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

[1]Division of Nursing, Midwifery and Social Work, School of Health Sciences, University of Manchester, Manchester, UK
[2]Public and Community Involvement and Engagement (PCIE) Panel, NIHR Applied Research Collaboration (ARC) Greater Manchester, Manchester, UK
[3]Division of Psychology and Mental Health, School of Health Sciences, University of Manchester, Manchester, UK
[4]NIHR Applied Research Collaboration (ARC) Greater Manchester, Manchester, UK
[5]School of Health Sciences, University of East Anglia, Norwich, UK
[6]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
[7]Carer Review Advisory Panel, NIHR HSDR project 18/01/01, University of Manchester, Manchester, UK

[*]Corresponding author

Disclosure of interests of authors

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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.

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Abstract

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

[1]Division of Nursing, Midwifery and Social Work, School of Health Sciences, University of Manchester, Manchester, UK
[2]Public and Community Involvement and Engagement (PCIE) Panel, NIHR Applied Research Collaboration (ARC) Greater Manchester, Manchester, UK
[3]Division of Psychology and Mental Health, School of Health Sciences, University of Manchester, Manchester, UK
[4]NIHR Applied Research Collaboration (ARC) Greater Manchester, Manchester, UK
[5]School of Health Sciences, University of East Anglia, Norwich, UK
[6]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
[7]Carer Review Advisory Panel, NIHR HSDR project 18/01/01, University of Manchester, Manchester, UK

[*]Corresponding author gunn.grande@manchester.ac.uk

Background: Family carers play a central role in supporting people at the end of life, but often suffer detrimental impacts on their own mental health as a result. This project conducted evidence synthesis of research into factors that may affect carers' mental health to help identify ways of maintaining their mental health. It worked closely with a carer Review Advisory Panel to help ensure the findings made sense and were communicated meaningfully from the carers' perspective.

Aim: To present: (1) principles and components that facilitated successful patient and public involvement in an evidence synthesis project to help inform patient and public involvement in similar projects; (2) recommendations for carer support that were instigated and produced by the Review Advisory Panel.

Process and principles: Nine Review Advisory Panel meetings including four to five carers, a lay Chair and three researchers were held.

Solid 'groundwork' was invested in recruitment and relationship-building prior to meetings, and it was ensured that there was agreement of how to work together and clarification of expectations at the first meeting.

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Key meeting principles were:

- having a majority of carers, and a Chair with both carer and patient and public involvement experience, to ensure carer voices remained at the fore
- substantial researcher representation, including the project lead, to highlight the value placed on Review Advisory Panel meetings
- flexibility to follow carers' agendas, enabling 'space to talk' and 'space to change'
- appropriate and prompt carer payment, again emphasising patient and public involvement value to the project.

Added general principles were: ongoing training, ample funded time for Review Advisory Panel preparation and ongoing communication outside meetings.

COVID moved all meetings online after the first meeting, but the principles were maintained.

Outputs: The project saw an evolution from patient and public involvement consultation to co-production. The main patient and public involvement output was recommendations for supporting carers based on project findings, instigated and produced by the Review Advisory Panel.

Reflection on successful components and challenges: Five carers (including the Chair) and six researchers responded to questions by e-mail. Analysis by one researcher, aided by two other researchers, was then reviewed by all participants and revised.

Both carers and researchers felt the components that made the patient and public involvement work were: (1) a shared sense of purpose of and gains from the Review Advisory Panel; (2) personal gains; (3) mutual commitment and respect; and (4) bridging between academic and lay perspectives, through investment in training, ensuring carers were able to meaningfully comment, and continuous negotiation and compromise.

Challenges were that the COVID-induced move from face-to-face to online meetings reduced informality, flexibility, personal connection and non-verbal communication. However, earlier groundwork facilitated group resilience to these challenges. Patient and public involvement representation on the wider Research Management Group proved less successful, flagging the importance of negotiating and defining patient and public involvement roles at all project levels.

Conclusion: The patient and public involvement principles employed, including meeting composition and chairing, and flexibility to follow carers' agendas, appeared to facilitate the evolution from consultation to co-production of carer recommendations, but require further testing. Preconditions for successful remote working should be further investigated, as the different advantages of face-to-face and virtual meetings may be combined through hybrid working. The iterative and responsive working required for genuine co-production may require more flexible patient and public involvement funding models.

Study registration: This study is registered as PROSPERO registration 2019 CRD42019130279 at https://www.crd.york.ac.uk/prospero/.

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List of supplementary material

Report Supplementary Material 1 Carer recommendations: full details

Supplementary material can be found on the NIHR Journals Library report page (https://doi.org/10.3310/TGHH6428).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.

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Glossary

Carer: The terms 'family' and 'informal carers/caregivers' are used interchangeably to refer to adult lay carers. The term 'lay carer' or 'carer' is defined according to the broad definition adopted by the National Institute for Health and Care Excellence [*Guidance on Cancer Services*, *Improving Supportive and Palliative Care for Adults with Cancer*, *The Manual*. NICE guideline; 2004:**159**. URL: https://www.nice.org.uk/guidance/csg4/resources/improving-supportive-and-palliative-care-for-adults-with-cancer-pdf-773375005 (accessed 9 September 2023)]: 'Carers, who may or may not be family members, are lay people in a close supportive role who share in the illness experience of the patient and who undertake vital care work and emotion management', which relates to unpaid carers who might be a partner, family member, friend or neighbour of the person they are caring for.

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List of abbreviations

ARC GM	Applied Research Collaboration Greater Manchester	NIHR	National Institute for Health and Care Research
CRT	Core Research Team	PCIE	public and community involvement and engagement
EOL	end of life	PPI	patient and public involvement
GRIPP	Guidance for Reporting Involvement of Patients and the Public	RAP	Review Advisory Panel
		RMG	Research Management Group

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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.

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Introduction

Patient and public involvement (PPI) in research has been defined as 'research being carried out "with" or "by" members of the public rather than "to", "about" or "for" them'.[1] The importance of involving patients, carers and members of the public in health research has long been recognised.[2] Such involvement can improve the quality, relevance and impact of research[2] by involving people who have direct, experiential knowledge of living with an illness and of being on the receiving end of services.[2–4] This brings different knowledge and expertise which can lead to greater insights than would be possible without PPI. Further, there is an ethical argument that people have a right to have a say in research that is likely to affect them and their care.[2,4]

Patient and public involvement in systematic reviews is important to ensure their relevance and meaning both to the people affected by a health condition or context and to people using the reviews to inform health policy and practice.[5] Benefits again include insights from first-hand experience, researchers and PPI members learning from each other, and improved relevance, communication and dissemination of findings.[6] PPI members may also gain new skills and confidence.[7,8]

This paper reports on PPI work with a carer Review Advisory Panel (RAP) in a metasynthesis of research on what might lead to, or prevent, poor mental health (e.g. anxiety, depression, distress) in carers who look after a family member or friend who is at the end of life (EOL). Stage 1 of the project involved separate syntheses of the relevant qualitative,[9] observational quantitative[10] and intervention literature, integration of these reviews within a common framework,[11] and creation of draft project outputs. Stage 2 involved one-off workshops and focus groups with key stakeholders (carers, patients, practitioners, commissioners, policy-makers) to help tailor contents and presentation of outputs to each stakeholder group.

The carer RAP provided PPI throughout stages 1 and 2. The RAP PPI was a secondary focus of the project, albeit a very important one where continuous, meaningful involvement was sought. The RAP planned role in stage 1 included a review of project evidence and findings to see if they made sense to carers, how they could be meaningfully presented and combined into a common framework, and whether there were gaps to be addressed in further research; in stage 2 they advised on consultation and dissemination. However, the role evolved over time as the RAP took more control over their contributions to produce carer-led recommendations from project findings. These recommendations became an important output in their own right alongside review findings.

Review Advisory Panel involvement was therefore initially limited to the roles of 'contributing', where there is indirect influence over the review process, and 'influencing', where there is direct influence on the review but without direct control over decisions or the process.[5] Alternatively, the role could be summarised as 'consultation'.[1,2] However, the aim was to truly listen and be responsive to carers' views, even if this took the project in new directions. The project therefore provided what Knowles *et al.*[3] refer to as 'space to talk' and 'space to change'. 'Space to talk' meant enabling shared dialogue and recognising carer and researcher expertise as equally valuable. 'Space to change' allowed for adaptation in response to carer feedback, both to the study and the way of working together.[3] Consequently, the RAP's role evolved into becoming more 'controlling'; that is, making decisions and controlling parts of the process,[5] or approaching more genuine 'collaboration' and co-production.[1–3,12] This evolution took place within the constraints imposed by the COVID pandemic, where involvement had to be adapted from face-to-face to remote working.

This paper aims to add to the limited literature on PPI in systematic reviews by reporting lessons learnt for creating space for genuine co-production within a tightly defined literature review project and achieving meaningful PPI in the context of remote working. It addresses a recognised need for more transparent and critical reporting of PPI in research to progress beyond separate case studies

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and capture the impacts of PPI, improve the evidence base, encourage innovation and enable robust appraisal.[4,8] The Guidance for Reporting Involvement of Patients and the Public (GRIPP2) reporting checklists have been developed to help address this.[13] As PPI was a secondary focus of the project, our reporting is guided by the GRIPP2 Short Form.[13]

The aims of the project overall were to help improve mental health among carers during EOL through evidence synthesis of factors related to carer mental health and translation of findings into accessible information for key stakeholders, to better target future efforts to improve carers' mental health. The aims of PPI were to ensure study findings and outputs were relevant and accessible to carers themselves and reflected a carer perspective.

The aims of this paper are to present principles and components that facilitated successful PPI in an evidence synthesis project to help inform PPI in similar projects.[13] This includes presentation of:

- methods, in the form of the principles and processes applied to foster good PPI in the project
- results, in the form of outcomes from PPI in the study, particularly carer recommendations initiated and produced by the RAP
- reflections by carers and researchers on what worked well and less well
- discussion, including critical reflection on principles, remote working, PPI resourcing and limitations.

Methods: principles and processes applied

Creating a carer Review Advisory Panel

The project included a carer co-applicant (JF) to ensure PPI in project design from the outset. JF had PPI experience as an advisor on the Public and Community Involvement and Engagement (PCIE) Panel of the NIHR Applied Research Collaboration Greater Manchester (ARC GM). Co-applicants highlighted the need for a carer RAP within the design to ensure the carer voice was a central part of the project.[5,14] This would facilitate carers being involved in all stages of the project, including having input into the search terms to identify relevant literature, analysing the qualitative data, ensuring that interpretation and synthesis of findings remained grounded in carers' experience and concerns, and ensuring that dissemination materials were understandable and meaningful from the carers' perspective.

The recruitment process aimed to ensure potential RAP members had a clear understanding of what they were being invited to do.[1,6] Plain English recruitment adverts and further information for carers interested in becoming involved were developed with JF and another carer on the PCIE Panel of ARC GM. These covered project aims, the role of the RAP and how it would work, and who could apply and how. Detailed documents were also provided on terms of reference, including RAP member role description, and payment policy.

Both open and targeted recruitment strategies were employed[5] to ensure wide reach. The project was advertised widely through Twitter with links to project webpage information. Further, local carer support groups were identified and were e-mailed flyers and further information. In a second recruitment drive, KB followed up with additional e-mails and phone calls, and located and contacted additional relevant groups. Finally, potential candidates known to JF were contacted directly.[1,5]

To help ascertain eligibility and ensure equitable access and diversity in the composition of the RAP, all candidates completed a brief application form, through e-mail, paper document or online survey. The project aimed to recruit six RAP members who varied in terms of age, sex, ethnicity, experiences of caring for patients with different conditions, and experience of PPI.[1] A selection process protocol was set up to shortlist applicants and conduct interviews to identify the final RAP membership. However, as there was only a small number of applicants (eight), KB conducted informal telephone conversations with all to check their understanding of the project and ability to commit to regular meetings, and to gain information on their demographics, background of caring and PPI. This information was anonymised, tabulated and mapped to the recruitment criteria to identify the candidates who represented the widest range of carer experiences; for example, five of the candidates were men, of whom three were selected to ensure gender balance. The resulting group had balanced numbers of males and females, ethnic minority community representation, and included carers of people with cancer or non-cancer diagnoses, with long-term or shorter-term experience of caregiving, and ranging from extensive PPI experience to none.

Pre-RAP preparation and relationship-building was facilitated by KB and TS through individual face-to-face meetings with the selected RAP members to explain what was required of the role in more detail[1,5,14] and give carers an opportunity to tell their story. This proved extremely beneficial in building researcher–carer relationships, so carers felt comfortable and able to contribute when attending their first RAP meeting. Unfortunately, the carer from the ethnic minority community stepped back before the first RAP meeting due to personal circumstances, leaving a total of five RAP members. A second carer stepped back towards the end of the project, as the role evolved to be more demanding, but was still able to make a substantial contribution.

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Meeting principles, formats and processes

The RAP met nine times in total. *Table 1* provides an outline of the meetings and their content.

Below we outline the principles that guided the meetings (see *Box 1* for summary).

TABLE 1 List of carer RAP meetings

RAP meeting (date)	Content
RAP 1 (11 February 2020)	**Introduction to the project** Core objectives: introduce research team; develop ways of working; provide an overview of the project; define PPI and role of RAP members; introduction to health research and systematic reviews; clarify PPI payment policy.
RAP 2 (28 April 2020)	**Training session for the carer advisory role: analysis of papers for the qualitative review** Core objectives: introduction to using Zoom; define qualitative research; introduction to systematic reviews – a recap; aims of qualitative systematic review – a recap; define role of carer advisor; introduction to analysis techniques (coding data from selected qualitative papers); outline the analysis task (to analyse three qualitative research papers and summarise the findings).
RAP 3 (15 June 2020)	**Feedback session for carer advisors: discussion of themes arising from analysis of three qualitative research papers** Core objectives: to discuss the themes identified by both carer advisors and research team and identify first-order construct themes from the qualitative literature that make sense to carers.
RAP 4 (30 July 2020)	**Presentation and discussion of preliminary quantitative observational review findings and overall qualitative findings** Core objectives: introduction to quantitative research – a recap; aims of observational review – a recap; overview and discussion of preliminary observational review findings; overview and discussion on the most helpful ways of presenting numerical findings (including results of meta-analysis); overview and discussion of the overall themes from the qualitative review.
RAP 5 (1 October 2020)	**Presentation and discussion of final quantitative observational review findings** Core objectives: introduction to quantitative research – brief recap; aims of observational review – brief recap; observational review process – brief recap; overview and discussion of final observational review findings.
RAP 6 (26 November 2020)	**Presentation and discussion of the 'pulling together' of the observational review and qualitative review findings** Core objectives: presentation and discussion of different levels of information; presentation and discussion of overarching map of themes; presentation and discussion of overarching map of themes mapped onto psychological models of stress and strains of caregiving.
RAP 7 (28 January 2021)	**Presentation and discussion of intervention review findings** Core objectives: overview and discussion of intervention review findings; introduction to making recommendations from the research evidence.
RAP 8 (25 February 2021)	**Developing recommendations** Core objectives: developing recommendations from the overall research evidence.
RAP 9 (15 July 2021)	**Project update, feedback on stakeholder consultation and discussion of project outputs** Core objectives: project update; feedback on stakeholder consultation; seek views on involvement in project outputs (e.g. podcasts, leaflets/booklets/posters and formal reports/publications); finalise recommendations; organise end-of-project get-together.

BOX 1 Principles for working with the carer RAP

Recruitment

- Clear information on what potential RAP members were invited to do
- A range of recruitment strategies, both open and targeted, for a broad reach
- Application form (with several response options: paper, e-mail, online) and a selection process protocol to help ascertain eligibility and ensure equitable access and diversity in the PPI group

Preparation

- Individual meetings between RAP members and researchers prior to RAP meetings to prepare RAP members and build researcher–carer relationships
- First RAP meeting focusing on: (1) relationship-building within whole group; (2) agreeing how to work together; (3) clarifying expectations; and (4) training in basic concepts

Ongoing principles

- RAP meeting principles
  - a majority of carers at meetings to ensure carers were comfortable to express views
  - substantial researcher representation, including the project lead, to highlight value placed on RAP meetings
  - a Chair with both carer and PPI experience, to ensure carer voices remained at the fore
  - space to follow carers' agenda, giving carers 'space to talk' about aspects outside the scheduled agenda and providing a 'space to change' project materials, processes and outputs in response to carer feedback
- Appropriate and prompt payment, including preparation work and reimbursement for travel
- Ongoing communication
  - proactive contact with RAP members by e-mail outside meetings
  - writing up and circulating carer feedback to ensure it had been properly understood
  - providing an alternative channel for raising carer concerns through the Chair
  - ensuring RAP members saw how their input made a difference
- Ample time for carers to prepare for meetings, with clear instructions
- Ongoing training, including new material and refreshing of previous material

Appropriate resourcing throughout to make the above principles possible

Starting-up principles

The first face-to-face meeting (3 hours) was essential in laying the foundations for the RAP collaboration and building trust. It focused on the core principles of (1) relationship-building, (2) agreeing how to work together, (3) clarifying expectations and (4) training.[1,5,14] First, time and space to socialise and share experiences were factored in at the beginning, during and at the end of the meeting. Second, identifying ways of working together was the first core agenda item, with both researchers and carers contributing to generating a list. This included keeping personal information confidential, treating others with respect and establishing that 'there are no silly questions' (see *Box 2* for the agreed list). Third, the group discussed what the RAP carers could expect from the project itself (its content and aims), and what they could expect from the research team. This included a good working relationship based on mutual trust and respect, clear information on what the team were asking of them, feedback on how their contribution was making a difference, and a contact outside meetings for queries and support. Then, to help define carers' role within the project, the researchers presented general principles of PPI and asked carers to discuss informally (during the break) what they expected to gain from the project. The group then talked through what it was hoped the RAP could contribute to the project, including helping to make sense of the evidence, communicating findings to others and identifying problems with the project and potential solutions. Finally, introductory training in systematic reviews and qualitative and quantitative research was provided. A 'jargon buster' list was started to define academic terms that carers were unsure of.[1,14]

BOX 2 Ground rules for ways of working

1. Any personal information is confidential and will not be shared outside the group
2. There are no silly questions
3. Everyone is valued
4. Observe personal boundaries
5. Everyone will be respected when talking
6. Deal with differences of opinion or conflicts in a calm and professional way
7. No racist, homophobic or sexist comments
8. All jargon will be explained (unfamiliar words to be added to a 'jargon buster' dictionary)
9. The agenda is used only as a guide to allow discussions to flow

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Ongoing meeting principles

To ensure carer voices were heard and valued, the project focused on the composition and chairing of the RAP meetings and on providing space to follow the carers' agenda. It also followed recommended principles for appropriate payment, training, preparation and communication.[1,5]

Review Advisory Panel meeting composition: carer majority and researcher commitment

Review Advisory Panel meetings comprised five or six carer members, including the Chair, and three researchers. The aim was that carers should be regarded as partners and should feel free to express their views and feel valued. To facilitate this, carers formed the majority group and researchers the minority group at meetings, so carers could more easily support each other and express their views. However, to highlight the importance of the RAP to the project, there was substantial researcher representation, with the Principal Investigator always one of the researchers present.

The Review Advisory Panel Chair should be a carer

It was considered crucial to have a carer chair the RAP, rather than a researcher. This gave a signal that carers' views were at the fore and that their input was valued equally to that of the researchers. However, it was also important to ensure this carer had chairing experience and felt confident and comfortable in the role, and to help ensure meetings were run efficiently and effectively. Consequently, JF was asked whether she was willing to take on the chairing, given her familiarity with the project as the carer representative on the project Research Management Group (RMG) and her previous PPI experience. JF agreed, but requested the role be properly defined so there was clarity regarding the expectations of her role as RAP Chair and how this would be combined with her RMG role. A member of the research team liaised with the Chair before meetings to review each meeting's aims and how best to conduct them and to ensure the Chair was up to date with project developments. During meetings, the Chair ensured carers' views remained at the fore and that all carer members were encouraged to participate in discussions.[1]

Space to follow carers' agenda

Although all meetings had a clear agenda, this served as a guide rather than a fixed structure for meetings, to encourage RAP members to express their perspectives freely and allow discussion to flow productively. This facilitated the principles of 'space to talk' and 'space to change'.[3] If carers began to explore aspects outside the scheduled agenda or materials, the meeting would follow these discussions through and then consider how they informed the project as a whole. This might only involve changes to project materials, but sometimes it had implications for future PPI work, which was then flagged and negotiated (see *Results*). Having a clear agenda, however, helped ensure core scheduled items were still returned to and addressed in the course of the meetings.

Proper and prompt payment

Project policy was to pay RAP members for time spent at the RAP meetings and time preparing for meetings, including analysis.[1,5,15] However, RAP members decided themselves whether they wanted payment or not, and whether in money or voucher form. Members were also reimbursed for any travel costs. The initial aim was to pay participants in cash at the end of each meeting, so there would be no delay in payment.[3] However, COVID and a move to online working meant this was only possible for the first and only face-to-face meeting. Payment thereafter was via bank transfer managed through the university claim form system.

Initially, higher pay rates were applied for meeting attendance than for meeting preparation. However, as RAP members were set tasks prior to meetings, or at least were required to engage closely with meeting materials, the effort involved in meeting preparation became more similar to that of the meetings themselves. The project therefore changed to a flat, high rate for all hours spent and an added a £5 fee per online meeting to cover members' internet connection.[15]

Enabling Review Advisory Panel members to prepare

Before each meeting, it was important that RAP members knew what they were being asked to do and what the meeting agenda and contents were, and that they had time to consider the meeting materials.[1,7] Meeting documents and slides were therefore sent well in advance, in each RAP member's preferred format (electronic or paper), allowing them at least a week to review materials and prepare.

Ongoing training

Training was an ongoing component of meetings.[1,6,7] The training included general introductions to health research, systematic reviews and qualitative and quantitative research, accompanied by more in-depth coverage of qualitative reviews, qualitative analysis techniques and coding of data with illustrative template(s), and similarly, quantitative review processes and presentation of numerical findings. Meetings covered both new materials and repetition of training related to previous meetings as required, to ensure members were familiar with or 'refreshed' regarding methods and concepts to be discussed (see *Table 1* for contents of each meeting). Templates with examples were provided for tasks. Questions were always welcomed and efforts were made to avoid jargon;[7] any new terms were added to the list of 'jargon buster' definitions.

Ongoing communication

The project followed the following principles for good communication:[5,7] (1) maintaining proactive contact with RAP members by e-mail so they felt supported, rather than wait for them to come to researchers with questions; (2) ensuring RAP feedback had been properly understood, by writing up and circulating feedback to ensure it captured what carers wanted to say; (3) providing an alternative channel for raising concerns, by encouraging RAP members to contact the Chair after meetings regarding any concerns or suggestions for improvement, which were fed back anonymously to researchers, as appropriate; (4) ensuring RAP members saw how their input made a difference,[6] through meeting updates, participation in stage 2 stakeholder meetings and a post-project meeting.

Adaptations in response to COVID

After the first face-to-face meeting, the project had to adapt to online meetings due to COVID restrictions. This was a challenge for some carers who had not used Zoom™ (Zoom Video Communications, San Jose, CA, USA) before or who had to borrow a computer to join the group. KB tested Zoom with each member before the first online meeting to ensure everyone would be able to link up; however, one member was unable to activate their camera. As Zoom meetings can be more taxing than those conducted face to face, the meetings had to become shorter (2 hours maximum, including a break) and were therefore also more structured, with more emphasis on pre-meeting preparation. However, flexibility to let meetings follow the flow of the group discussion was retained, and the group continued to work well.

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Results: outputs in the form of Review Advisory Panel contributions to the project

Review Advisory Panel involvement as planned

The RAP made the following contributions set out in the original project aims: reviewing the search strategy; contributing to qualitative review analysis; reviewing findings and helping shape the presentation of findings; considering how findings may fit together within a comprehensive framework; supporting the stage 2 stakeholder consultation; and reviewing final project products (dissemination materials and reporting). Some further details are outlined below.

Importantly, the RAP ensured the content of the synthesis was meaningful. They were central in ensuring that the qualitative literature synthesis identified factors associated with carer mental health and grouped them into themes that were meaningful from carers' perspective.[9] The main themes were 'patient condition', 'impact of caring responsibilities', 'finances', 'relationships', 'carer internal processes' and 'support'. Findings from the subsequent quantitative observational and intervention syntheses were then mapped onto these themes (with an added theme of 'contextual factors'). The RAP reviewed whether the subthemes to these main themes made sense to carers and whether anything was missing. One clear gap identified by the RAP was the lack of consideration of the impact of financial factors on carer well-being within the quantitative literature.[10] Additional missing components were: identifying as a 'carer', loss of own identity and limited consideration of ethnicity. Further, while the quantitative literature labelled some coping strategies as 'dysfunctional' or maladaptive, RAP members considered these as potentially helpful strategies in some circumstances, in the moment and in the context of an individual's caregiving situation. Rather than labelling coping strategies as 'dysfunctional' or 'functional', it was felt that these should be judgement-free and simply presented as coping strategies found to be associated with 'better', 'worse' or 'no change' to carer mental health within the literature.[10]

The RAP also advised on the presentation format of the findings. This included presentation of numerical data using colour-coded columns to highlight the number of investigations showing that a factor was associated with worse carer mental health (red) or better carer mental health (green), or showed no association (neutral colour).[10] Further, RAP members advised on how the total body of evidence could be organised into different levels of detail to enable stakeholders to first gain an overview of findings and then find the detailed content relevant to them (further detail will be reported elsewhere).

Finally, the RAP contributed to stage 2, where 'products' from syntheses were presented to other stakeholders (additional carers, patients, practitioners, commissioners, policy-makers) for feedback. The RAP advised on how to involve additional carers. Further, five RAP members, including the Chair, wanted to be involved in the stage 2 workshops and discussion groups, either as active participants or as observers. Four participated in the four online workshops with carers, practitioners and commissioners/policy-makers as participant (the Chair) or observers, and four RAP members each participated in one of two online discussion groups with GPs and carers. Further details about the stage 2 consultation and products will be reported elsewhere (https://www.arc-gm.nihr.ac.uk/carer-project-). Three RAP members agreed to feed back on the qualitative synthesis report,[9] and all members contributed to the current paper through participation in reflection on their RAP involvement and paper review.

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Changes to the project plan

The 'space to talk' within the project introduced perspectives beyond the original plan which were then accommodated through 'space to change'.[3] This led to greater RAP involvement in the qualitative review analysis, using a simplified framework to organise findings, and most importantly, the addition of carer recommendations to the project 'products'.

The RAP's wish to be involved in the analysis and to develop recommendations expanded the number of meetings from the planned six meetings to nine in total. The added resources required to cover additional RAP hours and project time were aided by cost savings in moving from face-to-face to online activities. We outline project changes further below.

Whole-group engagement in qualitative synthesis

The initial plan, introduced in meeting 1, was for the qualitative data extraction and analysis to be conducted by KB and one or two carer co-analysts. However, RAP members decided that they would all like to contribute to data extraction and/or analysis as a group. Three members of the group agreed to conduct data extraction, and then the group as a whole discussed the themes that emerged from the data.

To accommodate a change to whole-group analysis, KB delivered training on qualitative research methods in meeting 2 and recapped the systematic review training. The RAP members were given three papers (10% of the total) and asked to consider the results of the papers, identify sections that described things that affected carers' mental health, and write notes on the themes and subthemes within these. They were also given questions to help them think about themes and a template for recording thoughts on themes.[7,9] All received the same papers, selected for maximum variation and clarity, and completed data extraction in their own time. KB collated the findings, and these were then discussed at meeting 3. The fourth RAP meeting continued to focus on the qualitative metasynthesis. KB presented the themes and subthemes she had identified from the three papers, and the group discussed similarities and differences between the themes identified by the carers, how the findings related to the carers' experiences, and what themes they believed were missing (see Bayliss *et al.*).[9]

Simplified framework for organising findings

The project originally aimed to use existing psychological models of factors affecting carers' mental health[16–18] as a framework for the final organisation and presentation of findings for stakeholders in stage 2. However, work with the RAP on a potential updated model suggested that this may not aid presentation, and that a simple presentation of themes would be as helpful (and less confusing). In particular, RAP members felt the perspective on caregiving from models was too linear and did not reflect the dynamic nature of caregiving, the continuous interaction between themes, and the relationship and interaction between patient and carer. Further, they felt this perspective implied that negative mental health outcomes were inevitable despite strategies to improve mental health, and a more positive picture was required. What was important to communicate to other stakeholders was the themes themselves and evidence that they were likely to affect carer mental health. As the models were not seen as helpful in communication of findings, the project thereafter focused on presenting findings as meaningfully as possible for each theme, rather than pursing the models further.

Development of carer recommendations

The most important development was that the RAP decided they wanted to produce carer recommendations from the project. Originally, the project aim was solely to synthesise and present findings in ways that were meaningful to carers, and then use stakeholder engagement in stage 2 to help make the presentation of findings more accessible and useful to different stakeholder groups. Then it would be for stakeholders themselves to consider what actions may follow from findings (e.g. for practitioners, what direct support may be given in consultations; for commissioners, what services were important to fund; for policy-makers, what policy changes may help; for carer organisations, how best to target support of their carers). However, RAP members felt this left a notable gap in the project. They believed it was important to consider what findings told us about the support carers needed and for the RAP to produce recommendations on how to support carers that could be presented to other stakeholders alongside the findings themselves.

To enable this, a seventh RAP meeting in January 2021 included discussion of how project findings could be used to develop recommendations for improving carers' mental health, and some initial recommendations emerged at this meeting. Next, an additional February meeting was held to develop further recommendations. Before this meeting, RAP members requested a recap of total project findings and reflected on what actions could be taken within each theme to improve mental health for carers. Questions to consider included: what factors could or may be changed, what would be considered as priorities for change, how services could be changed (gold standard/minimum standard), and how factors that cannot be changed could help to identify carers who need added support. The RAP feedback, from both the January and February meetings, was synthesised (by TS) and reviewed by RAP members and the research team via e-mail.

Table 2 presents the final RAP-developed recommendations to support carers to maintain or improve their mental health. These are divided into 'overarching principles' which refer to recommendations that extended across all seven project themes, and 'theme-specific' recommendations that seemed to fit with individual themes from the research evidence (see *Report Supplementary Material 1* for full details; further summaries and resources can be found on the project website: https://arc-gm.nihr.ac.uk/the-carer-project-outputs).

The RAP highlighted that these recommendations should be seen within the context of key considerations for carers overall (see *Report Supplementary Material 1*). Firstly, that recommendations were based on making it as easy as possible for the carer to fulfil their role and 'removing obstacles which might stop them being a better carer', including removing or reducing unnecessary demands on their time to allow them more time to look after the person cared for. The RAP noted that it may have significant impact on a carer's mental health if they felt they 'might not be offering the optimum care'. Secondly, the RAP stressed the importance of carers feeling empowered, having their voices heard, and having proper engagement with services as active participants within their caregiving role. Further, recommendations focused on overcoming common challenges experienced by EOL carers, which may help to support the mental health of the majority; however, it should be recognised that experiences of individual carers will vary and that 'one size does not fit all'. The RAP also recognised the need to be pragmatic in their recommendations based on the limits of what services can provide. Recommendations therefore focused on what may realistically be changed, rather than representing an ideal 'gold standard'. The RAP mainly focused on developing recommendations that spanned themes and reflected the whole of the EOL caregiving journey (including post bereavement), as trying to fit recommendations to the seven specific themes from the research evidence was often difficult.

TABLE 2 Summary of recommendations from the carer RAP (see *Report Supplementary Material 1* for full details)

Overarching principles	Theme-specific recommendations
(1) *Awareness raising* Many good services exist but are not effectively communicated to carers in a timely manner in ways that meet their needs • Make carers aware of the support services available to them or the person they are caring for • Raise awareness among health-care professionals of the need to address the impact of EOL caregiving on carers	(1) *Patient condition* Carers are likely to experience better mental health if the following are in place • Accessible and timely information about the patient's EOL condition • Control of the patient's symptoms • Recognition that palliative patients may have other conditions that are still treatable (e.g. requiring dentists and opticians) that require continued referral and accessibility • Holistic approach to patients' treatment and care • Co-ordinated and continuous, rather than fragmented, patient care: ◦ Carers should not need to tell their 'story' repeatedly. They may be helped by having a folder with all relevant patient information that can be taken to appointments ◦ Provision should not depend on where the carer lives ◦ Patients should be able to see the same GP over the course of EOL care

continued

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TABLE 2 Summary of recommendations from the carer RAP (see *Report Supplementary Material 1* for full details) (*continued*)

Overarching principles	Theme-specific recommendations
(2) *Road map to support carers to navigate the EOL caregiving journey* • Provide carers with a 'road map' with all the relevant information to prepare and support them to navigate each stage of EOL caregiving and bereavement. This needs to be holistic and include: ◦ Information on what help is available locally ◦ Information on how to access specialist equipment and services for the patient at home ◦ Practical advice, including legal advice and making a Power of Attorney; financial advice; service advice ◦ Lists of useful telephone numbers, websites and e-mail addresses	(2) *Impact of caring responsibilities* • Carers should be able to spend quality time with the person they are caring for, and have sufficient time for caregiving and their own concerns. Helping carers with co-ordination, administration and navigation through the stages of EOL caregiving would help free up their time and reduce the impact of caring responsibilities
(3) *Bespoke support which recognises the carer has needs and identifies them through assessment* This should reflect that carers' needs are holistic, and support should be tailored where possible to the needs and situation of individual carers: • Service providers should recognise that carers have needs and use appropriate tools to assess them • Needs assessment should be comprehensive, including assessment of medical, personal and social needs, and take into account the carer's actual needs, rather than just what services can offer • Services should take into account the carer's personal circumstances	(3) *Finances* This was a fundamental issue that overlaps with overall recommendations for practical considerations • Carers should not be financially disadvantaged by their caregiving role. They need as an absolute minimum sufficient finances (e.g. through a decent Carer's Allowance) to ensure basic needs are met, including ability to pay rent and bills and 'put a decent meal on the table' • Carers should have access to practical advice, including early legal and financial advice, including Power of Attorney, will-making and Do Not Resuscitate orders where appropriate • Carers should receive timely advice on their eligibility for funding for care costs, including their eligibility for a housing adaptation grant
(4) *Standardised comprehensive assessment to assess actual rather than managed needs of the patient* To help ensure that the person cared for receives the support they need, carers' role in achieving this is understood, and carers feel able to manage caregiving tasks: • Patients should be assessed for their *actual* needs as opposed to their *managed* needs, to make visible all the support the carer provides, ensure the assessment does not conclude that the patient is more capable than they really are, and that their dependency on the carer's support is fully recognised • Assessment should be standardised across services and provide a comprehensive assessment of the patient's actual needs	(4) *Relationships* While acknowledging that carers may vary in their feelings about being a carer and in the quality of the patient–carer relationship: • Carers should be enabled to spend adequate time with the patient. Easing navigation through each stage of the journey of caregiving would take pressure off carers and free up time for them to do so
(5) *Co-ordinated and timely care by providing a single point of contact for the carer* Carers do not necessarily know how to navigate the health and social care system, and will need support in articulating their specific needs: • Provide carer access to a key worker as a single point of contact, to ensure patient care is timely, continuous and that care of both the carer and the person they are caring for is co-ordinated. This support should extend to: ◦ Comprehensive assessment of needs ◦ Helping carers with administrative tasks (e.g. filling in necessary forms) ◦ Signposting and/or referral to the relevant services ◦ Follow-up by relevant services, including post bereavement ◦ Advocacy support to help carers articulate what they need	(5) *Carer internal processes* Recognising that some carers may need 'permission' to feel the way they feel: • Carers need to have an outlet for 'venting emotions'

TABLE 2 Summary of recommendations from the carer RAP (see *Report Supplementary Material 1* for full details) (*continued*)

Overarching principles	Theme-specific recommendations
(6) *Practical considerations/essential resources* This needs to take into account that carers have to self-declare to be recognised as a carer, which some find difficult; that they may not live in the same household as the person cared for; and that time is of the essence for EOL caregiving. As a minimum: • Carers need to feel safe in the knowledge that their basic physical needs will be met, both during EOL caregiving and post bereavement • Carers should not be financially disadvantaged by their caregiving role, and need sufficient finances for basic needs (see *Finances*) • Equipment for the patient should be easily accessible and timely provided, not when the patient no longer requires it. Equipment should be retrieved promptly and sensitively following death • Carers should have access to practical advice, including legal and financial advice (see *Finances*) • Carers should be given timely advice on their eligibility for funding for care costs (see *Finances*)	(6) *Support* (a) Recommendations about support for the patient Given that carers are more likely to experience better mental health when the cared-for person receives the care and support they need: • Support for patients should be readily available, responsive, accessible and flexible, with: ◦ The option of receiving support at home or close to home wherever possible ◦ Home care services that are flexible and responsive to the patient's needs, including timing of visits • Joint support should be available for the carer and the person cared for, if that is their preference (b) Recommendations about support for the carer • Service providers should recognise that carers have needs, and use appropriate tools to assess them. Assessment should be comprehensive and take account of the carer's actual needs, not just what services can offer (See *Bespoke support*) • Individual formal carer support should be available ◦ Carers should be able to receive general counselling if they need a safe space to 'vent' ◦ Carers should be permitted to remain in the system post bereavement for bereavement counselling and other support services • Individual informal carer support should be available ◦ Carers should have early access to local support/peer support groups, which may also help identify further sources of help/support (7) *Contextual factors* All recommendations should take into account the specific context, personal circumstances and preferences of individual carers, wherever possible

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Carers' and researchers' reflections on Review Advisory Panel involvement

Feedback was sought from RAP members and researchers to gain insights into their perspectives on RAP involvement. An independent research project examining RAP involvement was not part of the original project protocol, but it was considered important to gain feedback from those involved to reflect on lessons learnt to inform PPI in future reviews. As such, this should be considered a collective reflective piece, rather than a research-based evaluation, as the RAP members and researchers who provided the feedback are also the authors of this paper.

Method

Feedback was collected from RAP members and researchers via e-mail, using open-ended questions and written responses. *Box 3* shows the questions asked. These were distributed to all RAP members and Core Research Team (CRT) members. Respondents were: all final RAP members, including the Chair (n = 5); CRT members who worked directly with the RAP (n = 4/5); and CRT members not directly involved with the RAP (n = 2/4). In the findings reported below, each respondent is allocated the ID codes RAP1–5, CRT1–4 and CRT 5–6, respectively.

BOX 3 Reflection questions

Questions for RAP members:

1. Briefly, what is your prior experience of patient and public involvement (PPI)?
2. What were your expectations of being involved in this project?
3. How did the experience of being involved match up to your expectations?
4. What did you gain?
5. What did you give?
6. What worked well?
7. What didn't work so well?
8. What would you say to other people, like yourself, about working on a similar project?
9. What were the challenges of completing this project during the COVID-19 pandemic/how did you cope with it?

Questions for CRT members who worked directly with the RAP:

1. Briefly, what is your prior experience of patient and public involvement and engagement (PPIE)?
2. What were your expectations for working with a carer RAP on this project?
3. What have been the gains for this project of the RAP involvement?
4. What have you gained or learnt from the RAP involvement personally or in your work?
5. Were there any challenges that you faced or had to solve of working with a RAP in general?
6. What were the challenges of working with a RAP during the COVID-19 pandemic/how did you solve it?

Questions for the rest of the CRT:

1. What have been benefits for this project that have resulted from working with a carer RAP?
2. Have there been any challenges for this project when involving a carer RAP?

KB and GG initially reviewed the collated materials from RAP and researcher respondents. Based on this, it was agreed that the material could broadly be organised into a framework of what made PPI work well or not so well. GG then worked through materials, writing freehand notes on the contents and then considered how the contents fitted the framework. Comments were next indexed according to the broad themes of what made the RAP involvement work and what were challenges. All materials relevant to a theme were collated for further in-depth scrutiny of any subthemes and how carer and researcher views compared or contrasted. The comments and resulting themes were reviewed in full by CR, and revisions made. Finally, all researchers and RAP members who had commented reviewed the resulting draft document to assess whether this had captured their perspectives. Thereafter, some further RAP feedback was incorporated in the final text and final adjustments made to subthemes.

Findings

What made patient and public involvement work well

Reflections mainly focused on what made the PPI work well: a shared sense of gains to the project from PPI; personal gain; mutual commitment and respect; and meaningful bridging between academic and lay perspectives.

Gains to the project from patient and public involvement

Review Advisory Panel members and researchers seemed to have a shared sense of the purpose of the RAP involvement, which is likely to have helped them work together effectively.

All the RAP members hoped that their involvement could contribute insights into carers' experience and make a difference in supporting other carers.

> *To share what I learned from being an end-of-life carer for my late wife with a view to improving carer experiences.*
>
> *RAP1*

> *I thought my experiences may prove of some use for other carers.*
>
> *RAP2*

Some also indicated the value of PPI in 'shaking up' the agenda or focus of researchers and clinicians.

> *… to be involved in research which had the potential to affect real people's lives rather than just project research papers for clinicians and academics.*
>
> *RAP5*

> *We will never find the right answers until we find out what the problems really are, not what professionals think they might or should be.*
>
> *RAP3*

The researchers' comments mirrored RAP members' perspectives. Firstly, in the value of having carers' experience informing the project:

> *… the RAP would be able to offer rich insights and perspectives of the carer experience and offer context to research findings using their lived experience.*
>
> *CRT4*

Secondly, how carers' involvement would help the project achieve its aim of making a difference to carers:

> *It is important that the findings make sense from a carers' perspective and resonate with their experience. If the project loses touch with carers' reality, it is less likely to achieve its aims.*
>
> *CRT2*

Finally, how the RAP may be able to challenge existing research and provide new insights:

> *… some of the key findings from the RAP group, such as financial difficulties and stressors, were interesting to see considering many of the trials and observational studies had not assessed these outcomes.*
>
> *CRT6*

> *I expected it to be a valuable contribution that would take us out of some of our academic ways of thinking and give us new insights.*
>
> *CRT2*

> *… the recommendations were not on anyone's radar at the start of the project, I don't think, but are such a valuable output.*
>
> *CRT3*

Researchers also noted the positives of being challenged by the RAP within the project:

> *It was also a nice way to be held accountable, too, in some ways.*
>
> *CRT3*

Personal gain

Comments also reflected a sense of personal gain from PPI involvement, which may have sustained the commitment to PPI by both parties.

All the RAP members stressed learning as a personal gain. This included learning about other carers' experiences:

> *I also realised the various dynamics at play in caring, the varying levels of intensity that I suppose must exist …*
>
> *RAP2*

> *A deeper understanding of the issues experienced across different carers.*
>
> *RAP4*

However, learning about research or technical aspects was also mentioned:

> *Gained some helpful insights into the preparation of a research paper.*
>
> *RAP5*

> *… I have a little more understanding of how qualitative research is conducted and hope to use this as a base to improve my knowledge in the future.*
>
> *RAP3*

Review Advisory Panel members also mentioned gaining from increased self-awareness, meeting people or having a sense of purpose through the COVID pandemic:

> *… I realised all the anxiety, stress, anger and guilt I had encountered over those seven years…*
>
> *RAP2*

> *Met some interesting people.*
>
> *RAP5*

> *I felt useful during a time that most people were finding challenging.*
>
> *RAP3*

While researchers said less about personal gain from PPI, they noted a gain in learning, in terms of both understanding carers:

> *I have gained a greater understanding of how it feels to care for those at the end of life that cannot be gained by reading papers.*
>
> *CRT1*

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and gaining insights into the overall benefits of PPI:

> *As mostly a quantitative researcher, I have become more aware of the importance of PPI …*
>
> *CRT6*

Mutual commitment and respect

Comments indicated that both researchers and RAP members were committed to the project and that this commitment was acknowledged by both parties:

> *… We had a good group of engaged individuals who were determined to see their work through.*
>
> *RAP5*

> *The amount of work the researchers did was amazing and I can only praise them for their professionalism.*
>
> *RAP2*

In working together, there was clear mutual respect expressed by both groups:

> *… we were lucky to have a very constructive, reflective and positive [RAP] group where everybody contributed and everyone was focused on the aims of the project, to make sure it would benefit carers.*
>
> *CRT2*

> *It was a great (research) project; the team were so thoughtful and accommodating, and I think we have produced a high-quality product.*
>
> *RAP4*

An integral component of respect for the RAP was that their views were taken seriously and that they had meaningful involvement:

> *I felt we were involved quite significantly throughout the process and our opinion was given due consideration.*
>
> *RAP3*

Payment was noted by RAP members as an important, tangible signal that RAP perspectives mattered:

> *Being paid for your time and effort is for me a marker that consultation is being taken seriously and is not just a box-ticking exercise. I was very impressed that the university gave us the option of being taxed or not – that was very accommodating of them.*
>
> *RAP3*

Bridging between academic and lay perspectives

Core to meaningful PPI involvement is bridging between academic and lay perspectives. This involved communicating research perspectives to carers, ensuring carers were able to comment meaningfully and have their perspectives heard, and negotiation and compromise between the two perspectives.

Enabling lay members to engage meaningfully with 'academic' materials can often pose a challenge and requires effort by both parties:

> *I was slightly worried about how well they would be able to work with the large volumes of synthesis data we would be producing – it was going to be a difficult balance between maintaining a high standard of reporting true to the findings while making it accessible to a lay person.*
>
> *CRT3*

> *… The arrangement of the themes was quite complicated and it took me a few meetings to get the hang of it. This was clearly the bulk of the work, and the researchers had no doubt spent many hours working out how to best present the evidence, but it was a lot of information to assimilate at once …*
>
> *RAP3*

The investment in training, time and guidance was an important means to overcome this:

> *Developing training that would be accessible and delivered in plain English, identifying support and training needs from the start …. Providing enough time and resources for the carers to be meaningfully involved … [and for analysis] Provide an example of how to feed back on a thematic analysis using a template, as lay members can vary greatly in how they interpret a task and provide feedback.*
>
> *CRT1*

Practical details also mattered in ensuring the RAP had time and opportunity to prepare feedback:

> *We were given copies of slides and documents in plenty of time for the next meeting, in digital and paper form, so we always had an opportunity to study them at leisure. Paper documents are important if you need to refer to them during a meeting, and printing them off yourself can be quite expensive if they are very colourful …*
>
> *RAP3*

Further, it was central that RAP members felt able to express their perspectives to researchers during meetings. Crucial to this was a feeling that carers and researchers were equal partners.

> *I think the project worked because of the mutual respect between the RAP and researchers, people were listened to and ideas were debated and modified if necessary.*
>
> *RAP2*

> *Obviously carers were usually in larger numbers in the RAP meetings, but I believed that irrespective of that, each individual (whether they be a researcher or carer) were on an equal par …*
>
> *RAP5*

This may have been facilitated by having a carer as chair:

> *To help the carers feel more comfortable to express their views, we had a lay Chair.*
>
> *CRT1*

However, core to making this work was a willingness by both parties to value different forms of knowledge and engage in negotiation and compromise in straddling the academic and lay worlds.

> *I think that PPI contributors and researchers can be working with different ideas about the value of different evidence – e.g. carers' experiences can seem anecdotal to researchers and researchers' preoccupations can seem just irrelevant to PPI partners. But I don't think that happened here …*
>
> *CRT5*

> *… we were coming at the issues from different standpoints. Practically, to produce meaningful joint work, compromise is essential and I think we would probably find each group felt that we gave ground …. We, in the RAP meetings, engaged in a process of negotiation, even though it felt like having entertaining discussions. I would say this is always a precondition for making the lay/researcher mix work: it is the price both sets pay to try to reach, if not consensus, a mutually acceptable way of moving forward.*
>
> *RAP5*

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Again, the role of the Chair may have formed an important part of bridging between groups:

> *I think she probably made a big difference to the project because of her contacts, her previous experience of this sort of work, and her outgoing personality, and wonder whether all projects need someone like her to straddle the Core Research Team and the public patient involvement and to lead the PPI.*
>
> *CRT5*

What made patient and public involvement work less well

The main issue voiced was the impact of COVID on communication, in both the move to online working and ongoing communication. Management of PPI outside the RAP context may also have been improved.

COVID impact on communication

Verbal, direct group communication was essential to the project. However, moving from face-to-face to online Zoom meetings due to COVID posed a serious challenge to this communication. In addition to challenges of coping with the technology, online working led to reduced informality, flexibility and personal connection:

> *… Zoom meetings had to replace classroom meetings during the pandemic. I thought this was a loss to the project's dynamic; nothing can replace personal interaction, a thought or an idea could arise over a coffee or an informal chat at break time, it's these little yet important things that can't be done over Zoom.*
>
> *RAP2*

> *… it's not quite the same as meeting in person where you can gain more insight about a person and build a stronger connection.*
>
> *CRT4*

Some of the above may have been ameliorated by utilising additional Zoom options:

> *Maybe more ongoing 'social' type meetings of some sort in breakout rooms might have been useful to cement further the RAP together.*
>
> *CRT3*

However, these would have required more time commitment, and managing the technology for ordinary Zoom meetings was already challenging for some RAP members. Further, the reduction in detection of non-verbal communication was an important online challenge that would still be hard to mitigate:

> *… it is hard to judge atmosphere remotely. When you are talking about very sensitive matters it is harder to show empathy/sympathy from a distance.*
>
> *RAP5*

> *… it's hard to get the balance right and make sure that everyone gets the chance to contribute … as there are less apparent cues which you can pick up on from people's body language to signal when someone is wanting to jump in and say something …. I think also given the sensitive nature of the subject of this research, working remotely makes it harder to read if people are struggling.*
>
> *CRT4*

COVID-induced home working also meant research team members were less able to follow up RAP communication outside meetings as proactively as they would under normal circumstances due to considerable stresses in juggling work and family roles:

> *This was extremely stressful as I felt torn between two very different roles of mother and researcher. It also affected how much time I could dedicate to regularly contacting carers.*
>
> *CRT1*

Being able to have a first meeting face-to-face made a big difference in mitigating some of the challenges of effective PPI through distance working, online meetings and e-mails, particularly when the issue was a sensitive one:

> *Building relationships and regular contact with RAP members are central to a successful working relationship. Luckily we were able to meet face to face, one to one, and as a group before the lockdown. This helped to build rapport.*
>
> *CRT1*

Management of patient and public involvement outside the Review Advisory Panel context

While the role of the RAP Chair worked well in the context of the RAP itself, the RAP Chair was also a participant in RMG meetings. Here the Chair's role on the RMG may have been better defined, as there was an element of her perhaps feeling like an onlooker listening to specialists.

> *… I always felt a bit on the outside. My main purpose was supposedly to provide PPI/PPE/lay input but this felt like an add-on on occasions, and we did have a member(s) on the [RMG] who were experts in PPI/PPE who probably felt more expert in this area …*
>
> *RAP5*

This highlights the importance of clarifying and negotiating how PPI fits in across the processes and management structure of the project as a whole.

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Discussion

This paper seeks to add to the limited literature on PPI in evidence synthesis by reporting principles and components that appeared to facilitate successful PPI, to inform future projects.[4,8] This includes an evolution from PPI consultation to co-production, whereas most systematic reviews remain at the level of consultation.[2] Further, it illustrates how meaningful co-production can be achieved during remote working, indicating the viability of hybrid ways or working. However, it also highlights the time and resources required for meaningful PPI.

Principles

The project ensured it created a strong, viable carer RAP whose perspectives could be properly expressed: firstly, by investing considerable time on recruitment processes to ensure an eligible, diverse and balanced group;[1,5,14] secondly, through the composition of RAP meetings, with carers in the majority for mutual support; and thirdly, through a Chair who combined carer and chairing experience, providing both an understanding of the carer perspective and the confidence to bring it to the fore, while nurturing 'novice' PPI members. Being an 'expert PPI member' also helped the Chair facilitate bridging of researcher and carer perspectives.

Further, the project signalled the value placed on PPI from the outset: firstly, through prompt and appropriate payment,[1,3] which demonstrated the tangible value ascribed to PPI (RAP feedback noted this as important); secondly, through strong and senior researcher representation at RAP meetings; and finally, by facilitating responsiveness to RAP input by providing 'space to talk' outside the agenda structure, and 'space to change',[1,5] which led to substantial project changes. Additional principles of ongoing training, proper preparation and ongoing communication[1,6,14] further ensured the RAP could contribute actively.

This enabled meaningful PPI and movement from mere consultation to the co-production of RAP carer recommendations based on findings (see *Table 2*). These were presented to the broader stakeholder groups in stage 2 alongside evidence synthesis findings, and perceived to be valuable in their own right (stage 2 will be reported in a future report).

Joint researcher and carer reflection indicated components underpinning this successful PPI. Firstly, there was a shared sense of the purpose and gains from RAP involvement. This may have been facilitated by individual pre-project meetings and 'foundations' laid in meeting 1. Secondly, there was mutual commitment and respect, possibly facilitated by early signalling of how carers were valued, clarification of project aims, and agreement of how to work together. Finally, there was meaningful bridging between academic and lay perspectives, based on sound principles of training and preparation, creation of a sense of equal partnership, and willingness by both parties to negotiate and compromise. Remote working enforced by COVID was perceived to hamper meeting communication, but there was sufficient resilience in the carer–researcher collaboration to overcome this.

The project applied principles drawn from existing literature.[1,3,5–7,14,15] Additionally, it carefully considered participant composition at meetings and use of the Chair to foster meaningful involvement, which has been given less attention, although Buck *et al.*[14] recommended using larger PPI groups, rather than single members. We cannot know to what extent successful project PPI was down to principles employed, as opposed to the characteristics of the participants (researchers and carers). However, it may be telling that the PPI input on the RMG worked less well, where some of the same participants were involved (Chair and research team), but there was less preparation and prior definition of roles and only one PPI member. Nevertheless, it is not a given that success would follow from mechanistic application of PPI principles in the absence of positive, constructive attitudes and a willingness to compromise and change.

Knowles *et al.*[3] concluded that relational openness was more important to build trust for successful PPI than any particular methods used. However, the above principles are probably an important bedrock on which such openness and trust can be built.

Hybrid working

Our project indicates that meaningful co-production can be achieved through a hybrid between face-to-face and remote working. COVID provided an enforced 'opportunity' to test how project PPI could be maintained through online video meetings. Virtual meetings led to reduction in informality, flexibility, personal connection and non-verbal communication, compared to face-to-face communication. However, early face-to-face groundwork, including relationship-building, agreement of how to work together and understanding of each other's roles, appeared to enable productive collaboration to continue remotely.

Online working also made meetings logistically easier to arrange and to attend, particularly for those more geographically distant (although the meeting preparation required from researchers and carers may actually have increased). This may have facilitated the consistently solid attendance across meetings. Research indicates that remote working increases inclusiveness in terms of geography,[7,19] and also race, ethnicity, education, income,[19] and accessibility for those affected by ill health or caregiving.[20] Previously, remote working may often have been limited to electronic communication through online forums[20] or e-mail,[7] with tele- and videoconferencing being relatively costly, limiting opportunity for dynamic interaction. However, online virtual meetings have now become a more viable, less costly option through greater access to online video meeting platforms, laptops and mobiles. While face-to-face working is still preferred[7,14] and probably necessary for relationship-building, further research is warranted on how and when remote working provides a viable alternative.

Resourcing meaningful patient and public involvement

Adequate resources need to be built into PPI budgets from the outset to achieve meaningful PPI.[2,5] This includes proper investment in recruitment and participant preparation[2] and ample time and resources for meetings to permit dynamic interaction and collaboration. In particular, allowing for 'space to talk' and 'space to change'[3] to achieve genuine co-production has resource implications. Accommodating change in our project not only required researchers' willingness to be flexible and make adaptations and RAP members' willingness to take on extra work and involvement, it also required proper resourcing: first, to enable payment for additional RAP hours to accommodate changes, and second, to allow extended and protected project time for researchers to facilitate communication and develop or adapt materials. Here, COVID in fact helped facilitate more 'space' to make changes, as the time and costs saved by moving to virtual meetings (on travel, venues, catering) provided more flexibility to incorporate required adaptations. However, projects cannot generally rely on such serendipity. The ability to work iteratively and make changes in response to PPI input is central to co-production. Such flexibility therefore needs to be built into projects. However, structures of academic funding can currently make this difficult,[3] and more flexible funding models for PPI may need to be considered.

Going forward, future projects must budget properly for PPI participants' time and ability to participate to allow meaningful engagement. This includes time for preparation, travel, meeting hours and review, and reimbursement for travel, subsistence and/or internet connectivity. However, a major PPI cost that may be overlooked in budgets is adequate researcher time for PPI in the project schedule, including time for proper meeting preparation (including procedures, documents and training), responding to meeting feedback (including production of new/amended project materials, procedures and schedules), and ongoing communication and engagement (including gaining PPI review and feedback for amendments). Preparing for PPI (before PPI engagement formally commences) is also resource-intensive, but proved

crucial to our project. However, this may pose a dilemma, as it should ideally take place before the start of the project proper, at which point funding may not be available. For example, we adopted a broad carer RAP recruitment strategy before project start, but it yielded few candidates, and would probably have been more effective had there been more resources for this; for example, to speak to carer group leads and present to group members. For longer-term longitudinal projects, it would also be beneficial to recruit and cost for a larger PPI group, to allow for potential dropout along the way. Additionally, building in 'space to change' would require PPI budgets that are realistic about costs, but where there is flexibility regarding details of how money should be spent, with allowance for viring between budget headings. Finally, meaningful PPI engagement for funded projects may be further aided by easier access to flexible PPI funds for preparing PPI before project start or accommodating unexpected, added work arising out of PPI feedback.

Limitations

A strength was the joint reflection of both researchers and carers on PPI in the project. However, it would have been beneficial to evaluate researcher and RAP experiences of PPI at each project stage rather than just at the end. This would have provided richer insights and enabled ongoing project improvements. However, the time and capacity for evaluation were limited within the tight timetable. The reflections from the RAP and researchers at the end of the project did provide some insight into their respective perspectives, but did not permit in-depth exploration. Further, this was a small set of respondents whose identities were known to analysts and could be guessed at by others. While group members (both RAP and researchers) were used to having open and frank discussion, this may still have made some respondents hold back on any negative feedback. The evaluation did not include a RAP member who stepped back towards the end of the project and who may also have had more mixed views of the experience. Finally, the analysis was conducted and written up by researchers who also had contributed responses, and reviewed by the group who had contributed responses as a whole. Although honest feedback and objective analysis was attempted, the conclusions may therefore be biased towards existing views. Researcher and RAP views therefore remain a piece of self-reflection, rather than an independent investigation.

Dissemination

Carer RAP recommendations and PPI work have been reported to stakeholder groups through project meetings, workshops and focus groups and will be disseminated via posters and leaflets, podcasts, webinars and the project website. Awareness of the findings will be raised via Twitter and through stakeholder networks of NIHR ARC GM and co-applicants. The current paper, reports for additional project components, and all project materials will be available through the project website https://www.arc-gm.nihr.ac.uk/carer-project-.

Equality, diversity and inclusion

Regarding the research itself, the evidence synthesis project ensured that carers' own perspectives were highlighted from the synthesis by making the qualitative review of carers' own experiences the central review, which then guided the synthesis of the quantitative reviews. Further, all reviews considered the ethnic composition of reviewed studies, and all reports presented any findings on ethnicity and noted the limited representation of ethnic minorities in the literature. The evidence synthesis was limited to Organisation for Economic Co-operation and Development (OECD) countries to enable comparison with countries whose health-care systems were likely to be comparable with the UK, and limited to publications in English and Scandinavian due to resource constraints, and this is noted as a limitation of

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the project. The work with the carer RAP and the stage 2 stakeholder consultation sought to ensure that project findings were presented in formats accessible to all carer groups and stakeholders.

Regarding the research team and other involvement, the project was shaped and guided by carers themselves, as described in this report. First, by having a carer co-applicant help develop the project; and second, by recruiting a strong and active carer RAP who helped shape the search strategy, conduct the analysis, interpret the results, and shape the presentation of project materials and dissemination, and whose carer recommendations became a key project outcome. Further, in the project's stage 2 stakeholder consultation, carers constituted nearly one-third of the meeting participants. Although there was no ethnic minority representation within the co-applicant team, the project was initially able to bring on board a carer advisor from an ethnic minority community group who was involved in RAP pre-meeting preparations, but had to withdraw before the first full RAP meeting proper. However, in the project's stage 2 stakeholder consultation one-tenth of the meeting participants were from ethnic minorities.

Conclusion

This paper outlines the principles and components that appeared to facilitate successful, meaningful PPI in this project, to help address the lack of information on what leads to meaningful PPI and inform PPI in other evidence synthesis projects.[5,8] Important elements were the emphasis placed on preparation work, RAP meeting composition and enabling 'space to talk' and 'space to change'.

This allowed RAP carer recommendations to emerge as a valuable and substantial project output. The recommendations highlight the importance of: awareness raising of and about carers; providing a carer 'road map'; bespoke carer support; accounting for carers' contributions in patient assessments; ensuring co-ordination; and dealing with practical matters, particularly finance. Importantly, the recommendations should have relevance for carers in a range of caregiving contexts (e.g. encompassing caregiving for short-term conditions with late diagnosis and short prognosis, through to long-term conditions such as dementia) and highlight the need for bespoke support based on holistic assessment of support needs.

While we have described principles that appeared to enable successful co-production in this project, these require testing in future work, including the importance of early relationship-building, group composition and chair selection. As online meetings may enable greater inclusiveness and flexibility, it would be important to investigate further the preconditions for successful online working, and which elements of face-to-face working may be replicated online and which cannot, and under what circumstances. Finally, the time and resources for meaningful PPI should not be underestimated, and flexible funding models should be considered to enable iterative and responsive working to allow genuine co-production.

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Contributions of authors

Gunn Grande (https://orcid.org/0000-0003-2200-1680) (Professor of Palliative Care, Chief Investigator, palliative care, carers, health psychology) developed the project protocol; provided support for the collaboration with the RAP and development of project materials; contributed to the reflections on PPI; analysed the reflections on PPI; drafted the manuscript; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Kerin Bayliss (https://orcid.org/0000-0002-9047-2516) (Research Associate, research staff, PPI and qualitative evidence synthesis) managed the collaboration with the RAP and developed project materials; contributed to the reflections on PPI; analysed the reflections on PPI; assisted with drafting the manuscript; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Tracey Shield (https://orcid.org/0000-0002-6747-613X) (Research Fellow, research staff, mixed-methods evidence synthesis) managed the collaboration with the RAP and developed project materials; assisted RAP members with producing the carer recommendations; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Jackie Flynn (PPI representative and RAP Chair, Co-applicant, caregiver experience and PPI) developed the project protocol; chaired the RAP; facilitated the collaboration between researchers and the RAP; contributed to the reflections on PPI, had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Christine Rowland (https://orcid.org/0000-0001-8628-4638) (Research Fellow, Co-applicant, health psychology and outcome measures) developed the project protocol; provided support for the collaboration with the RAP and development of project materials; contributed to the reflections on PPI; analysed the reflections on PPI; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Danielle Harris (https://orcid.org/0000-0002-3330-7346) (Research Assistant, research staff, PPI) provided support for the collaboration with the RAP and development of project materials; contributed to the reflections on PPI; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Alison Wearden (https://orcid.org/0000-0001-6074-6275) (Professor of Health Psychology, Co-applicant, health psychology and carers) developed the project protocol; reviewed and advised on

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the RAP collaboration; contributed to the reflections on PPI; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Morag Farquhar (https://orcid.org/0000-0001-7991-7679) (Professor of Palliative Care Research, Co-applicant, palliative care, carers and nursing) developed the project protocol; reviewed and advised on the RAP collaboration; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Maria Panagioti (https://orcid.org/0000-0002-7153-5745) (Senior Lecturer, Co-applicant, quantitative evidence synthesis, primary care, mental health) developed the project protocol; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Alexander Hodkinson (https://orcid.org/0000-0003-2063-0977) reviewed and advised on the RAP collaboration; contributed to the reflections on PPI; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Margaret Booth (carer RAP member, caregiver experience) helped with qualitative analysis; advised on project processes, findings and materials; helped shape the direction of the project and produced the carer recommendations; contributed to the reflections on PPI; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

David Cotterill (carer RAP member, caregiver experience) helped with qualitative analysis, advised on project processes, findings and materials; helped shape the direction of the project and produced the carer recommendations, contributed to the reflections on PPI; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Lesley Goodburn (carer RAP member, caregiver experience) helped with qualitative analysis; advised on project processes, findings and materials; helped shape the direction of the project and produced the carer recommendations; contributed to the reflections on PPI; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Cedric Knipe (carer RAP member, caregiver experience) helped with qualitative analysis; advised on project processes, findings and materials; helped shape the direction of the project and produced the carer recommendations; contributed to the reflections on PPI; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Penny Bee (https://orcid.org/0000-0002-5600-0400) (Professor of Applied Mental Health Research, Co-applicant, mental health, health services research) developed the project protocol; reviewed and advised on the RAP collaboration; had access to study data; reviewed the synthesis of project principles, outputs and reflections; provided critical revision of the manuscript for important intellectual content; and takes responsibility for data integrity and analysis.

Ethics statement/approval(s)

This is a report on the PPI in an evidence synthesis of existing literature and of the co-authors' reflections on the process. All data reported were generated by the co-authors and reviewed and approved by them. Consultation with the University of Manchester Research Practice Governance Office established that the project did not require ethics approval.

Information governance

There were no personal data involved in the production of this report.

Data-sharing statement

For further data relating to this report and the project as a whole visit the project website https://www.arc-gm.nihr.ac.uk/carer-project-. For further information on PPI processes and materials please contact the corresponding author. Individual reflections are not available due to confidentiality.

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