



# CLAHRCBITE

Brokering Innovation Through Evidence

May 2019

Uncovering the contribution, costs and economic value of family caregiving



**The National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Greater Manchester is a partnership between providers and commissioners from the NHS, industry, the third sector and the University of Manchester.**

We aim to improve the health of people in Greater Manchester and beyond through carrying out research and putting it into practice.

## What was the aim of the project?

We're working to find out the contribution that family carers make during end-of-life care. Carers' contribution is likely to substantially increase in the last three months of life and currently there's no quantification of the size and economic impact of a carer's contribution: it remains largely 'invisible' at government, commissioner and service provider level.

## What did we do?

After analysing and reporting on the survey results we now have a profile of the cancer carer population. We are still working with the data but hope to soon report:

- An estimate of the financial value that the care given by family members contributes to society.

- Which types of carers may be most in need of support.
- The work was featured in a number of local and national newspapers and e-circulations.

### Local and national impact

This is the first study to provide population-based information on the scale of cancer-related carer activity and out-of-pocket expenditures, to enable the economic value of carers' contribution to end-of-life care to be calculated. Importantly, this study identifies that carers' financial contribution to end-of-life care is substantial and could be much higher than some previous estimates suggest. The importance of this work is highlighted by the local and national exposure that the findings received:

- Prof. Gunn Grande and Tony Bonser (Dying Matters and NCPC Patient Ambassador) discussed the work live on BBC Breakfast
- Prof. Barbara Henratty spoke to 7 different regional BBC radio stations
- Jonathon Dimpleby discussed the findings from the work live on Good Morning Breakfast (on ITV)

### Why is it important?

Previous research in this area indicates that end-of-life carers feel unheard and unsupported; often palliative home care services do not recognise the importance of carers as co-workers and do not support them sufficiently to support the patient. Providing information on end-of-life caregivers and what they contribute will promote their visibility to commissioners and service providers which can enhance support for carers. This information is needed to plan and invest in carers to help them support patients, particularly as the delivery of care continues to move into the community.

### Who did we work with?

[University of Manchester](#)  
[University of York](#)  
[Office for National Statistics](#)

### What next?

We can see from these results that caregiving puts a substantial strain on people's health and that this happens on a much larger scale than we originally thought. Given this, we need to work with care agencies and social support services to ensure carers are better supported and able continue their valuable work. Our findings also show that the financial cost of informal caring is higher than has been previously estimated and we can now more accurately estimate the full economic value of family caregiving in the UK.

### What is NIHR CLAHRC GM?

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### Find out more

[www.clahrc-gm.nihr.ac.uk/projects/dimpleby](http://www.clahrc-gm.nihr.ac.uk/projects/dimpleby)

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