

# Carers' Experience Survey 2009–2010: Survey Development Project

PSSRU

RESEARCH  
SUMMARY

54

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## BACKGROUND

Around 4.9 million people in England provide unpaid care to support family members, friends or neighbours. Caring can be associated with lower income, poorer health and reduced access to leisure opportunities. The government's Strategy for Carers (Department of Health, 2008) identified four key outcomes to be achieved by 2018 (see box 1).

Asking carers about their lives and their experiences of health and social care services can help to monitor the impact of the strategy. Between November 2009 and February 2010, some local councils in England will send a survey questionnaire to a randomly selected group of carers.

### Box 1 Key outcomes to be achieved by 2018

- Carers will not be forced into financial hardship
- Carers will be supported to stay mentally and physically well and treated with dignity
- Carers will be able to have a life of their own alongside their caring role
- Carers will be respected as expert care partners

## RESEARCH AIMS

The aim of this project was to develop and test the self-completion questionnaire to be used for the Carers' Experience Survey 2009–2010.

## METHOD

The Carers' Experience Survey 2009–2010 builds on a previous questionnaire developed by PSSRU for Kent County Council (see Smith et al., 2009). We reviewed previous research with carers and focus groups and interviews with carers, and this suggested a large number of topic areas that the survey might cover. A list of possible topics we could ask about was circulated to key stakeholders (see box 2) who were asked to rank the topics in order of importance. Questions were developed for those topics that stakeholders ranked 'very important' or 'moderately important'.

These questions were then tested by carrying out interviews with thirty carers living in Manchester and Kent. The interviews allowed the researcher to check that the questions were easy to understand and that people were interpreting the words used in the same way. Questions that were unclear were re-written and tested again in later interviews.

### Box 2 Acknowledgements

This project was funded by the Department of Health. Input from stakeholders was fundamental to developing the questionnaire and we would like to thank the following for their contributions:

Carers UK  
Crossroads  
The Healthcare Commission  
The Princess Royal Trust for Carers  
The Social Services User Survey Group (SSUSG)  
The Strategic Information Group on Adult Social Care (SIGAC)

Our thanks are also due to Sue Williams and Richard Benjamin at Kent County Council, Ben Collier at Manchester City Council and the staff at Manchester Carers Centre for their help putting us in touch with carers.

Our warmest thanks go to those carers who gave their time to take part in the interviews.

## FINDINGS

The interviews were very useful in identifying which questions may be difficult to answer. For example, a question asking whether a carers' assessment has been carried out was difficult for some respondents to answer. Although some carers had been involved in discussions with professionals about their caring role, it was often unclear to them whether a formal assessment had taken place. Due to this uncertainty, information about the completion of carers' assessments will be collected from social services information systems instead.

Different ways in which people interpreted the wording was highlighted during the interviews. The term 'expert carer' was often misunderstood by people, who thought it meant a paid trained carer or professional rather than a carer who knew a lot about what they were doing. Some people felt very uncomfortable defining themselves as 'experts'. In the light of these findings, the term 'carer' was used and a paragraph containing a definition of the term was added to the front of the questionnaire.

The interviews were also useful in identifying topics considered important by carers that were not covered by the questionnaire. One question asked what help and support carers provide. The question had a range of options and carers were asked to tick all the options that applied to their circumstances. Some of the people interviewed highlighted that the list of options did not include 'providing emotional support'. Carers of people with mental health problems, in particular, spent a lot of time providing emotional support, so it was added to the list of options.

The interviews also allowed us to get a sense of which questions were asking about the things that were most important to carers. The majority of the carers interviewed felt that the questions asking about their quality of life were the most important – so in designing the questionnaire we made sure these questions were towards the beginning.

## KEY MESSAGES

This study highlights the importance of in-depth testing of questionnaires before conducting large-scale surveys.

Using interviews to test questionnaires can identify where there are different understandings of key terms or gaps in topic areas.

Finally, the interviews identified which questions were considered most important by carers.

## REFERENCES

- Department of Health (2008) *Carers at the Heart of 21st-century Families and Communities*, HM Government, London.
- Smith, N., Netten, A., Holder, J. and Fox, D. (2009) *Carers' Experiences and Outcomes: The 2008 Kent Carers Survey*, PSSRU Discussion Paper 2652, Personal Social Services Research Unit, University of Kent, Canterbury.

### Further information

For more information on this project, see Fox, D., Holder, J., and Netten, A. (2009) *Carers' Experience Survey 2009–2010: Survey Development Project*, PSSRU Discussion Paper 2643, Personal Social Services Research Unit, University of Kent, Canterbury ([www.pssru.ac.uk/pdf/dp2643.pdf](http://www.pssru.ac.uk/pdf/dp2643.pdf))

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