

## **Survey questions on older people's receipt of, and payment for, formal and unpaid care in the community**

**Meera Balarajan, Margaret Blake, Robin Darton, Michelle Gray, Ruth Hancock, Linda Pickard and Raphael Wittenberg**

Most countries, including the United Kingdom, are facing the challenge of meeting the needs of increasing numbers of older people who require care and support. The development of policy and practice on care for this group requires good evidence on patterns of need for help, the extent to which formal services and unpaid care from family and friends meet that need, and the costs of care and how these costs are met by the state, the service user and their family. Household surveys and evaluations of specific forms of care are important sources of such evidence.

Collecting such information directly from survey respondents poses some challenges. An older person may receive a service which is arranged by a public body but provided by a private sector agency; and he/she may pay all, part or none of the cost of that service depending on eligibility for public support. Initiatives such as 'direct payments' and 'personal budgets', which are intended to provide service users with more choice, blur the boundary between public and private care. Moreover, terminology used by professionals may not be understood in the same way by survey respondents.

This paper reports research which developed a new module of questions to collect data on the needs of older people (aged 65 and over) living in the community, their receipt of unpaid 'informal' care and 'formal' care services and payment for those services, and also questions on the provision of unpaid care. Our overall aim was to develop a valid and robust module of questions which could be used in household surveys and in evaluations. This was important because no such module was available which met the challenges of producing up-to-date data which adequately reflected the complexities of the adult social care system.

The research reported here was the second phase of a study in which phase one was used to define the scope of a new module and learn from relevant past work. Phase one comprised a review of the relevant questions in existing surveys, a systematic review of questions used in economic evaluations, and a stakeholder consultation. King et al. (2010) provides details of phase one; and a full report of the systematic review is available in Martin et al. (2012). Phase one established a clear need for a new module of questions. In particular, the teams responsible for the Health Survey for England (HSE)<sup>1</sup> and the English Longitudinal Survey of Ageing (ELSA)<sup>2</sup> expressed interest in the development of a new module.

Phase two of the study had three stages. The first stage involved in-depth interviews with service providers and focus groups with service users, to gain a full picture of current service provision and service users' understanding of what is provided to them. In the second stage, an initial set of survey questions was developed and tested, first with a panel of experts and then by two rounds of cognitive interviewing with a small sample of older people. Lastly, the questions were refined through expert review of a draft questionnaire and piloted as part of the process of incorporating them into the HSE and ELSA.

## **Methods used during Phase 2**

### **Stage 1**

The first stage was intended to ensure that the new questions were comprehensive and grounded in the context of current social care provision. It explored how service delivery and payments work in practice, and, importantly, the levels of knowledge and awareness of service users. Thirteen in-depth interviews were undertaken with people providing services in the public, private-for-profit and voluntary sectors, plus interviews with providers of unpaid care and with one organisation supporting unpaid carers. Two focus groups were also convened, each with six service users. Balarajan et al. (2009) contains full details of this stage of the research.

<sup>1</sup> <http://www.hscic.gov.uk/healthsurveyengland>

<sup>2</sup> <http://www.elsa-project.ac.uk/>

## Stage 2

The second stage began with the development of a preliminary questionnaire. Questions were either formulated from scratch or drawn from existing surveys. This was followed by two rounds of cognitive interviews to address whether the proposed questions would provide valid and reliable data. For both rounds, three types of respondent were recruited: people aged 65+ who had received formal services and/or unpaid care; unpaid care-givers (aged 18+); and people aged 65+ who had neither received nor provided care. Thirty cognitive interviews were conducted in round one and 26 interviews in round two. All were conducted face-to-face. Qualitative analysis was carried out using detailed notes made by interviewers from interview audio recordings. Further details are available in Balarajan et al. (2010).

## Stage 3

The draft questionnaire was discussed in multi-disciplinary expert panels, composed of subject experts, survey researchers and question design specialists, drawn from the research team and other colleagues from their organisations. Towards the end of the study, the HSE and ELSA teams confirmed their interest in incorporating the module in their surveys. This raised important practical matters which had an impact on the finalisation of the module and also provided a valuable opportunity for field piloting.

## Findings and outline of the module of social care questions

### General findings

Stage 1 confirmed the importance of developing questions that could be readily understood by respondents, given the complexity of the social care system. For example, the terms 'help' and 'helper' worked better than 'care' and 'carer'. Although the terms 'direct payments' and 'personal budgets' were not universally understood, it was best to use these descriptors but with explanation of their meaning. It was not always clear to service recipients *who* provided their care. The solution was to distinguish help arranged with involvement of a local authority from help where the local authority had not been involved.

The cognitive interviews were important in establishing whether people could be asked about payments for care and in what level of detail. The first round of these interviews revealed that some individuals did not know precisely how their care was organised and paid for. This was partly because care may be arranged by someone other than the respondent. In such cases, proxy responses or assistance with replying to questions might improve the accuracy of the data. It was clear also that it would be difficult to obtain the exact amounts that respondents pay towards their care, but questions to establish whether they paid all, some or part of the cost of their care worked reasonably well.

The second round of cognitive interviews showed that it was possible to ask about direct payments and privately purchased services. Those interviewed were mostly aware of whether they were in receipt of direct payments or if they paid privately for a service. The questions about types of care received, who provides this care and patterns of receipt were flexible enough to be asked of those arranging their own care as well as those using care arranged (or paid for) directly by the local authority. In contrast, questions about the *amounts* paid were difficult for people with direct payments because people either found the information too personal or did not know.

Unmet need was best identified by using a task-based approach to find out i) whether respondents *need* help with particular Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs) and if so ii) whether they *receive* any help with those tasks. This would capture situations where some needs are met but others are not.

Discussions on incorporating the module into the HSE and ELSA highlighted two practical issues. First, there was a need for a shorter version to encourage such surveys to use at least some of the questions, while avoiding the pitfalls of *ad hoc* cuts to limit interview length. The final module therefore consists of a short and a long version. Secondly, ELSA already included questions about ADLs and IADLs which could not be changed. The tasks included in the new module were therefore designed to align with a subset of tasks in the existing ELSA questions.

### The question module

The module has two main sections: Section A covers *receipt* of social care, both formal care and unpaid care, and Section B covers the *provision* of unpaid care. The module begins with questions about ADL and IADL tasks with which people might

need help. By starting with tasks, the questions are likely to be easier and more salient for the respondent, and remain relevant over time. Thirteen ADLs and IADLs were identified for inclusion in the module. They were chosen to: cover a range of activities relevant to older people; to include all the tasks necessary to derive approximations to the Katz and Barthel indices (Katz et al., 1963; Mahoney and Barthel 1965); to fit with those already in ELSA; to include tasks requiring physical and cognitive ability; and to ensure that the overall selection of tasks is as gender-neutral as possible.

The questions first establish a respondent's ability to perform each of the 13 tasks and then whether they receive help, and if so from whom. Since asking who helped with each of the 13 individual tasks would be an excessive burden on interviewees, the tasks are grouped for this purpose. They were grouped in three ways designed to make sense to respondents: help with bathing/showering; help with other ADL tasks and indoor mobility; and help with IADL tasks and outdoor mobility.

The module then asks about hours of care received in the last week and patterns of care (such as whether care is received at the weekend). Questions on payments for care come next. The module first identifies whether the individual is in receipt of a direct payment or personal budget, and whether a local authority was involved in arranging any formal care. It then asks whether the older person pays for all, some or none of their care, with an option to obtain the exact amount where possible. It allows for information on payments to be obtained from someone other than the individual receiving care.

Parallel questions about care *provided* by adults (aged 16+) to people aged 65+ were also developed, using the same categories. Care-givers are asked about the hours of care they provide, support they receive in their caring role, and the effects of caring on their health and their employment.

Features of the long version of the module that do not appear in the short version include: exact hours of care received; the timing of care received; exact amounts paid for care; receipt of equipment and adaptations; and payments received by carers who are family and friends.

Feedback from the pilot and 'dress rehearsal' of the short version of the module in the 2010 HSE was positive, and no major problems arose during the first and second years of its inclusion (2011 and 2012). In 2013 the full longer version of the module was included in the HSE, and in 2014 the payments questions from the longer module were included with the remainder returning to the shorter module. The longer module has been included successfully in ELSA Wave 6 (2012-13) and Wave 7 (2014-2015) after piloting and a dress rehearsal.

## Discussion

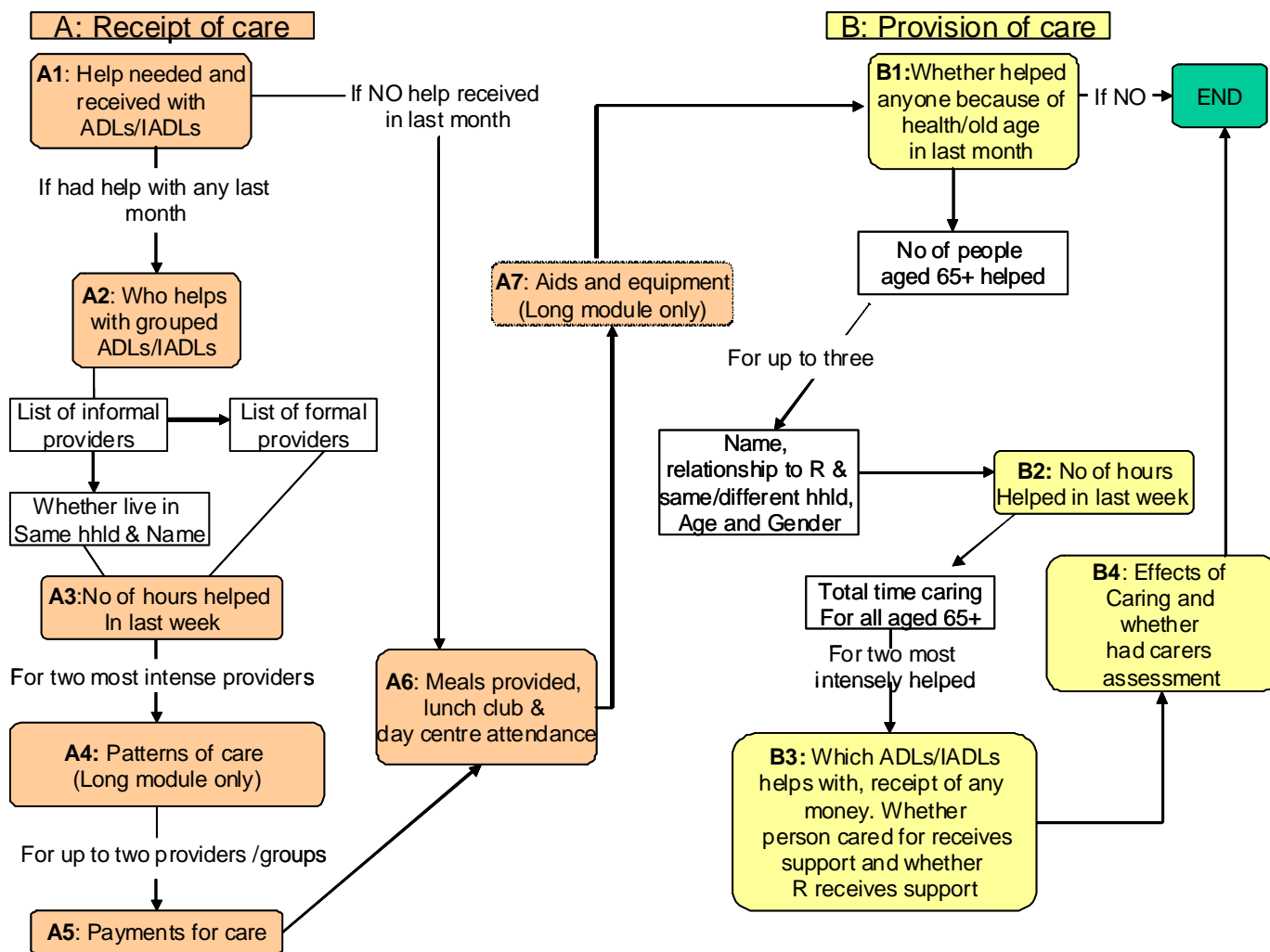
The new module was designed to be used in general population surveys or evaluations, in shorter or longer versions. It can be used to establish both need for care and whether different types of need are being met by formal and/or unpaid care or not at all. Unlike previous modules, it covers payments for care and accommodates the current policy emphasis on more personalised formal care services delivered via direct payments and personal budgets. It allows information on receipt and provision of care to be collected together. Its strength lies in the considerable development work that underpins its structure and wording.

The module has some limitations. It was designed to be asked in surveys of the household population, and would need considerable adaptation for use in care homes, with the possibility of proxy answers. Although the module is being used for people aged 50+ in ELSA, a different approach might be needed for younger adult user groups. The module was designed for England: since some aspects of the social care system are different in Scotland, Wales and Northern Ireland, the module would need adaptation for use there. The questions were designed for use in a CAPI interview. Owing to the module's complexity, it would be difficult to administer it as a paper or self-completion questionnaire or by telephone interview.

The module should be reviewed periodically and updated to reflect any policy changes. We have discussed with the HSE team changes required to reflect the provisions of the Care Act 2014 concerning personal budgets and (from 2020) independent personal budgets. In due course, further changes may be needed to evaluate the effects of the Care Act reforms. A balance will need to be struck between adapting the module to maintain its relevance and providing consistency over time.

To encourage use of the module, documentation is freely available on the project's website (NatCen 2010).<sup>1</sup>

Figure 1: Structure of the module



<sup>1</sup> <http://www.natcen.ac.uk/our-research/research/social-care-questions-for-over-65s/> [accessed 20 October 2015]

## Acknowledgements

We are grateful to the Nuffield Foundation for funding the main stage of the research on which this paper is based and to the Department of Health who funded phase one. We are also grateful to other members of the study team: Catherine Henderson, Juliette Malley, Marcello Morciano and Derek King. All responsibility for what is reported here, and for any views expressed, rests with the authors.

## References

- Balarajan, M., Gray, M., Blake, M., Green, S., Darton, R., Fernández, J-L., Hancock, R., Henderson, C., Kearns, D., King, D., Malley, J., Martin, A., Morciano, M., Pickard, L. & Wittenberg, R. (2009) *Developing social care questions: findings from qualitative research with service users*. NatCen Social Research, London. Available at: <http://www.natcen.ac.uk/media/205501/qualitative-report.pdf> [accessed 27 August 2015].
- Balarajan, M., Gray, M., Blake, M., Green, S., Darton, R., Fernández, J-L., Hancock, R., Henderson, C., Kearns, D., King, D., Malley, J., Martin, A., Morciano, M., Pickard, L. & Wittenberg, R. (2010) *Cognitive testing of social care questions for people aged 65 and over*. Available at: <http://www.natcen.ac.uk/media/205500/cognitive-report.pdf> [accessed 27 August 2015].
- Katz, S., Ford, A.B., Moskowitz, R.W., Jackson, B.A. & Jaffe, M.W. (1963) Studies of illness in the aged. The Index of ADL: a standardized measure of biological and psychosocial function, *Journal of the American Medical Association*, 185, 12, 914-919.
- King, D., Balarajan, M., Blake, M., Cheshire, H., Darton, R., Gray, M., Hancock, R., Henderson, C., Jones, A., Legard, R., Malley, J., Martin, A., Morciano, M., Mugford, M., Pickard, L., Shemilt, I., Snell, T. & Wittenberg, R. (2010) *Developing improved survey questions on older people's receipt of, and payment for, formal and informal care*. Available at: <http://www.natcen.ac.uk/media/205499/stage-1-report.pdf> [accessed 20 October 2015].
- Mahoney, F.I. & Barthel, D.W. (1965) Functional evaluation: the Barthel Index, *Maryland State Medical Journal*, 14, 2), 61-65.
- Martin, A., Jones, A., Mugford, M., Shemilt, I., Hancock, R. & Wittenberg, R. (2012) Methods used to identify and measure resource-use in economic evaluations: a systematic review of questionnaires for older people, *Health Economics*, 12, 8, 1017-1022.
- NatCen Social Research (2010) *Social Care for people aged 65+: questionnaire documentation*. Available at: <http://www.natcen.ac.uk/our-research/research/social-care-questions-for-over-65s/> [accessed 27 August 2015].