NIHR | Applied Research Collaboration Wessex

BU Bournemouth University

DEVELOPING CARER RESEARCH CAPACITY

Building Regional Carer Research and Identifying Research Priorities

Key Findings

January 2026

Context

In 2025 we completed a Wessex wide mapping exercise with unpaid carers, asking them to identify priority areas for future carer research. This formed part of a larger research NIHR ARC Wessex-funded project exploring carers' needs, experiences and views on improving carer involvement in research.[1]

A carer is anyone who provides unpaid care to a family member, partner, or friend who is unable to manage without support due to an illness, frailty, disability, mental health issue, or addiction.

In 2023, Bowness et al.[2] conducted the first review of participatory research and public involvement with carers. They found that carer involvement throughout the research process was often limited by research structures and caring responsibilities, but the literature did identify flexible ways carers could contribute, maximizing their impact, while attending to relationships and power imbalances.[3]

What Were the Aims of the Research?

We were interested to explore the potential supports required to enable carers to effectively combine research activity involvement alongside their caring responsibilities and participants' ideas for future research.[3]

Grounded in Carer Experiences

An online survey was used to gather unpaid carer experiences of research participation and non-participation. Carers were involved in its development through patient and public involvement, including exploratory work with carer organisations; a questionnaire development workshop with six carers; and a questionnaire review by two workshop attendees before publication.

Collecting the Data

The online survey was distributed across four counties in the South of England. Unpaid carers were recruited via online and university channels, carer charities, local authority support services, and attendance at local carer events.

Data were collected between December 2024 and July 2025, with 25 unpaid carers completing the survey. Most respondents were aged 18–74, with two aged 75 or over; 72% identified as female (n=18), 24% as male (n=6), and one response was missing.

Key themes emerged on carers' experiences of research and their priorities for future research, particularly the **need for research into carer stress, anxiety, mental health, and related triggers.** Although participation was lower than hoped, responses still highlight important barriers and enablers to research and the priority research concerns for careers in this region.

This document shares the key findings from the Developing Carer Research Capacity research project. It outlines suggestions for future carer research priorities, most prominently around increased research on carer stress, anxiety, mental health and the triggers for these.

---

[1] Pulman, A. and Fenge, L.-A., 2025. Caring and working: developing insights into the world of the working carer. Health & Social Care in the Community.

[2] Bowness, B., Henderson, C., Akhter Khan, S.C., Akiba, M. and Lawrence, V., 2024. "Participatory research with carers: A systematic review and narrative synthesis." Health Expectations 27 (1): p.e13940.

[3] NIHR. 2022. Evidence: Supporting family and friends: how can research help carers? NIHR. https://evidence.nihr.ac.uk/collection/supporting-family-friends-how-can-research-help-carers/

1. Interest in Research

- A significant number of participants (n=24; 96%) were interested in participating in research, but a relatively smaller number (n=7; 28%) had been able to participate in research projects to date.

2. Individual-Level Barriers

- Fatigue precluding contribution might include feelings of apathy based on previous contribution to research not leading to any significant change in circumstances for the carer or the person being cared for at a local or national level:

> “...our voices need to be the thread of research so our experiences can be learnt from and new solutions found. Governments must listen.”
>
> P06

> “...as no one take any notice it’s a waste of my time.”
>
> P07

- A general feeling of a lack of representation making the carer feel invisible:

> “I am an invisible carer not the image portrayed in the public eye, so I don’t think this will change anything but you try.”
>
> P08

- Participation in research might also be restricted if the carer was unaware of a study being undertaken or if they weren’t included in the invite being sent out.
- The caring role and the time that this took might also preclude participation in research. In the case of working carers this might be because of the dual roles of working and caring.

3. Organisational Barriers

- Being able to contribute thoughts and reflections to health and social care organisations is imperative for the carer.
- They sit front and centre of the role and face it head on, every single day.

> “I can give information about my 4 years + struggle to get any support from social services.”
>
> P02

- Highlighting the needs of the person that they are caring for who might not be able to respond of their own volition:

> “You can have the highest degree available, but the true experts are those living with these conditions every day. If they are complex like my child, then the next best thing is to obtain the views of their carers who have a thorough understanding of the needs of who they care for.”
>
> P12

- Participation provides a sense of value to a carer and allows organisations to obtain valuable data and observations which their own staff might not be able to provide:

> “There is no substitute for experience and carers know what they need and what the problems are and it is not easy for professionals to second guess this. Carers need to know that not only are they listened to but that action is taken as a result. It saves money to consult with carers instead of being prescriptive in providing services.”
>
> P16

- There is a need to improve communication regarding opportunities to contribute to research evaluations and consultations.
- More consideration for those with difficulties journeying to events or fitting in real time participation.

- More allowance for those with no access to digital technology or with conditions making contribution to online written surveys difficult.
- Putting a financial value on research participation both to show their time spent contributing was meaningfully appreciated and also helped reduce the burden on them being able to participate:

[What would encourage or enable you to participate in research?]
"Time. Time. And money." P25

- A full rather than sporadic approach by organisations to involving them in the end to end process of research, evaluations and consultations.

"Many surveys for carers trust and council. Also consultation about re shaping CAMHS in [LA] but they dragged me to lots of meetings then dropped me so I don't know if I was listened to or not." P16

3. Difficulties finding information (e.g. knowing where to access resources or who to contact).

"...there is a lot of support out there, but the hardest part is trying to locate what is right for your particular circumstances. Many professionals do not have the time to sit and help you, so offer leaflets and links to websites. As someone who is a full-time carer, who also looks after the other members of my family, as well as works 30 hours a week, I certainly do not have available the many hours that would be required of me to filter through all of the many links and documents in which I receive, to try to locate something that might be useful to me." P17

4. Stress and anxiety relating to PIP/Mandatory Reconsideration/Tribunal worry.

"Being able to voice personal concerns without judgement or any negative comeback". P15

4. Future Carer Research Priorities

Participants noted a need for increased research on:

1. Carer stress and anxiety.

"I feel totally isolated and have no family to support me. I see my financial situation get worse and worse every year and I cannot go out for coffee, let alone lunch. Understanding anxiety and how to manage it and how to set goals for myself to make my life better and in turn make my [child's] life better." P25

2. Carer mental health.

"Care for the carer's-support for the trauma experienced." P03

Recommendations

For Health Research and Social Care Funders

- Often the poor relation in research funding, it is imperative that more funding is made available to conduct carer research.

For Organisations

- Strengthening the research culture at all levels within local authorities, charities and third sector organisations is a key pathway to encourage more carer research.
- Health and social care organisations should make much more effort in seeking out PPI representatives from the carers world even though this might be more difficult to arrange and see through to completion due to the nature of the caring role.

For Researchers

- Focusing on mental health and anxiety and stress concerns through research projects is currently the most pressing issues which need to be investigated in more depth within Wessex.
- Carers are actively sought out, encouraged to participate in research projects and made to feel welcome as a full and not interim partner in the research journey from initial planning through to dissemination.
- Valuing carer involvement in research and also being able to compensate them for taking part in research activities is one way in which interest in research can be built upon and the burden on the carer taking part can be decreased.

Project Information

The Developing Carer Research Capacity research project was developed by Dr Andy Pulman and Professor Lee-Ann Fenge as part of a larger body of National Institute for Health and Care Research (NIHR) ARC Wessex research exploring the experiences of unpaid carers in the South of England and helping to developing carer research capacity in Wessex.

Ethics

Ethical approval for this study was granted by Bournemouth University Social Sciences & Humanities Research Ethics panel during December 2024 (Ref: 60029)

FUNDED BY

NIHR | National Institute for Health and Care Research

This study is funded by the National Institute for Health and Care Research ARC Wessex. The views expressed in this publication are those of the author(s) and not necessarily those of the National Institute for Health and Care Research or the Department of Health and Social Care.

Contact

For further information, please contact:
Professor Lee-Ann Fenge
lfenge@bournemouth.ac.uk