

# Involving carer advisors in evidence synthesis to improve carers' mental health during end-of-life home care: co-production during COVID-19 remote working

Gunn Grande,<sup>1\*</sup> Kerin Bayliss,<sup>1</sup> Tracey Shield,<sup>1</sup> Jackie Flynn,<sup>2</sup> Christine Rowland,<sup>3</sup> Danielle Harris,<sup>1,4</sup> Alison Wearden,<sup>3</sup> Morag Farquhar,<sup>5</sup> Maria Panagioti,<sup>6</sup> Alexander Hodkinson,<sup>6</sup> Margaret Booth,<sup>7</sup> David Cotterill,<sup>7</sup> Lesley Goodburn,<sup>7</sup> Cedric Knipe<sup>7</sup> and Penny Bee<sup>1</sup>

<sup>1</sup>Division of Nursing, Midwifery and Social Work, School of Health Sciences, University of Manchester, Manchester, UK

<sup>2</sup>Public and Community Involvement and Engagement (PCIE) Panel, NIHR Applied Research Collaboration (ARC) Greater Manchester, Manchester, UK

<sup>3</sup>Division of Psychology and Mental Health, School of Health Sciences, University of Manchester, Manchester, UK

<sup>4</sup>NIHR Applied Research Collaboration (ARC) Greater Manchester, Manchester, UK

<sup>5</sup>School of Health Sciences, University of East Anglia, Norwich, UK

<sup>6</sup>NIHR Greater Manchester Patient Safety Translational Research Centre, Division of Population Health, Health Services Research and Primary Care, School of Health Sciences, University of Manchester, Manchester, UK

<sup>7</sup>Carer Review Advisory Panel, NIHR HSDR project 18/01/01, University of Manchester, Manchester, UK

\*Corresponding author [gunn.grande@manchester.ac.uk](mailto:gunn.grande@manchester.ac.uk)

## Disclosure of interests of authors

**Full disclosure of interests:** Completed ICMJE forms for all authors, including all related interests, are available in the toolkit on the NIHR Journals Library report publication page at <https://doi.org/10.3310/TGHH6428>.

**Primary conflict of interest:** The authors declare no potential conflicts of interest with respect to the research, authorship and/or publication of this article. In addition to the grant for the current project, the authors declare the following NIHR board committee memberships and NIHR funding active during the lifetime of the project or up to 3 years prior to the contract start date:

### Gunn Grande

#### Grants

- NIHR HSDR, NIHR16/02/17: Systematic review and meta-analysis of the effectiveness and cost-effectiveness of inpatient specialist palliative care in acute hospitals for adults with advanced illness and their caregivers (CI Bajwah) £118,802, 12 months, start May 2017.

- NIHR RfPB PB-PG-0614-34070: Peer support to maintain psychological wellbeing in people with advanced cancer: a feasibility study for a randomised controlled trial (CI Walshe) £249,767, 36 months, start November 2015.
- NIHR CLAHRC GM IS-CLA-0113-10021: NIHR Collaboration for Leadership in Applied Health Research and Care Greater Manchester (CI Boaden), £9,998,769 (£555,487 end-of-life care), 60 months, start January 2014.

### **Christine Rowland**

#### Funded post

- NIHR Greater Manchester Research Design Service: part-time funded front-line advisor. Start December 2019.

### **Danielle Harris**

#### Funded post

- NIHR ARC NIHR200174: Research Assistant NIHR Applied Research Collaboration Greater Manchester Healthy Ageing Theme.

### **Morag Farquhar**

#### Fellowships

- NIHR Career Development Fellowship, NIHR-CDF-2012-05-218: Trajectories in advanced chronic obstructive pulmonary disease (COPD): determining a new paradigm for the care and support of patients and their informal carers at the end of life (Living with Breathlessness study). £601,925, 48 months, start December 2012.

#### Grants

- NIHR ARC EoE NIHR200177: NIHR Applied Research Collaboration East of England (CI Jones), £9,000,000 (£225,103 palliative and end-of-life care), 60 months, start October 2019.
- NIHR RfPB PB-PG-0418-10045: Online Acceptance and Commitment Therapy for family carers of people with dementia: a feasibility study of a new mode of delivery (iACT4CARERS) (CI Kishita). £232,622, 24 months, start September 2019.
- NIHR RfPB PB-PG-1216-20022: Development, refinement and acceptability of an educational intervention for informal carers of patients with breathlessness in advanced disease (Learning about Breathlessness study 2: LaB2) (CI Farquhar). £149,622, 20 months, start September 2018.
- NIHR School for Primary Care Research grant no. 343 – within SCPR-2014-10043: 'I'm fine': exploring patient and carer assertions of status in advanced COPD and clinical implications for primary care (CIs Gardener & Duchinsky). £24,420, 12 months, start April 2017.
- NIHR HSDR NIHR 16/02/18: An evidence synthesis of holistic services for refractory breathlessness in advanced malignant and non-malignant disease (CI Maddocks). £128,612, 14 months, start February 2017.
- NIHR SCPR FR11: Seedcorn funding for SNAP2 preparatory work (CI Gardener). £9696, 3 months, start December 2016.
- NIHR RfPB PB-PG-0712-28073: Effects of ambulatory oxygen on breathlessness, quality of life and mobility in patients with idiopathic pulmonary fibrosis (CI Renzoni). £317,202, 30 months, start August 2014.

## **Maria Panagioti**

### Grants

- NIHR GMPSTRC-2012-1: NIHR Greater Manchester Patient Safety Translational Research Centre (CI Campbell). £7,562,320, 60 months, start 1 April 2017.
- Project 390 NIHR School for Primary Care Research: Improving the evidence base for primary care: NIHR Evidence Synthesis Working Group (CI Heneghan). £1,917,000, 36 months, start 1 April 2018.
- Project 408 NIHR School for Primary Care Research: Investigating burnout in general practitioners and indicators of suboptimal patient care using the RCGP Research Surveillance Centre database (CI Panagioti). £208,631, 24 months, start 1 April 2019.
- PR-R20-0318-21001 NIHR Policy Research Programme: Reducing avoidable patient harm in prison health care (CI Shaw). £1,233,446, 48 months, start 1 June 2019.

## **Alexander Hodkinson**

### Fellowship

- NIHR 'Three Schools Mental Health' Senior Fellowship. £250,350, 30 months, start January 2020.

## **Penny Bee**

### Committee memberships

- Member of NIHR RfPB Northwest Funding Panel 2016–18 and renewed membership for a second term between 2018 and 2020.
- Invited member of the Scrutiny Sub-committee for the NIHR RfPB/RfSC Mental Health Research Call in Northern England 2021.
- Holder of 4-year tenure on Subcommittee A Stage 2 Programme Grants from 2022.

### Grants

- NIHR ARC NIHR200174: NIHR Applied Research Collaboration for Greater Manchester (CI Cullum) – Mental Health Theme. £8,999,722 (£2M mental health), 60 months, start 1 October 2019.
- NIHR i4i NIHR203827: Improving mental health literacy among children and young people aged 11–16 in the United Kingdom. £150,000, 12 months, start 1 January 2021.
- NIHR RfPB PB-PG-0418-20011: Co-adaptation of a social network intervention to support recovery for people living with severe mental illness (ConNEct) (CI Brooks), £150,000, 18 months, start 1 July 2019.
- NIHR HTA NIHR 17/80: Psychosocial intervention to address the mental health needs of parents/carers of children newly diagnosed with autism (CI Green), £1,395,164, 42 months, start 1 May 2019.
- NIHR HSDR NIHR 17 September 2008: Services to support early intervention and self-care for children and young people referred to Children and Young People's Mental Health services (CI Pryjmachuk), £643,000, 36 months, start 1 October 2018.
- NIHR PGfAR RP-PG-1016-20010: Enhancing the quality of psychological interventions delivered by telephone (CI Bee), £2,524,745, 60 months, start 4 February 2018.
- NIHR HTA 16/101/02: De-escalation techniques and the use of restrictive interventions in adult mental health units (CI Price), £520,112.84, 30 months, start 1 January 2018.

- NIHR HTA 15/38/04: A non-inferiority RCT comparing the clinical and cost-effectiveness of one session treatment with multi-session CBT in children with specific phobias (CI Wright), £1,371,954, 48 months, start 1 January 2016.
- NIHR HTA 14/68/08: Multicentre RCT of a group psychosocial intervention for postnatal depression (CI Husain), £1,964,501, 48 months, start 1 February 2016.

Published October 2023  
DOI 10.3310/TGHH6428

## Plain language summary

Involving carer advisors in evidence synthesis to improve carers' mental health during end-of-life home care: co-production during COVID-19 remote working

Health and Social Care Delivery Research 2023  
DOI: 10.3310/TGHH6428

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

# Plain language summary

## Background

Family carers are crucial in supporting people nearing the end of life, but their own mental health may often suffer as a consequence. This project summarised what is known about what makes carers' mental health better or worse. Researchers worked with a carer Review Advisory Panel to ensure that project findings were understandable and useful to carers.

## Aims

To report key findings on what made the teamwork between researchers and carers successful; to help improve teamwork in other projects; and to present carers' own recommendations on how to improve their mental health.

## Process and principles

Nine Review Advisory Panel meetings were held which included four to five carers, a lay Chair and three researchers. Important early preparation included getting to know each other and agreeing how to work together. Key meeting principles were: (1) bringing carer voices to the fore by having a majority of carers and an experienced carer as Chair; (2) highlighting the value placed on meetings by having several researchers attend, including the project lead; (3) flexibility to include carers' own agenda and project changes; and (4) appropriate and prompt carer payment. Meetings had to adapt to online working due to COVID-19.

## Outputs

Carers moved from being advisors to taking more initiative and producing their own carer recommendations, which became a main project output.

## Reflection

Written reflections by carers and researchers indicated that successful teamwork arose from a shared sense of purpose and gains, mutual commitment and respect, and bridging between researcher and carer perspectives through training, communication, negotiation and compromise. Early preparation helped the group adapt to the challenges of online working. Carer representation on other project committees could have been improved.

## Conclusion

Project principles enabled good researcher-carer teamwork and produced valuable carer recommendations, but need proper investment in time and resources. Online working can be successful, but needs good face-to-face preparation.

