Developing Improved Survey Questions on Older People’s Receipt of, and Payment for, Formal and Informal Care

King D.,1 Balarajan M.,4 Blake M.,4 Cheshire H.,4 Darton R.,2 Gray M.,4 Hancock R.,3 Henderson C.,1 Jones A.,3 Legard R.,4 Malley J.,1,2 Martin A.,3 Morciano M.,3 Mugford M.,3 Pickard L.,1 Shemilt I.,3 Snell T.,1 Wittenberg R.1

1. Personal Social Services Research Unit at the London School of Economics; 2. University of Kent; 3. University of East Anglia; 4. The National Centre for Social Research (NatCen)

1 Introduction

Robust data are needed on the characteristics of people providing and receiving informal care and on people receiving formal care and support, including details of their financial circumstances and contributions to care costs. Information currently collected in surveys does not clearly identify who arranges services (e.g. whether private care is arranged with or without the involvement of a local authority or council), which care recipients pay for services and which services they pay for. Moreover, developments such as Direct Payments and Personal Budgets are not yet reflected in survey questions and may blur the boundary between paid and unpaid care.

This study aims to develop an improved set of survey questions on older people’s receipt of, and payment for, formal and informal care. This is a report of stage one of the study, which involved:

• a review of questions on receipt of formal care, disability benefits and informal care in existing surveys;
• a consultation with stakeholders for their views on existing survey questions and the potential for data linkage with administrative data; and
• a systematic review of economic evaluations which included questions to service users or their carers on the types, amounts and costs of formal social care services.

This stage of the study was funded by the Department of Health and conducted by researchers at the Personal Social Services Research Unit (PSSRU) at LSE and Kent and researchers at the University of East Anglia (UEA) in collaboration with the National Centre for Social Research (NatCen).

Stage two of the study is funded by the Nuffield Foundation and is being conducted by NatCen in collaboration with PSSRU and UEA. It involves the preparation of a draft questionnaire module on the basis of stage one, consulting with an expert panel on the questionnaire content, conducting cognitive testing and, after further review, finalising a module of questions.
2 Aims of the Study

The overall aim of the research is to produce modules of questions on receipt of care services and related benefits, payment for care services and provision and receipt of informal care, that would be suitable for longitudinal or cross-sectional population surveys that cover community-based care and for use in economic evaluations. These, it is envisaged, would be of value for the new Health and Social Care Survey and future waves of the English Longitudinal Survey of Ageing (ELSA)\(^1\).

We proposed that the modules of questions would cover:
- Community-based social care services, including respite care
- Direct Payments and Personal Budgets for care
- Privately-purchased care
- Community equipment
- Community nursing and other health services
- Supported housing, such as Supporting People funds
- Disability benefits
- Frequency/intensity of service receipt
- User contributions/charges for social services
- Informal care by relatives and friends (receipt and provision)

Our analysis completed in stage one suggested that people have difficulties understanding some aspects of social care services. As a result of this we have had to prioritise social care services at the expense of questions on Supporting People services. Supporting People services would need a separate project (and module of questions) to determine how well these services are understood and their prevalence.

3 Review of Survey Questions

Objectives

The team set three objectives for the stage one research:

1. Identify the strengths and weaknesses of; (a) existing survey questions on receipt of formal and informal care, provision of informal care and payment for formal care, including how well they work alongside questions on disability (or other need indicators) and receipt of disability benefits; and (b) tools for collecting data about the costs (and data about who meets the costs) in economic evaluations of relevant health and social care interventions.
2. Detail what is required from an improved set of questions in the light of the review of existing survey questions/economic evaluations and consultation with stakeholders.
3. Investigate what is recorded in relevant administrative data (including care plan records) held by local authorities, central government and other bodies, that if linked with survey data might supplement or substitute for survey questions on care receipt.

\(^1\) See glossary (page 17) for description and references for all surveys.
4 Methods

Stage one of the study commenced in April 2009 with the aim of completing this first stage by end of June 2009. The second stage commenced in July 2009 and is scheduled to be completed by June 2010. The review of existing surveys on questions on receipt of formal and informal care and provision of informal care were jointly conducted by PSSRU and UEA members of the study team. Reviews of data requirements on payment for formal care and a systematic review of tools for collecting service use and costs in economic evaluations were conducted by members of the study team at UEA.

Two stakeholder consultations were conducted. The first, by PSSRU at LSE, sought stakeholders opinions on defining the scope of a survey instrument on receipt of care services and related benefits, payment for care services and provision and receipt of informal care. This consultation also asked stakeholders for their views on the potential for data linkage. NatCen conducted a stakeholder consultation which asked about the feasibility of asking questions about formal and informal care receipt, the provision of informal care and information on financial circumstances and contributions to care costs.

5 Findings on Formal Care

Derek King, Marcello Morciano, Tom Snell, Robin Darton, Cate Henderson Ruth Hancock and Raphael Wittenberg

5.1 Methodological issues

An initial analysis looked at the rate of non-response in the General Household Survey (GHS) 2001/2, ELSA Wave 3 (2006), Health Survey for England (HSE) 2005, Family Resources Survey (FRS) 2004/5, British Household Panel Survey (BHPS) 2007, the PSSRU 2005 Home Care Survey (Darton et al., 2006) and the Partnerships for Older People Projects (POPP) (Windle et al., 2009).

To assess the existing data on receipt of formal services, analysis was conducted on the questions and consistency of rate of receipt of services in the GHS, ELSA, HSE, FRS and BHPS. Comparisons were made based on the subsamples of individuals aged 65 and over and resident in England. The formal services analysed were home help, private help, district nursing and day centre visits.

The following methodological issues arose:

1. Questions about private home care need to make clear that the key issue is care related to needs arising from disability. The wording of the GHS question which refers to ‘private domestic help’ appears not to limit positive responses to people needing care: many of the positive responses are from people who report no disability.
2. Questions need to distinguish clearly between care purchased privately without the involvement of the council and care provided by the private sector but arranged through, and possibly subsidised by, the council.

3. Questions about community nursing need to make clear whether they relate to all types of community nursing as opposed to, for example, just district nurses.

4. The NHS/SSD label used in the BHPS dates back to wave 1 (1991) so is out of date in terms of wording. Moreover, it does not make it explicit that it refers to all local authority-brokered home care as opposed to just home care directly provided by local authorities, presumably since the independent sector played a very small role at the outset of BHPS.

5.2 Non-response/response rates

The rate of item non-response across the services was very low in the GHS, HSE and ELSA Wave 3. In the FRS there are no identified missing cases as imputation procedures were used by the Department for Work and Pensions prior to releasing the data.

The PSSRU 2005 Home Care Survey (Darton et al., 2006) and the Partnerships for Older People Projects (POPP) (Windle et al., 2009) offer further insight into item response in surveys covering service receipt, pensions and benefits. The Home Care Survey showed that the respondents (service recipients or proxies) answered the questions on the receipt of services without difficulty, and they were usually able and willing to provide answers to questions on the frequency of receipt, either in absolute terms or by selecting a frequency band. The majority, around 90%, were able to answer the question on Attendance Allowance, but the questions on the receipt of pensions were answered by about 60% of respondents, and smaller proportions were able to answer the other questions on benefits.

The POPP survey contained an abbreviated Client Service Receipt Inventory (CSRI), containing questions on receipt of formal health and social care services and also on community services, benefits, and informal care. Most formal care questions were asked in terms of both any receipt and the frequency of receipt in the past few months. Missing responses appear to be higher for services that one might consider to be associated with traumatic events (hospitalisation, GP home visits). Questions asking about the frequency of use seemed to vary quite markedly in the frequency of missing values depending on the type of service, with very high proportions (99-100%) of people giving an estimate of frequency of use for more universal services such as libraries, bus passes, dial-a-ride and also more sociable services such as lunch clubs and drop-in/resource centres. These figures also varied quite substantially by age band with higher rates of missing values among the older age groups. As in the Home Care Survey, response rates for questions about benefit receipt were lower. For instance, 34% of responses were missing for both Disability Living Allowance and Attendance Allowance receipt by those 65 and over.

While previous surveys can indicate the types of questions that are more likely to elicit a response, a new module of questions must also determine if the responses are likely to be based on a correct understanding of what information is being asked and
whether or not responses are likely to be accurate. The second stage of this project aims to address these issues through the cognitive testing of proposed questions.

The Home Care Survey conducted interviews with proxies where necessary. These accounted for 21% of interviews. Proxy responses were more likely to be provided for older females and younger males. With regard to refusal to take part in the survey, receipt of intensive care was more prevalent among those who refused as compared to those that responded. While the difference was not statistically significant (Darton et al, 2006, p.63), it highlights a concern that the survey under-represented more frail service recipients, particularly those with dementia.

A further issue that arose in the Home Care Survey related to accessing financial information from local authority records, where permission had been given. Attempts to access this information were only successful in a limited number of cases. This was likely due to time constraints on local authority staff and in some cases, the data being missing (Darton et al, 2006, p.70).

5.3 Prevalence of service receipt

Questions about receipt of formal services were asked in the GHS, ELSA, HSE, FRS and BHPS. The age standardised prevalence of receipt of services was calculated for each survey. Age standardisation eliminates differences between surveys which are attributable to differences in the age composition of the samples in each survey. Initial estimates were based on the entire samples as the HSE and FRS do not have an assessment of disability that is consistent with the measures in the other surveys. In the FRS, formal services appear on a list of people from whom care may be received. This question was only asked of households where there was at least one person receiving help or support because they have long-term physical or mental ill-health or disability or problems relating to old age.

Proxies were not asked the questions on receipt of formal services in the GHS and ELSA Wave 3. The HSE interviewed proxy respondents for data on children only. The analysis of the FRS excluded proxies in order to be comparable with analyses from the GHS, ELSA and HSE.

The prevalence rates of receipt of formal services were also estimated based on the subsample of individuals reporting difficulty with bathing for the GHS, ELSA and BHPS. Difficulty with bathing has been shown to be similarly prevalent across studies where it is reported (Jagger et al 2009)\(^2\). This analysis will reduce variability across the surveys that is due to differences in the underlying level of disability within each survey sample. The FRS does not ask specifically about difficulties with bathing.

Using the data from the nationally representative studies, the age standardised prevalence of receipt of each service was compared across studies by applying the Cochran-Mantel-Haenszel test as described by McDonald (2009) and Woolson and Bean (1982). The age standardised prevalence of receipt of home help was

\(^2\) It should be noted that, although previous analysis has shown that prevalence of difficulty with bathing is similar across surveys, cognitive testing of questions about bathing, carried out as part of the present study by NatCen, has indicated that there are some issues about the bathing question in terms of people needing help with bath but not shower and vice versa.
significantly lower in ELSA Wave 3 and the BHPS as compared to the GHS and HSE (Table 1). The prevalence in the FRS was in between these two pairs of estimates, statistically significantly lower than the GHS and HSE and statistically significantly higher than the ELSA and BHPS. If the samples were restricted to only those reporting difficulty with bathing (not available in the HSE and FRS), the prevalence of receipt of home help in the GHS was 10.0%, as compared to 7.7% in ELSA and 6.3% in the BHPS.

The age standardised prevalence rate of receipt of private help was significantly higher in the GHS than in the HSE and in turn, was significantly higher in the HSE than in the other surveys. The difference between the GHS and ELSA and BHPS remained when the comparisons were restricted to those reporting difficulty with bathing (13.7% versus 7.8% and 6.5%).

The age standardised prevalence of receipt of district nursing was similar in the GHS and the HSE (5.5% and 5.2% respectively). This prevalence was significantly lower in the ELSA Wave 3 and the FRS, although the questionnaires from these surveys do not explicitly refer to district nursing, but rather they refer to a nurse.

The age standardised prevalence of attendance at a day centre was similar in the GHS (3.0%) and HSE (2.3%). These were the only surveys containing a question on this service.

These comparisons suggest that the rate of formal care receipt tended to be higher in the GHS than in the other surveys. These differences were not accounted for by restricting the analyses to comparable levels of disability across surveys.

5.4 Gaps in data collection

Data on receipt of formal services by people aged 65 and over

The surveys differ in their coverage of which formal services they ask about and inclusion of questions on the intensity of service receipt. The GHS has a comprehensive set of questions, but these data have not been collected since 2001/2. Wave 3 of ELSA and the BHPS collect data on receipt of home help only. Questions pertaining to the receipt of social services are not included in ELSA waves 1 and 2. The 2005 HSE included questions on receipt of formal services but not on levels of difficulty in performing a range of activities of daily living (ADLs) and instrumental activities of daily living (IADLs). The FRS includes only limited questions about receipt of formal care. None of these surveys adequately covers the complexities of current service receipt and payment systems.

Relating receipt of services to levels of disability

Questions on receipt of services should follow questions on levels of disability and the task that require older individuals to seek formal care services. In particular, receipt of private home help was often reported without any difficulty with ADLs or IADLs.

Coverage of services
Questions should encompass, if possible, a wider range of services including rehabilitation and telecare for example. The majority of councils now offer rehabilitation/reablement services.

Questions on how people spend direct payments and personal budgets will need to include options for: payments to friends/relatives on a regular or ad hoc basis; formal employment of personal assistants; and purchase of commercial services – taxis, meals etc

**Frequency/intensity of care**

Questions about frequency of care are important and could use banded response categories which, if the same across formal and informal care, would enable comparisons to be drawn across informal and formal care.

### 6 Review of Questions on Receipt of Informal Care

*Linda Pickard, Marcello Morciano, Tom Snell, Derek King, Ruth Hancock and Raphael Wittenberg*

#### 6.1 Methodological issues relating to questions on informal care receipt

Questions about receipt of informal or unpaid care by disabled or older people are asked in ELSA, the FRS and, until recently, the GHS. There do not seem to be any questions on receipt of informal care in any of the BHPS waves (although there are questions on provision of informal help in the BHPS, described in the next section). Where questions about receipt of informal help are asked, disabled people or care-recipients are typically asked who helps them, with options including both unpaid care (e.g. from family members) and paid care (e.g. from social/health service workers).

Detailed analysis of the questions on receipt of informal help has been conducted using ELSA Waves 1 and 3 (2002/3, 2006/7), GHS (2000/01) and FRS 2004/05.

In ELSA, questions about receipt of help are only asked of people with a functional disability, that is, a difficulty with at least one ADL or IADL. Therefore, in evaluating the extent to which questions on informal care receipt in different surveys elicit similar response rates, it has been necessary to confine the analysis to people with a functional disability.

#### 6.2 Non-response/response rates for questions on informal care receipt

The rate of item non-response was very low in the GHS and ELSA Wave 1. As mentioned earlier, imputation procedures were used by the Department for Work and Pensions prior to releasing the FRS data. In ELSA and the GHS, questions on receipt of help were not asked in proxy interviews, although these questions were asked in proxy interviews in the FRS.
6.3 Population prevalence: receipt of informal care

Age standardised proportion receiving informal care with a range of tasks

A comparative analysis was undertaken of the age standardised proportions of people aged 65 and over receiving informal care with a range of IADL and ADL tasks in England in ELSA Wave 1 and the 2001/2 GHS. Questions about IADLs and ADLs were not asked in the FRS (Jagger et al., 2009) and the analysis of the FRS here relates to informal help received by people aged 65 and over who receive help or support because they have long-term physical or mental ill-health or disability (or problems relating to old age).

In the analysis of ELSA Wave 1 and the 2001/2 GHS, informal help is defined as help with a list of specific IADLs and ADLs (Comas-Herrera & King, forthcoming). Informal care receipt is derived from variables, which ask about receipt of informal and formal care, in both ELSA and the GHS. The analysis is described fully in Pickard (2008). Age standardised rates are expressed as a percentage of the population aged 65 and over and the underlying sample base excludes proxies and item non-responses.

The age standardised proportions of informal care receipt (as defined above) among older people are considerably higher in ELSA (22.0%) and the GHS (20.3%) than in the FRS (11.4%) (Table 2). The lower prevalence of informal care receipt in the FRS probably arises because the FRS does not include information on IADLs or ADLs and the types of problems with which help is given are therefore different. In comparison with the FRS, the age standardised proportions of informal care receipt in ELSA and the GHS appear fairly similar, although there is nevertheless a statistically significant difference between them.

Age standardised proportion receiving informal care: bathing only

In addition to the analysis of help with a range of tasks, the analysis also looks at help with a specific task, difficulty with bathing. The reason for focusing on help with this ADL is that, as already indicated, difficulty with bathing has been found in previous analysis to give a similar prevalence across surveys (after standardisation) (Jagger et al., 2009). The analysis of help with bathing therefore allows for greater control of underlying differences in the measure of disability between surveys.\(^3\) This type of analysis is only possible using ELSA and the GHS because the FRS does not contain information on ADLs.

Two different analyses of informal help with bathing are reported here. In both types of analysis, the ways the questions are asked mean that a sub-set of those who have difficulty with bathing is analysed. In the first, help with bathing is defined as help received by people who experience difficulties with no other IADLs or ADLs. For this group, ELSA Wave 1 and the 2001/02 GHS are used. In the second analysis, help with bathing is defined as help received by people who experience difficulties with no other ADLs (though they may experience problems with IADLs). For this group, ELSA Wave 3 and the 2001/02 GHS are used.

\(^3\) In connection with questions about bathing, see footnote 2 above.
The results show that the age standardised proportion of receipt of informal help with bathing among older people is similar in both ELSA and the GHS, whether the first or second type of analysis is carried out (Table 2). There are no statistically significant differences between the surveys.

6.4 Gaps in data collection and recommendations for questionnaire design

Overall evaluation of questions on informal care receipt

Current questions about informal help with IADL and ADL tasks in ELSA (and the GHS) appear to work fairly well. Differences in age-standardised proportions receiving care appear to be due to underlying differences in measures of disability, rather than to the questions on informal care receipt themselves. Where there is greater comparability in the measurement of disability across surveys, as with the results relating to difficulty with bathing, so there is greater comparability in the measurement of informal help with that disability.

Questions about help with specific tasks

It is helpful for questions to be asked about informal help with specific tasks, as in ELSA Wave 3 and the 2001/02 GHS. It seems important to know whether help is provided to someone who needs it for all the tasks with which they need help, however that help is given. If someone has difficulties with, for example, shopping and bathing, they may receive help (formal or informal) with the first but not the second. It is important to know this but it cannot be ascertained unless questions are asked about each task separately.

Questions on informal and formal care

Even if detailed questions about formal services are asked separately from questions about receipt of informal and formal care (as Wave 3 of ELSA has begun to do), it may still be helpful to include formal services in the list of options in the receipt of care questions to ensure respondents differentiate between informal and formal help.

Intensity of informal help received

It would be helpful to collect information about the amount of informal/formal help received (e.g. hours per week). Some stakeholders have questioned whether intensity information from the older person is likely to be reliable, and have suggested that the people providing informal care are asked about this. There are, however, limits to how far this suggestion can be operationalised. Where co-resident informal care is received, it is possible also to ask the person providing care how much care they provide. However, where the older person receives help from someone in another household (extra-resident care), there seems little option but to ask the older person how much help they receive. It may not be feasible to ask about hours of help received by older people for each task – it may be more realistic to ask the older person how much help per week he/she receives from each person who helps him/her, e.g., daughter, home care worker, etc. It makes sense to use common time-bandings for intensity of care.
Payments for informal care

It would be helpful to ask older/disabled people who receive informal help whether they provide any sort of payment (regular or ad hoc, cash or kind) for this. Perhaps such questions should be confined to people who receive substantial amounts of informal care to distinguish between help that is likely to be broadly reciprocal and help that may have become one-sided due to disability. Questions about potential payment for informal care need not be confined to people who receive Direct Payments (DPs) or Personal Budgets (PBs).

Questions on disability

It would be useful to consider asking more detailed underlying questions on disability in surveys such as ELSA. Questions about help with specific tasks could be preceded by questions about the ability to perform those tasks. This is what happened in the GHS, where, for example, older people were first asked whether they carried out a particular task, then (if they did not) were asked who helped them. Now that ELSA, for example, asks separately about help with specific tasks, it would be relatively easy to ask about the ability to perform that task first. Analysis is more precise where the ability to perform each task can be separated out.

7 Review of questions on provision of informal care

*Linda Pickard, Marcello Morciano, Tom Snell, Hayley Cheshire, Derek King, Ruth Hancock and Raphael Wittenberg*

7.1 Methodological issues relating to questions on informal care provision

Questions about provision of informal or unpaid care are asked in ELSA, FRS, BHPS, the 2001 Population Census and, until recently, GHS. Most of the surveys ask a question on informal care that relates to looking after someone who has long-term physical or mental ill health or disability, or problems related to old age (GHS; Census; FRS; BHPS; ELSA Wave 4).

In addition, there are other, more general questions on care provision that are asked in all the waves of ELSA. These questions are asked about all care provided, so that the person cared for is not necessarily sick, disabled or elderly, but might, for example, include a (healthy) grandchild, child or spouse. These questions are likely to encompass a broader type of care provision from those asked in other surveys and are unlikely to be comparable.

Detailed analysis of the questions on provision of informal help has been conducted using the following surveys: ELSA Waves 1, 3 and 4 (2002, 2006, 2008); GHS (2000/01); Census 2001 (using the Sample of Anonymised Records or SARs); FRS (2004/05; 2005/06) and BHPS (2007).

7.2 Non-response/response rates for questions on informal care provision
The rate of item non-response for questions on informal care provision was very low in the GHS and ELSA. In the FRS there were no missing cases as imputation procedures were used by the Department for Work and Pensions prior to releasing the data. In ELSA and the GHS, questions on provision of help are not asked in proxy interviews.

7.3 Population prevalence: provision of informal care

A comparative analysis was undertaken of the age standardised proportions of people providing informal care in England. Only two of the surveys (the Census and FRS) include children and young people under the age of 16 providing informal care, so the analyses focus on the adult population.

Comparisons are possible for the population aged 16 and over between the 2000 GHS, 2001 Census, FRS and BHPS. Comparisons are possible for the population aged 50 and over between the 2000 GHS, FRS, BHPS and ELSA Wave 4 (although it should be noted that the analysis of Wave 4 of ELSA, presented here, only includes people aged 55 and over, not aged 50 and over, and is provisional).

Comparison of ‘heavy duty care’, provided for 20 hours a week or more is possible, for the population aged 16 and over, using the GHS, Census, FRS and BHPS. Only one survey allows for the analysis of provision of care to the older population aged 65 and over (the 2000 GHS). However, comparison of provision of care to the population aged 65 and over is possible for co-resident care in a number of surveys. A comparison is made here between the GHS, FRS and BHPS.

The underlying sample bases exclude proxies and item non-responses. The analysis here uses the 2005/6 FRS, although the results would be very similar if the 2004/5 FRS had been used.

Prevalence of informal care provision among the population aged 16 and over

The prevalence of informal care provision among the population aged 16 and over is comparable in the 2000 GHS and the 2007 BHPS (Table 3). The BHPS prevalence rate is slightly higher than the GHS rate, but the difference is not statistically significant.

Prevalence of informal care provision is lower in the Census and FRS than in either the GHS or BHPS (Table 3). Possible reasons for this include some differences in the questions asked and differences in the methods of asking questions. In relation to the latter, one issue is that both the Census and the FRS questions are asked of one respondent on behalf of the household, rather than of all adults in the household (as in the GHS and BHPS) and this may lead to a lower reporting of informal care provision in the Census and FRS.
Prevalence of informal care provision among the population aged 50 and over

The prevalence of informal care provision among the population aged 50 and over is lower in the FRS than in the GHS or BHPS and lower in ELSA Wave 4 than in any of the other surveys included in the study (Table 3). The reason why the prevalence in Wave 4 is relatively low is probably connected with the filtering of this question on ‘wpact’. This is a question about activities during the last month, with ‘cared for someone’ being one option, and is asked in an earlier part of the questionnaire.

The effects of filtering on ‘wpact’ in ELSA was examined further by analysing the more general questions on care provision in the different waves of ELSA. The filtering of these questions on care provision in ELSA using ‘wpact’ began in Wave 2. Comparison of Wave 3 with Wave 1 suggested that the prevalence of care provision among the population aged 50 and over was lower in Wave 3 of ELSA than in Wave 1. This was likely to have been due to the impact of filtering on ‘wpact’. The relatively low prevalence of informal care provision in Wave 4 may therefore also result in part from the filtering of this question on ‘wpact’.

Provision of informal care for 20 hours a week or more by people aged 16 and over

The provision of informal care for 20 hours a week or more by people aged 16 and over is broadly comparable in all the surveys, where this could be examined, that is, the GHS, Census, FRS and BHPS. The prevalence of ‘heavy duty’ care provision is around 4 per cent of adults (3.5% to 4.1%) (Table 3).

Information on provision of informal care to people aged 65 and over

Information on provision of informal care to people aged 65 and over (both inside and outside the household) is only available in the GHS. Provision of informal care to people aged 65 and over living in the same household is broadly comparable in the GHS and the BHPS but lower in the FRS (Table 3). The relatively low prevalence rate in the FRS may be for reasons identified earlier.

7.4 Gaps in data collection and recommendations for questionnaire design

Scope of informal care provision questions

It is useful that many surveys include a question on informal care provision to sick, disabled and older people, including Wave 4 of ELSA. It also seems useful that this question is not confined to care provided in the last week. Specifically in relation to ELSA, it would be useful to consider not filtering the questions on informal care provision by ‘wpact’.

It would be helpful to collect further information on provision of informal care to sick, disabled and older people in surveys like ELSA, such as hours of care provided, whether care is co-resident or not etc. The issue would then arise as to whether it is also necessary to collect this information relating to the more general questions on informal care provision in ELSA, and whether, to do so, might be confusing to respondents. If the focus was on provision of informal care to the sick, disabled and
older people, then the number of respondents answering follow-up questions could be restricted by using the GHS definition of informal care.

**Data on provision of informal care to people aged 65 and over**

Since the GHS ceased to collect information on informal care provision, there has been no survey, carried out on a regular basis, which collects information on care (both co- and extra-resident) provided to people aged 65 and over. The GHS collected information on the age of people cared for as part of a sequence of questions about care for each person cared for (up to six cared-for people). These included questions about the relationship with the person providing care; the age, gender and type of impairment of the cared-for person; as well as the hours and type of care provided. These questions allow for analysis of the prevalence of care provision to people aged 65 and over, as well as many other types of analysis. If questions of this sort were to be asked in another survey, the number of cared-for people about whom questions were asked could probably be lower than the six included in the GHS.

**Intensity of informal care provision**

On the detail of questions asked, it has been suggested by stakeholders that the same time bands (hours per week) as in the Census should be used. We think this should read as meaning that the time-bands used should be compatible with those used in the Census (i.e. compatible with 1-19; 20-49 and 50+). However, these time bands are (unnecessarily) broad when a face-to-face interview is being carried out and more detailed time bands, for example, those employed in the GHS, are useful. This is especially true of the more detailed bands used in earlier versions of the GHS (e.g. 1995 GHS = 0-4; 5-9; 10-19; 20-34; 35-49; 50-99; 100 or more; varies - under 20 hours; varies - 20 hours or more; other). It would, however, be useful to split the first category into <1 and 1-4, to enable more accurate comparisons with the Census to be made.

**Limitations to the coverage of informal care provision**

Stakeholders have listed large numbers of potential questions on informal care provision that could be asked in surveys. The resources of the current study have not stretched to reviewing all possible questions on informal care provision, but this should not be taken to mean that other questions are not important.

8 Payment for Care

*Ruth Hancock, Alex Jones, Adam Martin, Miranda Mugford and Ian Shemilt*

We found few surveys or economic evaluations that ask respondents how much they pay for any formal (or indeed informal) care they receive. A new set of questions should be capable of collecting such payments. The four main circumstances that need to be distinguished are as follows:

1. The respondent receives formal care services arranged through a local authority and pays the cost of that care. In some cases they may pay separately
for each kind of service they receive, in others they may pay a total amount. Priority should be given to collecting the total amount, but where respondents pay for each service separately, it may be necessary to ask about each payment (in which case recording the separate amounts provides additional and useful information). Payments are usually means tested so some people may receive services but pay nothing.

2. The respondent receives a Direct Payment (cash in lieu of services) or Personal Budget (may be cash or a ‘virtual’ budget) whose value represents the gross cost of meeting his/her assessed needs less any user charge. Ideally questions should ask about the gross and net value. However, it is not clear whether respondents will know the gross value or only the net. The situation where the user is charged 100% of the gross cost presents particular problems because the net value of his/her personal budget is zero.

3. The respondent receives formal services which he/she has arranged privately and pays for privately, with no involvement of the local authority.

4. The respondent receives care from a friend/relative (i.e. ‘informal’ care) for which he/she pays the carer something, possibly out of a Direct Payment or a Personal Budget.

These are not mutually exclusive and it is important that questions on payments and questions on receipt of services take account of the fact that services arranged via a local authority are often provided by a private or voluntary organisation. Questions need to be worded carefully to avoid confusion between 1 and 3 above.

9 Review of Economic Evaluations

Alex Jones, Adam Martin, Miranda Mugford, Ian Shemilt and Ruth Hancock

9.1 Objectives

The objective of this analysis was to identify questions that have been used to collect resource use data in economic evaluations alongside studies of care effectiveness in the UK. Based on a systematic review of literature, an attempt was made to identify full or partial economic evaluations which included questions to service users or their carers to elicit information on the types, amounts or costs of community-based formal social care support provided to people over age sixty-five.

9.2 Methods

The analysis followed established methods for systematic reviews. Search strategies were developed for use in five electronic databases: Medline, Embase, CINAHL, NHSEED and PsychINFO. Searches were restricted to studies that undertook primary data collection within UK populations. Additional materials were also sought from the grey literature, bibliography searches and discussion with authors.

The review was limited to papers based on surveys of formal care receipt amongst older people in the UK for the purpose of conducting an economic evaluation.
9.3 Findings

The initial searches identified 1,946 papers of potential interest. Screening titles and abstracts eliminated all but 113 papers. The full paper was retrieved for all 113 papers. Of these, 54 met the inclusion criteria. A further 15 papers were excluding at the stage of data extraction primarily because while resource use data were included in these papers, the survey on which each paper was based was not the source of the resource use data. One additional paper was identified from the footnotes, bibliographies and contacts with authors and was judged to be relevant and suitable for data extraction. Thus, the total number of papers for which data extraction took place was 40.

The information relating to the methods of the surveys was provided by very few of the authors of the reviewed studies. For example, 29 studies did not refer to a specific survey instrument and approximately half of the studies did not report the response rate amongst over 65s. Other information such as the recall period used in the survey was rarely reported.

It can be concluded from the systematic review of this literature that when eliciting information from older people in the UK about their use of formal care services, clinical studies do not routinely report the use of validated questions. One issue identified by participants and/or researchers in these studies was the burdensome nature of completing questions on resource use as part of a wider survey.

10 Stakeholder Consultation

Juliette Malley, Michelle Gray, Margaret Blake, Meera Balarajan and Robin Legard

Separate consultations were performed to gain feedback on defining the scope of a survey instrument aimed at soliciting information in the areas we are interested in, and on the feasibility of asking questions which relate to these areas. The former was performed by PSSRU while the latter by NatCen. The consultation by PSSRU also sought stakeholders’ views on the potential for data linkage.

10.1 Stakeholder views on survey questions

The consultation on the scope of survey questions aimed to establish views on what information on receipt of formal community-based care services and on provision and receipt of informal care it would be valuable to collect through surveys, that would usefully supplement information available from other sources (mainly local authority data). The consultation questions focused on the coverage of services and the level of detail required.

Those consulted were keen that the question module captured as much of the variety in service forms as possible and in particular captured information about privately-purchased care. Omissions from the list drawn up were reablement services, telecare and Supporting People services (recall that Supporting People services were deemed to be outside the scope of the module of questions being developed). However, it was noted that if questions were too specific they may quickly become out of date, given
the move towards self-directed support and changes in policies. Stakeholders felt it was important to develop lasting questions to enable comparisons over time.

There was a lot of support for understanding what services are actually doing or, in the context of personal budgets, what people are spending their money on. Interest was also shown in understanding what self-funders spend their money on. However, there was some concern that people may be unwilling to divulge these details where they are receiving personal budgets for fear that what they are doing with their money is in fact illegal. It was also noted that it has been difficult to identify how disability benefits are used (The Social Policy Research Unit at the University of York is currently conducting work on this) and this may also be the case for personal budgets. The value of focusing questions on capturing the activities of care and aligning those activities with service forms, such as ‘reablement’, ‘home care’, ‘Supporting People’ and so on is that such an approach seems less likely to become outdated.

Stakeholders were keen that a high degree of detail was collected. In particular, quantity and frequency of service use were seen as essential, but time bands were acknowledged as necessary because of fluctuation in users’ needs and the possibility that use may vary. It was felt that the bands for informal and formal care should be the same to allow for analysis across informal and formal care. Information on who pays what for what types of care was also seen as important, but there was less interest in knowing who provides the service (e.g. charity, for profit provider, and so on) and it was thought that users may anyway not know this information.

Regarding questions asking about provision of informal care there was a lot of support for asking informal carers themselves about the care they provide, e.g. how much, to whom and so on. There was also support for understanding whether informal carers are in any way compensated for their care. In particular whether informal payments or other gifts are given in exchange for care and whether carers are receiving any type of support, such as services or benefits.

In general stakeholders were interested in a broader range of issues, including experiences of using services and outcomes for users and carers. For carers, respondents suggested that the questions should be extended to examine how long the person had been a care-giver and the impact of caring on the carer’s health and employment. These issues suggest the types of questions that it may be useful to collect alongside a module on receipt and provision of care to allow more detailed analysis of the impact of caring and receipt of care on well-being.

10.2 Service user and provider views on survey questions

Local authorities and other stakeholders were consulted on the feasibility of asking questions relating to the areas of interest – receipt of formal care, receipt and provision of informal care and information on financial circumstances and contributions to care costs. Those consulted suggested that it would be possible to ask service users about which services they receive. There was a strong feeling, however, that people might not know who provides them. Service users may just know someone by name and, more confusingly, they may have input and involvement from many different people from different organisations. There was evidence to suggest that it should also be feasible to ask about payment for services.
Some stakeholders had concerns that the study may miss some hard to reach groups such as people living in residential care homes and those with dementia and other cognitive disorders.

Stakeholders also emphasised the importance of avoiding technical language in the wording of questions about the types of services received. It is important that everyday language that is not out of date or inappropriate be used.

In a question module about receipt of care, it would be necessary to capture all of the non-conventional care too, such as alarms (or telecare) and transport.

10.3 Stakeholder views on data linkage

Stakeholders from both local and central government were also asked about the possibilities for linking social services data on receipt of publicly-funded services to survey data. Stakeholders did not have detailed comments on the potential for linkage with local government records to establish receipt of publicly-funded services. Local government respondents indicated that they would find it useful to link data across government and suggested that the Information Centre for Health and Social Care (IC) could have a role in supporting such an initiative. It was clear, however, that linkage is not possible at present as individual-level data on service use is held by councils, and it would not be feasible to match data with 150 organisations each with a different recording system. There are plans under the National Adult Social Care Intelligence Service (NASCIS) programme within the IC to move towards extraction of individual-level data from council records. It may be possible in time to link social care administrative data to survey data through the NASCIS programme.

Work is also currently underway within government to establish the NHS number as the unique identifier across health and social care. This could also aid linkage to survey data (as well as other administrative data) when implemented. The IC is also developing an honest broker service to enable linkage of data through pseudo-anonymisation, which again could help link survey and social care administrative data in the future.

11 Conclusions: What is Required from an Improved Set of Questions

Stage one has identified limitations in existing survey questions on receipt and payment for formal social care services and in provision and receipt of informal care. In addition, few economic evaluations where service users or their carers have been asked about their use of formal services have used validated instruments for collecting such data and details on the instruments used were often poorly reported.

Data from current surveys and feedback from stakeholders are consistent in the finding that interview respondents do not have difficulty answering questions on the receipt of formal services and informal care and the provision of informal care. There was evidence, however, that the scope of these questions can be improved. Also, questions regarding benefit receipt are problematic for respondents and data linkage is
not currently feasible. Other important issues are the omission of individuals with dementia and individuals living in communal accommodation.

The study has confirmed a need for robust data on the numbers and characteristics of people providing and receiving informal care and on people receiving formal care and support, including details of their financial circumstances and contributions to care costs. There is also scope for improving the quality of cost-effectiveness analysis of interventions which affect use by older people of formal social care by employing an improved and validated set of questions on social care use.

Stage two of the study involves the design of possible modules of questions. NatCen will develop a module of questions drawing upon the analysis and findings presented here. The module will be tested and revised through an iterative process of cognitive testing and review of the questions. A final module will be available for use in future surveys.
GLOSSARY

BHPS  
**British Household Panel Survey**
The main objective of the British Household Panel Survey is to further understanding of social and economic change at the individual and household level in the UK, and to identify, model and forecast such changes and their causes and consequences in relation to a range of socio-economic variables. It is conducted as a longitudinal study, where each adult member (aged 16 years and over) of a sampled household is interviewed annually. The survey is conducted by the ESRC UK Longitudinal Studies Centre, together with the Institute for Social and Economic Research at the University of Essex.


CSRI  
**The Client Service Receipt Inventory**
The Client Service Receipt Inventory (CSRI) is a research tool developed by staff in the Centre for the Economics of Mental Health and the Personal Social Services Research Unit for collecting cost-related information about people with mental health problems for use in mental health service evaluations. The CSRI is a questionnaire which collects retrospective information about the interviewee’s use of health and social care services, accommodation and living situations, income, employment and benefits. The service receipt section is the largest part of the questionnaire. The data collected through the CSRI enables a package of care to be identified: this information, together with information about the costs of services, can be used to calculate a total weekly cost of care package.


ELSA  
**English Longitudinal Study of Ageing**
The English Longitudinal Study of Ageing is about the lives of people in England who are aged 50 and over (and about their partners, if they are under 50). The study covers a broad range of topics such as people's health, economic situation and quality of life. It is helping us learn about how people's experiences vary and how their circumstances change over time. The first set or wave of interviews took place in 2002 with the findings released in December 2003. Subsequent waves have taken place at two year intervals.

FRS  
**Family Resources Survey**  
The Family Resource Survey is conducted by the Department for Work and Pensions. It aims to: support the monitoring of the social security programme; support the costing and modelling of changes to national insurance contributions and social security benefits; provide better information for the forecasting of benefit expenditure. From April 2002, the Family Resources Survey was extended to include Northern Ireland.  

GHS  
**General Household Survey**  
The General Household Survey (now known as the General Lifestyle Survey), is a multi-purpose continuous survey carried out by the Office of National Statistics. It collects information on a range of topics from people living in private households in Great Britain. The survey has run annually since 1971, except for breaks in 1997/8 (when the survey was reviewed) and 1999/2000 when the survey was re-developed.  

HSE  
**Health Survey for England**  
The Health Survey for England is part of a wider programme of surveys commissioned by the Department of Health, and is designed to monitor trends in the nation's health. It is an annual survey which focuses on different health issues each year, although a number of core questions are included every year. The HSE 2005 was designed to provide data at both national and regional level about the population living in private households in England. The sample comprised three components: the core (general population) sample; a boost sample of people aged 65 years and over (those living in institutions were not included); and a boost sample of children aged 2-15.  
REFERENCES


ANNEX

Table 1: Age-standardised prevalence of receipt of formal services by people aged 65 and over, England, 2001 - 2007: percentage of respondents and 95% confidence intervals (CIs, in brackets)

*Percentage of respondents & 95% CIs*

<table>
<thead>
<tr>
<th></th>
<th>Home help</th>
<th>Private help</th>
<th>District nursing</th>
<th>Day centre</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>All</td>
<td>with difficulty bathing</td>
<td>All</td>
<td>with difficulty bathing</td>
</tr>
<tr>
<td>GHS</td>
<td>4.3</td>
<td>(3.5, 5.2)</td>
<td>10.0</td>
<td>(7.5, 12.6)</td>
</tr>
<tr>
<td>ELSA</td>
<td>2.3</td>
<td>(1.8, 2.8)</td>
<td>7.7</td>
<td>(5.7, 9.8)</td>
</tr>
<tr>
<td>HSE</td>
<td>3.9</td>
<td>(3.3, 4.5)</td>
<td>10.0</td>
<td>(9.1, 10.9)</td>
</tr>
<tr>
<td>BHPS</td>
<td>2.0</td>
<td>(1.2, 2.8)</td>
<td>6.3</td>
<td>(1.4, 11.2)</td>
</tr>
<tr>
<td>FRS</td>
<td>3.2</td>
<td>(2.7, 3.6)</td>
<td>2.8</td>
<td>(2.4, 3.3)</td>
</tr>
</tbody>
</table>

*Sources: 2001/2 GHS; 2006 ELSA; 2005 HSE; 2007 BHPS; 2004/5 FRS (secondary analyses by authors)*

23
Table 2: Age-standardised prevalence of receipt of informal care by people aged 65 and over, England, 2001-2007: percentage of respondents and 95% confidence intervals (CIs, in brackets)

<table>
<thead>
<tr>
<th></th>
<th>Informal help with a range of tasks</th>
<th>Informal help with bathing (1)</th>
<th>Informal help with bathing (2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GHS</td>
<td>20.3 (18.8, 21.8)</td>
<td>0.9 (0.6, 1.3)</td>
<td>2.2 (1.6, 2.7)</td>
</tr>
<tr>
<td>ELSA Wave 1</td>
<td>22.0 (20.9, 23.1)</td>
<td>1.1 (0.8, 1.4)</td>
<td>-</td>
</tr>
<tr>
<td>ELSA Wave 3</td>
<td>-</td>
<td>-</td>
<td>1.9 (1.5, 2.4)</td>
</tr>
<tr>
<td>FRS</td>
<td>11.4 (10.7, 12.1)</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

Sources: 2001/2 GHS; 2002/3 ELSA; 2006/7 ELSA; 2004/5 FRS (secondary analyses by authors)

Notes: # In the GHS and ELSA, help with a ‘range of tasks’ refers to help with a list of specific ADLs and/or IADLs; in the FRS, help with a ‘range of tasks’ refers to help or support received by people who have long-term physical or mental ill-health or disability (or problems relating to old age); † help received by people who have difficulty with bathing but no difficulties with other IADLs or ADLs; ‡ help received by people who have difficulty with bathing but no other ADLs; for further details of analyses, see text.
Table 3: Age-standardised prevalence of provision of informal care#, England, 2000-2009: percentage of respondents and 95% confidence intervals (CIs, in brackets)

<table>
<thead>
<tr>
<th></th>
<th>by people aged 16 and over</th>
<th>by people aged 50 and over</th>
<th>for 20 hours a week or more by people aged 16 and over</th>
<th>to people aged 65 and over by people aged 16 and over</th>
<th>to people aged 65 and over in the same household by people aged 16 and over</th>
</tr>
</thead>
<tbody>
<tr>
<td>GHS</td>
<td>16.1 (15.4, 16.7)</td>
<td>8.8 (7.7, 9.9)</td>
<td>4.1 (3.8, 4.4)</td>
<td>12.0 (11.4, 12.6)</td>
<td>2.2 (2.0, 2.5)</td>
</tr>
<tr>
<td>Census</td>
<td>12.3 (12.2, 12.3)</td>
<td>3.9 (3.9, 3.9)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>ELSA Wave 4++</td>
<td>-</td>
<td>3.1 (2.4, 3.9)</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>BHPS</td>
<td>17.0 (16.1, 17.9)</td>
<td>9.6 (8.1, 11.2)</td>
<td>3.5 (3.1, 4.0)</td>
<td>-</td>
<td>2.6 (2.2, 3.0)</td>
</tr>
<tr>
<td>FRS 2004/5</td>
<td>11.1 (10.7, 11.4)</td>
<td>5.8 (5.2, 6.4)</td>
<td>3.6 (3.4, 3.8)</td>
<td>-</td>
<td>1.5 (1.3, 1.6)</td>
</tr>
<tr>
<td>FRS 2005/6</td>
<td>11.8 (11.5, 12.2)</td>
<td>6.0 (5.3, 6.8)</td>
<td>3.6 (3.4, 3.8)</td>
<td>-</td>
<td>1.6 (1.5, 1.7)</td>
</tr>
</tbody>
</table>

Sources: 2000/1 GHS; 2001 Census (SARs); 2008/9 ELSA; 2007 BHPS; 2004/5 FRS; 2005/6 FRS (secondary analyses by authors)

Notes: # Table shows results for questions about provision of informal or unpaid care to someone who has long-term physical or mental ill-health or disability or problems related to old age; + information on provision of informal care by people aged 50 and over not obtainable from SARs (2001 Census) because of age-categories used; ++ results for ELSA Wave 4 are for people aged 55 and over and are provisional; for further details of analyses, see text.