospice at home care in the last days of life was the time given to provide hands-on care and develop relationships in the home, by staff experienced in death and dying. Earlier contact from a hospice at home service also had a positive impact on outcomes, and another important factor for success was support for the family carer in the home.

Hospice at home services could be improved by considering their integration with wider local health services and their role in terms of medical/clinical versus hands-on care at different stages. They could look at using volunteers more flexibly and offering bereavement care aligned to what bereaved carers wanted, which was support from staff who were directly involved in the care. Commissioners could facilitate patient preference and reduce the number of hospital deaths by working with hospice at home services to secure their financial position and increase the numbers and range of patients admitted to hospice at home services, without compromising on key features of hospice at home that benefit patients and their family carers.

### **Health and Social Care Delivery Research**

ISSN 2755-0060 (Print)

ISSN 2755-0079 (Online)

Health and Social Care Delivery Research (HSDR) was launched in 2013 and is indexed by Europe PMC, DOAJ, INAHTA, Ulrichsweb™ (ProQuest LLC, Ann Arbor, MI, USA) and NCBI Bookshelf.

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

This journal was previously published as *Health Services and Delivery Research* (Volumes 1–9); ISSN 2050-4349 (print), ISSN 2050-4357 (online)

The full HSDR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr.

#### Criteria for inclusion in the Health and Social Care Delivery Research journal

Reports are published in *Health and Social Care Delivery Research* (HSDR) if (1) they have resulted from work for the HSDR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

#### **HSDR** programme

The HSDR 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 HSDR programme please visit the website at https://www.nihr.ac.uk/explore-nihr/funding-programmes/health-and-social-care-delivery-research.htm

#### This report

The research reported in this issue of the journal was funded by the HSDR programme or one of its preceding programmes as project number 14/197/44. The contractual start date was in February 2017. The final report began editorial review in March 2021 and was accepted for publication in November 2021. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HSDR 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 and Care 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, the HSDR 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, the HSDR programme or the Department of Health and Social Care.

Copyright © 2022 Butler et al. This work was produced by Butler et al. under the terms of a commissioning contract issued by the Secretary of State for Health and Social Care. This is an Open Access publication distributed under the terms of the Creative Commons Attribution CC BY 4.0 licence, which permits unrestricted use, distribution, reproduction and adaption in any medium and for any purpose provided that it is properly attributed. See: https://creativecommons.org/licenses/by/4.0/. For attribution the title, original author(s), the publication source – NIHR Journals Library, and the DOI of the publication must be cited.

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

#### **NIHR Journals Library Editors**

**Professor John Powell** 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 (HSDR, PGfAR, PHR journals) and Editor-in-Chief of HSDR, 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 Consultant in Public Health, Delta Public Health Consulting Ltd, UK

**Dr Peter Davidson** Interim Chair of HTA and EME Editorial Board. Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Ms Tara Lamont Senior Adviser, School of Healthcare Enterprise and Innovation, University of Southampton, UK

Dr Catriona McDaid Reader in Trials, 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 James Raftery** Professor of Health Technology Assessment, School of Healthcare Enterprise and Innovation, University of Southampton, UK

**Dr Rob Riemsma** Consultant Advisor, School of Healthcare Enterprise and Innovation, University of Southampton, UK

**Professor Helen Roberts** Professor of Child Health Research, Child and Adolescent Mental Health, Palliative Care and Paediatrics Unit, Population Policy and Practice Programme, UCL Great Ormond Street Institute of Child Health, London, 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

Please visit the website for a list of editors: www.journalslibrary.nihr.ac.uk/about/editors

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