

Cognitive testing of social care questions for people aged 65 and over

Authors: Meera Balarajan¹, Michelle Gray¹, Margaret Blake¹ and Sophie Green¹

Robin Darton²; José-Luis Fernandez³; Ruth Hancock⁴; Cate Henderson³; Dan Kearns³; Derek King³; Juliette Malley³; Adam Martin⁴; Marcello Morciano⁴; Linda Pickard³; and Raphael Wittenberg³.

Date: November 2010

Research funded by the Nuffield Foundation (OPD/3609) and the Department of Health

¹ National Centre for Social Research (NatCen)

² Personal Social Services Research Unit (PSSRU) University of Kent

³ Personal Social Services Research Unit (PSSRU) London School of Economics

⁴ Health Economics Group, Faculty of Health, University of East Anglia



Content

Content

Acknowledgements

Introduction

1	Background	10
1.1	The purpose of this report	11
1.2	Aims of the Cognitive Testing	11
1.3	Report Structure	12
2	Methodology	13
2.1	Methodological Overview	13
2.2	Analysis of cognitive interview data	14
3	Help Needed and Help Received	18
3.1	Identifying Help Needed and Help Received (Q1 and Q2)	18
	Findings	20
	Overall Q1 and Q2	20
	Introduction to Q1 and Q2	21
	Time Reference	21
	Thinking about help received from someone and help from aids or equipment	22
	Inclusion of help received because of the way household tasks are divided	22
	Understanding of tasks	23
	Answer codes	23
	Appropriateness of the questions	23
	Final recommendations for Q1 and Q2	27
3.2	Who provides care (Q3a, Q3b, Q3c)	29
	Findings	30
	Which informal and formal provider provides care for each task (Q3a, Q3b and Q3c)	30
	Home care worker / Home help/Personal assistants can also be friends	30
	Understanding of formal providers	30
	Division of household roles and responsibilities	31
	Time reference	31
	Administration	31
	Final Recommendations for Q3a, Q3b and Q3c	31
3.3	Identifying the different types of home care workers a respondent has (Homehelp)	32
	Findings	32
	Final Recommendation for Homehelp	33
3.4	Identifying the name of information carers and the names of home help/home care worker/personal assistant (Q4a and Q4b)	33
	Findings	34
	Providing the name of the informal carer (Q4a)	34
	Providing the name of the home help/ Home help/ personal assistant (Q4b)	34
	Final Recommendations for Q4a and Q4b	34



4	Amount and Patterns of Care received	35
4.1	Whether provider lives in the household (Q3d)	35
	Findings	35
	Final recommendation for Q3d	35
4.2	Selection of providers for looping through detailed questions about care received (WHPROV).....	36
	Final Recommendations for WhoProv	36
4.3	Help provided remotely (Remote and Remoft)	37
	Findings	38
	Whether respondent receives help by phone or email (Remote).....	38
	Frequency of contact by phone or email (Remoft)	38
	Final Recommendations for Remote and Remoft	38
4.4	Amount and patterns of help received by respondent (Q6, Q7, Q8 and Q9).....	39
	Findings	40
	How often the provider helps (Q6).....	40
	How many times a day the provider helps (Q7)	40
	Whether care received during the day time or night time (Q8)	41
	Whether care received during week or weekend (Q9)	41
	Final Recommendations: Q6, Q7, Q8, Q9	42
4.5	Intensity of care received (Q10 , Q10i and Q10a)	43
	Findings	44
	Hours of care received in the last week (Q10 and Q10a) (Round 1)	44
	Time the provider 'had' to be with respondent in the last week (Q10i) (Round 2).....	45
	Time the provider 'had' to be with respondent in the last week using broader categories (Q10j) (Round 2).....	46
	Hours of 'active' help with tasks received in the last week (Q10) (Round 2).....	46
	Hours of 'active' help with tasks received in the last week with broader categories (Q10a) (Round 2)	47
	Final recommendations for Q10, Q10a, Q10i, Q10j	47
4.6	Whether last week was a usual week (Q11)	48
	Findings	48
	Whether last week was a usual week (Q11)	48
	Final recommendations for Q11	48
5	Care services used	49
5.1	How people over 65 have received food for their main meals over the last month (MEALS)	49
	Findings	50
	Final Recommendations for MEALS	50
5.2	Frequency of meals on wheels in the last month (MWtimesc).....	50
	Findings	51
	Final Recommendations for MWtimesc	51
5.3	Whether respondent has used a lunch club within the last month (LnchClub)	51
	Findings	51
	Final Recommendations for LunchClub	51
5.4	Whether respondent has used a Day Centre in the last month (DayCen)	52
	Findings	52
	Final Recommendations for DayCen	52
5.5	How often respondents have used lunch clubs in the last month (LCTimes)	52
	Findings	52
5.6	How often respondents have used Day Centres in the last month (CenTimes)	53
	Findings	53
5.7	Amount of time respondents spend at a Day Centre (CenDur)	53
	Findings	53



Final Recommendations for CenDur.....	53
---------------------------------------	----

6 Payments for Care 54

6.1 Overview of payments module.....	54
Round 1 structure.....	54
Round 2 structure.....	55
6.2 Local Authority involvement in arranging care (Q5a and IncAss)	56
Findings	56
Whether Local Authority involved in arranging care (Q5a) (Round 2 only)	56
Whether respondent has had an income assessment (Incass) (Round 2 only)	57
Final Recommendations for Q5a and Incass	57
6.3 Whether respondent pays anything for care and how much.....	58
Findings	60
Whether respondent paid anything for any informal providers (Q12newa, Q12newb) (round 1 only)	60
Whether respondent paid anything for providers (Q12, Q12b, (for informal providers))	60
Frequency or period for amount paid (Q12freq, Q12bfrlp)	61
Whether and how much respondent paid for local authority arranged care (Q12lump,Q12blump, Q12bfrlp)	61
Final recommendations for Q12 and associated questions	62
6.4 Obtaining proxy answers where respondent does not have the necessary information	63
Findings	63
Whynoq12, Finhelp	63
Final recommendations for WhynoQ12 and Finhelp	63
6.5 What proportion of the cost of care respondent pays	64
Findings	64
Q17	64
Allcost	64
Final recommendations for Allcost.....	65
6.6 Collecting information about direct payments.....	65
Findings	66
Whether other person or organisation paid for care (Q13)	67
Whether LA payment made directly or by direct payment/ personal budget (Q14)	67
Whether respondent pays their contribution using direct payment/ personal budget (Q16)	68
Amount and frequency of payment for direct payment/ personal budget (Q15, Q15freq)	69
Final Recommendations.....	69
6.7 Payments made by family members (Q18)	70
Findings	70
Final recommendation for Q18	71
6.8 Reasons for no payment being made for care (Q19)	72
Findings	72
Final recommendations for Q19	72
6.9 Feelings about being asked questions about payments and financial matters.....	73

61

7 Aids and Equipment 74

7.1 Identifying whether respondents have a sensory alarm (SenAlarm).....	74
--------------------------------------------------------------------------	----

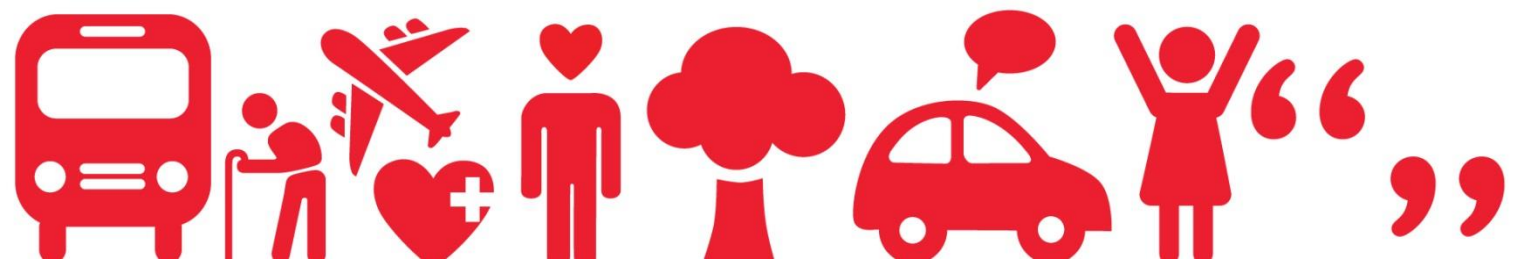


Findings	74
Final Recommendations for SenAlarm	75
7.2 Identifying if respondents have equipment to help them with daily living (Equip2)	75
Findings	75
Final Recommendations for Equip2	75
7.3 Identifying who provided respondents with any equipment identified at Equip2 (Equipy)	76
Findings	76
Final Recommendations for Equipy	76
7.4 Identifying whether respondents have major adaptations to their homes to help with daily living (Equip1)	77
Findings	77
Final Recommendations for Equip1	77
7.5 Identifying who provided respondents with any major adaptations identified at Equip1 (Equipx)	77
Findings	78
Final Recommendations for Equipx	78
7.6 Identifying if respondents have stair lifts in their home for their use (Stairlift)	78
Findings	78
Final Recommendations for Stairlift	79
7.7 Identifying if respondents use equipment related to mobility (Mobility)	79
Findings	79
Final Recommendations for Mobility	79
7.8 Identifying if respondents have used a council' Handy Man's service in the last three months (HandyMan) ..	80
Findings	80
Final Recommendations for HandyMan	80
7.9 Identifying what type of accommodation respondents live in (SheltType)	80
Findings	81
Final Recommendations for SheltType	81
8 Provision of care	82
8.1 Identifying Providers of Care (Q61, Q61b and Q62)	82
Findings	83
Q61 (Whether provided help or support due to health problems or old age in the last month)	83
Q61b (Follow up check to Q61 only included in round 2)	83
Q62 (Number of people aged 65 and over provided help or support to)	83
Final Recommendations for Q61, Q61b and Q62	83
8.2 Names of those aged 65 and over who are cared for (Q63)	84
Findings	84
Final Recommendations for Q63	85
8.3 Whether those aged 65 and over who are cared for live in the same or a different household (Q64)	85
Findings	85
Final Recommendations for Q64	85
8.4 Relationship of those cared for to provider (Q65a)	86
Findings	86
Final Recommendations for Q65a	86



8.5 Age of those cared for (Q65b)	87
Findings	87
Final Recommendations for Q65b	87
8.6 Activities or tasks provider helps or supports with (Q66)	87
Findings	88
Final Recommendations for Q66	90
8.7 Remote help (RemoteP) and frequency of remote contact (RemOfP)	90
Findings (from round 2 testing only)	91
Remote help (RemoteP)	91
Frequency of remote contact (RemOfP)	91
Final Recommendations for RemoteP and RemOfP	91
8.8 Hours of provision (Q67i, Q67, Q68 and Q68b)	92
Findings	94
On-hand vs. Active help (Q67i and Q67)	94
Banded version of active help question (Q68)	95
Hours help in an average week (Q68b)	95
Final Recommendations for Q67i, Q67, Q68 and Q68b	95
8.9 Receipt of money for the help provided (Q69)	96
Findings	96
Final Recommendations for Q69 and Q70	97
8.10 Support received for caring (Q71)	97
Findings	98
Final Recommendations for Q71	98
8.11 Whether person cared for receives support (Q72)	98
Findings	98
Final Recommendations for Q72	99
8.12 Total time spent caring for all people, aged 65 or over, cared for (Q73)	99
Findings	99
Final Recommendations for Q73	100
8.13 Health effects of caring (Q74 and Q75)	100
Findings	100
Final Recommendations for Q74 and Q75	101
8.14 Affect of caring on ability to stay in employment (Q76)	102
Findings	102
Final Recommendations for Q76	102
8.15 Whether received a carer's assessment (Q77)	103
Findings	103
Final Recommendations for Q77	103
9 Shortening the questionnaire	104
Technical Appendix	106
Study Design	106
Cognitive Methods	106
Sample and Recruitment	107
Conduct of Interviews	108





Acknowledgements

We would like to thank the Nuffield Foundation and the Department of Health for funding this research.

We would also like to express our thanks to the cognitive interviewers: Amanda Maltby, Ann Roberts, Colin Tuck, Karen Joyce, Sue Archer and Oxana Metiuk; and to Chris Massett and her team in the NatCen Telephone Unit for their help with recruiting respondents. We would also like to thank Ian Shemilt for his support. Finally, we would like to express our gratitude to those who took part in the cognitive interviews as without their help this research would not have been possible.

Introduction

This report outlines the details of and findings from two rounds of cognitive question testing. The aim of this report was to provide a focused bullet point record of the cognitive findings from round 1 and 2 and to document the question development process. Following the second round of cognitive testing, the research team went through various iterative stages to finalise the questionnaire. This report, however, does not provide details of this later process as discussions mainly took place during meetings and over email which are difficult to document. The final social care questionnaire has therefore, moved on some way since the time this report was written in May 2010 soon after the second round of cognitive testing took place. Some of the recommendations that NatCen have made to the final questionnaire signal discussion amongst the group to clarify measurement aims or prioritise data needs. A final version of the questionnaire can be found on the social care webpage: <http://www.natcen.ac.uk/social-care-questions-for-over-65s>. We would like to highlight to the reader that the variable names (and question numbers) referred to in this report do not link to those in the final questionnaire. This report is a standalone record of findings and recommendations from two rounds of cognitive testing.

1 Background

The Nuffield Foundation and the Department of Health funded the Questionnaire Design and Testing (QDT) Hub at the National Centre for Social Research (NatCen) to work with academics from the University of East Anglia and the Personal Social Services Research Unit (PSSRU) at the London School of Economics and the University of Kent to develop a clear set of survey questions about social care for people aged 65 and over which can be used in a range of national surveys.

Social surveys have gathered minimal information on the receipt and payment for care. The questions vary between surveys and this inconsistency makes question comparison difficult. Existing questions that cover receipt and payment of care may be difficult to answer accurately due to the complexity of social care provision. Service users may find it difficult to distinguish between providers of social care (i.e. private care agencies) and those funding social care (i.e. Local Authorities). Additionally the charging arrangements for funding services are complicated and developments such as Direct Payments (cash) and Personal Budgets (accounts) are not reflected in existing survey questions. There is a desire across several fields for up-to-date information about receipt and payment for care, especially in relation to people aged 65+. The overarching aim of the research is to develop clear and robust questions that could be included in social surveys and economic evaluations on:

- 1) receipt of care and support services by older people;
- 2) payment of social care for older people;
- 3) receipt of informal care by older people; and
- 4) provision of informal care.

More specifically, it is hoped that the modules of questions will cover:

- Community-based social care services
- Respite care
- Direct Payments and Personal Budgets for care
- Privately-purchased personal care and domestic help
- Community equipment
- Community health services
- Supported housing, such as supporting people funds
- Disability benefits
- Informal care by relatives and friends (receipt and provision)

Where relevant, questions aim to cover frequency and intensity of care service receipt and user contributions/charges.

1.1 The purpose of this report

A large programme of work is currently underway with six overall objectives, including a review of current care questions (objective 1), consultation with key stakeholders (objective 2) and data owners (objective 3). A review of data linkage procedures has been included (objective 4) in hope of linking survey data with Local Authority administrative records about the characteristics of their clients and the social care services they receive. A key objective of the project is to develop a module of survey questions on social care receipt and provision (objective 5). The final stage involves piloting a question module (objective 6) which would be funded separately.

This report addresses the second, third, fourth and fifth stage of objective 5 of the overall programme of work (shown below). The first stage was documented in a previous report and the fifth stage will follow on from this report.

1. NatCen and academic teams shall work together, consulting external experts to develop a shared understanding of the different types of formal services, the terms used to describe them, methods of service delivery and receipt, and how user charges are determined and collected. It will be important to understand these social care factors from both user and professional perspectives. We envisage in depth interviews with service providers and Local Authorities as well as depth interviews or focus groups with service users¹.
2. On the basis of this work a draft questionnaire will be prepared.
3. Conduct first cognitive pilot (possibly more than one strand if the content of the questionnaire is too great to be tested in one strand). The focus is on testing new questions, although testing questions drawn from previous surveys that have not formerly been cognitively tested might be useful. Cognitive testing would also cover questions aimed at gaining consent for data linkage.
4. Review questionnaire, make recommendations.
5. Share revised questionnaire and cognitive findings with funders and data users.

1.2 Aims of the Cognitive Testing

The cognitive testing had two main aims. The aim was to look at the cognitive answer process to explore how the questions are understood, examining the judgement, recall and response processes respondents used in formulating their answers. It is important to obtain a comprehensive understanding of the question-answer process for each module of questions as there will be a diverse range of social care receivers, some with particularly complex needs, answering the questions. Through testing, we can evaluate the questions to ensure that they

¹ The first stage was reported in Gray, M. And Balarajan, M (2009) Developing social care questions: *Findings from qualitative research with service providers and service users*

measure the intended measurement aims, find out whether the answer categories provided are appropriate and explore the respondents' acceptability of the sensitive topics in question.

1.3 Report Structure

This chapter (chapter one) provides background details. Chapter two presents an overview of the methodology used for the cognitive interviews. The other chapters in this report deal with each set of questions separately. For example, we dedicate a whole chapter (chapter 8) to the provision of care. In the appendix we provide a detailed account of the methodology used for this study (Appendix A), a copy of the questionnaire used in round 1 (Appendix B) and round 2 (Appendix C) and duplicates of the advance letters used in both rounds (Appendix D and E).

A module of questions was designed to collect data about care received for those aged 65 or over. The module contains six sections, each exploring a particular dimension of social care. The six dimensions explored are:

- Help needed and help received and who provides help (chapter 3) ;
- The amount and patterns of care received (chapter 4);
- Care services used (chapter 5);
- Payments of care received (chapter 6);
- Aids and equipment used (chapter 7)

A module of questions was designed to collect data on the provision of informal care, details of which can be found in chapter 8.

A final chapter discusses ways in which the questionnaire could be shortened, both as a whole, but also further cuts for a short version which we refer to as the short module. The long module being all the questions we recommend for inclusion in the module. Cuts for specific questions are mentioned in the relevant chapters. However this section brings it all together.

In this report the findings of round 1 and round 2 have been amalgamated. In order to advise improvements on the new questionnaire content and provide a written record of the process, not all the detailed findings from both rounds have been included. We have predominantly focussed on findings which relate to recommendations. The questions used in both rounds have been presented with wording from round 1 in black and wording for round 2 in red and underlined. In general it can be assumed that the wording for round 1 was also incorporated in round 2, unless indicated by a note.

2 Methodology

2.1 Methodological Overview

Two rounds of cognitive testing were carried out that tested questions developed by the QDT Hub in consultation with academic colleagues. Thirty face-to-face cognitive interviews were conducted in round 1 and twenty-six interviews in round 2. In round 1 the interviewers used a paper questionnaire and in round 2 the interviewers administered a computer assisted personal interview (CAPI). The CAPI was administered in round 2 to replicate how the questions would actually be administered in a real survey.

Cognitive interviews utilise techniques derived from cognitive psychology to explore the ways in which respondents understand and react to the question being asked. Respondents are recruited to reflect the range and diversity of the population of interest, who could take part in the actual survey. The cognitive interviews were conducted with three types of respondents for this study:

1. Type 1: People aged 65 or over who received social care either from a formal provider, informal carer or both; and or,
2. Type 2: Informal carers aged 18 or over who provide care to someone aged 65+; or,
3. Type 3: People aged 65 or over who neither received nor provided care to someone aged 65 or over.

Each interview lasted approximately one hour, although interviews with those who receive care and those who receive and provide care were slightly longer. The interviews were carried out by six experienced cognitive interviewers, all members of NatCen's core team, as well as by NatCen researchers trained in cognitive interviewing techniques. The areas in which interviewing took place were:

- London,
- South East,
- Grantham and Nottingham,
- Lancashire, and
- Leeds and West Yorkshire.

The interviews for round 1 were conducted in November and December 2009 and the interviews for round 2 were conducted in February and March 2010.

We present here an overview of the sample used in both rounds of cognitive testing; further details can be found in Appendix A. A purposive or 'quota' sample was used for this project. For both rounds of testing we recruited three types of respondents as indicated above. In total fifty-six interviews were conducted for this project. For round 1, we recruited respondents who had taken part in the Health Survey for England in 2005 and agreed to be re-contacted to take

part in future research. For round 2, we wanted to recruit sufficient respondents who had received direct payments or personal budgets (also known as individual budgets) to pay for the social care they had received. We therefore adopted four recruitment strategies for this round of testing.

1. We wrote to individuals who are currently taking part in the English Longitudinal Survey for Ageing (ELSA) as dress rehearsal panel respondents and invited them to contact the research team if they were interested in participating in this study.
2. We advertised this study with the help of Local Authorities and Age Concern, asking anyone interested in the study to contact the research team.
3. We asked interviewers to help with advertising the study in their areas and ask anyone interested to contact the research team.
4. We contacted respondents who took part in the Health Survey for England in 2005 and who had not been contacted in round 1 because quotas had already been met.

All prospective respondents were screened in the study using a telephone screening questionnaire to identify suitable respondents.

Respondents who were 'screened in' and agreed to participate in this research were sent a confirmation letter confirming their participation. The letter explained the study and the name of the interviewer who would be contacting them to arrange a suitable time for the interview. After the interview, respondents were given a £20 voucher as a token of our appreciation for taking part in the interview. On the next page we present the characteristics of those interviewed (table 1). (Appendix B contains the test questionnaire and probes and Appendix C contains copies of the recruitment document).

2.2 Analysis of cognitive interview data

Following the cognitive interviews, interviewers listened back to the recordings and made notes of their individual interviews. The research team entered the notes in an analytical framework, or 'chart', called Framework. This is an analytical tool developed by the former Qualitative Research Unit at NatCen. This chart organised the data in a coherent and structured way. For round 1 the data was analysed using the standalone Framework software, for round 2 analysis a framework a matrix was set up in Excel, which listed the areas explored in the interviews as column headings along the page and individual cases down the page. The matrix included a summary of the characteristics of respondents, such as whether they were a provider of care and/or a receiver of care or neither. Under each column a summary was made of each respondent's thoughts and the issues that they raised while answering the question (as noted by the interviewer). Thus, data could be read horizontally as a complete case record for an individual, or vertically by area, looking across all cases. Once the matrix was completed the data was reviewed. Through analysing the matrix the full range of issues were unravelled.

Table 1: Sample Characteristics of respondents in round 1 and round 2

Characteristic	Characteristic	Number with Characteristic in round 1	Number with Characteristic in round 2
Gender	Male	16	6
	Female	14	20
	Total	30	26
Age groups	18-64	4	4
	65-74	7	5
	75-84	13	9
	85+	6	8
	Total	30	26
Type of help	Formal only	1	7
	Informal only	11	3
	Both	9	7
	Total	21	17
Funding for formal care	From LA	7	3
	Private	2	2
	Combination	-	3
	Didn't know	1	1
	Total	10	9
	Direct Payments/Individual Budgets	-	2
	LA pays directly	-	3
	Combination of the above	-	1
	Total		6
	Types of informal care received	Spouse only	6
Child(ren)/grandchild(ren) only		5	5
Others only (other family members, friend, neighbour)		1	0
Mix of family and others		8	1
Total		20	10

Characteristic	Characteristic	Number with Characteristic in round 1	Number with Characteristic in round 2
Types of Formal Care Received	Home Help/Home Care Worker/ <i>included Personal Assistant in round 2</i>	7	13
	Nurse	3	0
	Personal Assistant	1	n/a
	Occupational Therapist/Physiotherapist	2	0
	Cleaner	4	2
	Voluntary worker	1	1
	Other	2	1
Receipt of different types of carers	Only one type of care received	6	8
	More than one type of care received	4	9
	Total	10	17

Providers of informal care	Spouse	3	1
	Child	1	3
	From another family member	1	1
	(mutual care provided by a spouse)	2	0
	To different people	0	1
	Total	7	6

3 Help Needed and Help Received

3.1 Identifying Help Needed and Help Received (Q1 and Q2)

Question 1 and 2 are asked of all respondents aged 65 and over to identify what tasks they need help with and whether they receive help with each particular task. The tasks selected for inclusion in this module of questions feed into social care indicators such as the Katz measure and the Barthel index.

The question introduction, question stem, individual question and answer codes used in both rounds of testing are presented below. The text in red and underlined indicates the new wording tested in round 2 following recommendations from round 1. Following round 1, the questions were reordered so personal tasks were asked first to help with the administration of the showcards and to assist respondents in understanding what was meant by help (the new order is presented in the right hand side of the box below). The wording for the bladder and bowel question are different so are presented at the end. These two questions were asked after Q1j (using the toilet) in both rounds.

Question Introduction	
<p>Q1 INTERVIEWER READ OUT ...“The next few questions are about some tasks that some people may need help with and help that you may have received in the last month. Thinking only about help you need because of long-term physical or mental ill-health, disability or problems relating to old age, for each task, I’d like you to tell me which option applies to you. <u>Please don’t think about help you have always received because of the division of labour in your home.</u></p> <p>Q2Int. INTERVIEWER READ: For this part, please think about and include all help you received even if it was received for a short time or provided by your husband/wife or another family member”</p>	
Question Stem	
Thinking about..... (please look at this card and tell me the option which best applies to you)?	
Individual questions used in	
Round 1	Round 2
shopping for food (a):	getting in and out of bed on your own (e):
preparing hot meals (b):	washing your face and hands (f):
doing routine housework (c):	having a bath or a shower, , including getting in and out of the bath or shower (g):
doing laundry (d):	dressing or undressing (h):
getting in and out of bed on your own (e):	using the toilet (i):
washing your face and hands (f):	eating, including cutting up food (j):
having a bath or a shower, including getting in and out of the bath or shower (g):	taking the right amount of medicine at the right times, <u>including prescribed medicines as well as medicines you can buy over the counter</u> (k):
dressing or undressing (h):	getting around indoors (l):
using the toilet (i):	
eating, including cutting up food (j):	

<p>taking the right amount of medicine at the right times (k):</p> <p>getting around indoors (l):</p> <p>getting up and down stairs (m):</p> <p>going out (n):</p> <p>doing paperwork or paying bills (o):</p>	<p>getting up and down stairs (m):</p> <p>going out for example, getting out of the house to go to the <u>doctors</u> or visit a friend, in the last month (n):</p> <p>shopping for food <u>including getting to the shops, choosing the items, carrying the items home and then unpacking and putting the items away</u> (a):</p> <p>preparing hot meals (b):</p> <p>doing routine housework (c):</p> <p>doing laundry <u>including loading and unloading the washing machine, putting clothes out to dry and ironing</u> (d):</p> <p>doing paperwork or paying bills (o):</p>
Answer Code used in	
<p>Round 1</p> <ol style="list-style-type: none"> 1. I can do this without help 2. I have difficulty doing this but manage on my own 3. I can only do this with help 4. I cannot do this 	<p>Round 2</p> <ol style="list-style-type: none"> 1. I can do this without help <u>from anyone</u> 2. I have difficulty doing this but manage on my own 3. I can only do this with help <u>from someone</u> 4. I cannot do this 5. It is not my role or responsibility to do this

BladProb

SHOWCARD B

Do you suffer from problems with your bladder? By bladder problems we mean accidentally having wet pants, leaking urine, needing to go to the toilet frequently or urgently, sometimes not making it to the toilet in time, or using aids or appliances to manage bladder problems or incontinence. Please include problems with your bladder caused by any medicines that you take.

1. Yes
2. No
3. Prefer not to stay

BowProb

SHOWCARD C

Do you suffer from problems with controlling your bowels? By problems controlling your bowels we mean accidentally having soiled pants, leakage from the bowel, needing to go to the toilet frequently or urgently, sometimes not making it to the toilet in time, or using aids or appliances to manage bowel problems or incontinence. Please include problems with your bowel caused by any medicines that you take.

1. Yes
2. No
3. Prefer not to stay

Findings

Overall Q1 and Q2

A task based approach was adopted to explore help needed and help received to inform a number of measures used to analyse receipt of social care such as the Katz measure. Cognitive testing of this approach found that this was an easy way for respondents to think about their need and identify help received.

Question 1 and Q2 worked well in both rounds of testing, with receivers of social care, providers of social care and those who neither received nor provided care, able to select an appropriate answer to the individual questions. Respondents thought about help in the context of help that they needed. When respondents received care, they generally thought about the care they received so included informal and formal providers of care (specific question findings are reported below). In round 1 we tested two different approaches to asking respondents if they *need* help with a task and if they *received* help with the particular task. The format of Version A asked if the respondent needed help with a particular task followed by a question asking if they received help with the particular task. Version B asked if the respondent needed help with all 15 tasks first and then asked if they received help with all 15 tasks. Following round 1 testing we made the recommendation to use Version A as the cognitive technique ‘think aloud’ showed respondents think about if they need help followed by who helps them, if help is needed. As in round 1, the evidence from round 2 testing indicates that the approach of Version A did not cause respondents any problems. However, it should be noted that questions 1 and 2 are very wordy and involve the repetition of the same phrases by the interviewers.

The amendments introduced following round 1 testing on the whole worked as intended. Some tasks were slightly reworded after round 1 and these changes did help clarify the understanding of the particular task (see table 3 for explanation). In round 2, only the bladder question and the bowel question were found to be sensitive on occasions for those who suffered from either or both of these problems. The other tasks were not considered sensitive irrespective of whether the person needed assistance or received help with a particular task or if did not need assistance. There is no evidence from round 2 to indicate that the reordering of the tasks, with personal tasks asked first, caused any problems.

Below specific problems on how Q1 worked are presented. This section focuses on findings:

- Not fully addressed since round 1; and,
- New problems found with round 2 testing which were not found in round 1.

Introduction to Q1 and Q2

Testing from round 2 revealed that a better introduction to these two questions is needed for a number of reasons we shall now summarise.

- Both interviewers and respondents found the introduction wordy, as illustrated by the following quote.

“I think it’s trying to say what can I do by myself.... I don’t really need to know what the questions are, or what the philosophy of the question are, do I?” (Male, 75-84, R does not receive or provide care).

- High end service users felt that the questions were repetitive when they had identified that they cannot do anything and needed help with everything. The introduction needs to let respondents know they will be asked questions about the different tasks.

“I already told you that I can’t do anything” (Female, 93 years old, receives 24 hour specialist home care)

- There are risks of both under-recording and over-recording. Testing in both rounds, revealed that respondents could under-record the help they needed because they either forgot the informal or formal help they receive because it is so regular or because they do not want to be seen as receiving this help. The latter scenario was identified in Q3a and Q3b when the respondent who provided the care was identified and the respondent explained what tasks they required help.
- It was revealed that there is a rare group of respondents who are inclined to answer the question without using the answer codes provided by the showcard and prefer to answer each question in Q1 as an open question, so just talking about their answer. This was demonstrated by the respondent needing a lot of interviewer direction including re-reading the answer codes but still not able to select any answer codes, (shown by the respondent saying that they have answered the question or cannot say anymore) or able with this support to select a suitable answer.

Time Reference

Following testing in round 1, it was found that a time reference was needed in Q1 and Q2 because respondents thought about different times when they answered the questions e.g. just about the time since they fell ill, ever needing help, ‘a bad day’, a usual month rather than last month. In round 2, we included a reference of the last month in the introduction to Q1 and in the question stem of Q2. Generally respondents were able to think about this time period when

answering all the questions in Q1 and Q2. Testing revealed that when respondents did not use the reference period this was because:

- The bladder question and the bowel question did not include a time reference so the respondent made the conscious decision to answer these two questions generally and the other questions in Q1 and Q2 in reference to last month;,
- The respondent decided to answer Q1a only in the context of the future because the respondent anticipated having problems with this task; or,
- The respondent answered Q1m (stairs) thinking hypothetically because this question was irrelevant to them, as he/she had not used the stairs in her home for 11 years.

Thinking about help received from someone and help from aids or equipment

Help was well understood in the context of the respondents' needs for the specific question in both rounds of testing. Clarifying the answer codes at Q1 has helped address the problem identified in round 1 of respondents thinking about help in the context of equipment or aids that they use but it has not eliminated this problem completely. The error occurred rarely in round 2. Overall, respondents who did use equipment understood that they should not include this in the question and answered the question correctly despite not always being entirely confident in their answer.

Inclusion of help received because of the way household tasks are divided

Testing in round 1 revealed that a group of respondents included help that they received because of the way household divisions were divided in their home as help rather than thinking about help they received because of long standing illness, disability or old age (i.e. the measurement aims of this question). The tasks where this tended to occur were shopping, preparing hot meals, routing housework and cleaning. To address this problem, a statement was added to the introduction and an additional answer code ('It is not my role or responsibility to do this') was provided for these more practical tasks. Testing from round 2 suggests that when this problem has been addressed, it is primarily a result of the new introductory statement.

Answer code 5 ('It is not my role or responsibility to do this') at Q1 did capture help provided because of the division of labour in the home but more often than not, it was misunderstood.

Further respondents who did understand code 5 thought they should not have been asked Q2, because they did not do the task so did not need help and answered 'it is not my responsibility' but did not select an answer code or selected answer code 2 'No'.

When code 5 at Q1 was misunderstood it was taken to mean:

1. Cannot do a task and hate someone to do the task for them;

2. Not the respondent's responsibility anymore because he/she cannot do the task now, or not allowed to do it any more and their formal carer and or informal carer now does the task all the time for them; or,
3. It did not mean anything.

The implication of this answer code 5 ('It is not my role or responsibility to do this') at Q1 not being well understood by respondents is that it is not always selected when it should be (i.e. for the mutual support and/or division of labour). Respondents therefore still selected 'Yes' to indicate that they do receive help with the task because of the way household roles and responsibilities are divided and not because they need help because of long standing illness, disability or old age and are therefore routed through the rest of the receiver questions.

Understanding of tasks

On the whole, the tasks were well understood and worked as intended. The clarifications added following round 1 did help to clarify the understanding of individual questions. In round 1, Q1a (shopping) and Q1d (laundry) were thought about in two ways: broadly, and about all aspects of that task or with a focused understanding of that task. To help these two questions achieve the measurement objectives and encourage respondents to think about the entirety of the tasks, examples were added to both questions in round 2. Testing revealed that on occasion for both questions the examples added made the question difficult to answer. This was the case for respondents who could manage some of the tasks listed in the example but not others e.g. at Q1a (shopping) a respondent could choose items but needed help with carrying the shopping. Nevertheless, universally these respondents correctly answered the question thinking about the help they needed with any aspect of the particular task.

Answer codes

The answer codes 1 to 4 for Q1 worked as intended generally in round 1 and round 2. On one occasion in round 2, answer code 2 and answer code 3 were perceived as overlapping. The implication was that this respondent used both answer codes 2 and 3 when answering individual questions in Q1. We have already discussed the difficulty found with answer code 5.

Appropriateness of the questions

There were rare occasions in round 1 when the questions overall were viewed as sensitive. This finding was not reported in round 2. When this arose it was because:

- The respondent became aware of how much their informal carer was doing for them which they had not thought about before. Also the informal carer who was interviewed for this study played down how much help they provided.

- A respondent felt he/she was being tested to justify his/her benefits so he/she thought about his/her worst day when answering Q1 and Q2. It is very important that the interview is administered sensitively and respondents are told the purpose of the research before the interview begins.

The two individual questions which were sensitive on occasions were the bladder and bowel question. The sensitivity arose because either:

- The respondents did suffer from a bladder or bowel problem;
- Felt uncomfortable to answer the question when the interviewer was of the opposite sex; or,
- The informal carer who helps was present at the interview.

These two questions were designed to be administered on showcards to address the issue of sensitivity. When the respondent could read the showcard this worked well to address issues of sensitivity. However, on occasions when the interviewer had to read out the showcards, testing showed that this mode of administration, as anticipated, could be uncomfortable for the respondent and or the interviewer. Despite the sensitivity of the topic and or the way the question was administered, universally respondents could answer these questions. Testing also revealed that respondents who do suffer from bladder or bowel problems could also be very comfortable answering these types of questions because they are so used to answering such questions. In both rounds of testing, respondents who did not have a problem did not find either question difficult to answer irrespective of reading the showcards themselves or listening to an interviewer read the showcards.

In the second round of testing, not all the respondents could read the showcards because of their disability which prolonged the administration of Q1 and Q2. Moving between showcard A and B or reading the showcards was difficult for select respondents due to their particular health conditions, including arthritis, weak wrists, poor eye vision and blindness.

To assist respondents' supporters were allowed to be present at the interview at the respondent's request. Interviewer comments suggest that the supporter can think differently to the respondent about whether they help with a particular task. This needs to be borne in mind for when the survey is administered so to avoid respondents changing their answers if others are present at the interview and also if proxy questions are developed.

Table 3 below summarises the tasks which have been identified, through cognitive testing, to be problematic in either round of testing.

Table 3 Specific findings relating to tasks which were found to be problematic in either round of cognitive testing (presented in the order tested in round 2).

Question tested in round 2	Reason for rewording findings from round 1 and round 2
Having a bath or shower, including getting in and out of the bath or shower (g):	Overall, this question worked as intended in both rounds. In round 1, on a rare occasion when a respondent had difficulty with one aspect of the question (getting in and out of the bath) but not with the other (getting in and out of the shower), the respondent answered about the aspect(s) he/she did not find troublesome so selected 'I can do this without help' for Q1g and no for Q2g. To address this, an interviewer instruction was added for this question in round 2 so if respondents requested clarification the interviewer was instructed to ask the respondent to think about the washing facilities they use. This seems to have addressed this problem, as this problem was not reported in round 2.
Do you suffer from problems with your bladder?.... <u>Please include problems with your bladder caused by any medicines that you take.</u>	This question was understood but can be a sensitive question for those who do suffer from bladder problems. Testing in round 1 revealed that when a respondent had bladder problems due to the side effect of their medication they could select either answer code. When a respondent selected Yes, it was because he/she decided they did have a problem with their bladder or if they answered No, they did so because he/she decided they only had the problem because of their medication. Testing in round 2 showed that the amendment has addressed this problem.
<u>Do you suffer from problems with controlling your bowels?.... Please include problems with your bladder caused by any medicines that you take.</u>	This question was added in round 2 to inform the Katz measure. This question was understood but can be a sensitive question for those suffering bowel problems, but not universally so. On an occasion, a respondent answered No to bowprob although the respondent did have problems with their bowels because he/she did not have the problems indicated on the showcard such as soiling their pants.
taking the right amount of medicine at the right times, <u>including prescribed medicines as well as medicines you can buy over the counter.</u> (k)	Universally respondents who took medicines thought about both aspects because they receive instructions on how much to take and when in round 1 and round 2. This question was easy to answer with respondents selecting an appropriate response if they received help or did not receive help.
Getting around indoors (l)	On the whole there was a consistent understanding of this term as moving from room to room and going upstairs in both rounds. On a rare occasion, it was misunderstood as 'help around the home' (Female, 79, receives informal care and has a cleaner and ironer).
getting up and down stairs (m)	Overall respondents thought about the stairs in their homes and when they did not have stairs in their home respondents thought about stairs elsewhere, such as in shops. Testing revealed that respondents who can manage stairs at home may find steps outside their home difficult. When respondents experienced this difficulty they all answered the question based on the steps at home. It was found in the second round of testing that a N/A is needed for Q1m to cover two scenarios 1) when a respondent lives in a bungalow or 2) when a respondent does not use stairs at all because they cannot manage them. In testing when the latter situation arose the respondent selected answer code 4 at Q1 'I cannot do this' but went on to select 'Yes' at Q2 because her husband could help her if she <i>had</i> to go upstairs, but the respondent had not been upstairs in her

Question tested in round 2	Reason for rewording findings from round 1 and round 2
	own home for 11 years. In round 1, stair lifts were occasionally thought about when answering this question. The intention was to include a clarification not to include the use of stair lifts in round 2 but this was missed in error and will be included in the final version.
going out for example, getting out of the house to go to the <u>doctors</u> or visit a friend, in the last month (n)	This question worked well in both rounds with respondents providing a variety of examples of physically getting out of the house e.g. visiting the doctors, attending a hospital appointment, visiting their children/grandchildren, going out for dinner, walks, church or day centre or any purpose to leave their house. The example go to the shops was swapped with the doctors example in round 2 because going to the shops was also captured at Q1a and was resulting in double counting. Changing the example here did not introduce new problems.
shopping for food <u>including getting to the shops, choosing the items, carrying the items home and the unpacking and putting the items away</u> (a)	Although the examples made the question harder to answer for respondents who need help with some aspect of the task, the question universally worked and respondents were able to select an appropriate answer. Detailed findings are reported in the section entitled understanding of tasks.
preparing hot meals (b):	Preparing hot meals was on the whole well understood, and was understood as cooking as well as heating up a meal in the microwave or in the oven.
doing routine housework (c)	The question tested in round 1 was doing routine housework or cleaning . Testing showed on occasions respondents included infrequent cleaning tasks such as changing the curtains or cleaning windows. When this occurred respondents answered answer code 3 (I can do this with help) because they could manage the routine household tasks but not the infrequent cleaning tasks. As this question is measuring regular cleaning tasks the question wording was changed. This has worked.
doing laundry <u>including loading and unloading the washing machine, putting clothes out to dry and ironing</u> (d):	Although the examples made the question harder to answer for respondents who need help with some aspect of the task, the question universally worked and respondents were able to select an appropriate answer. Detailed findings are reported in the section entitled understanding of tasks.
Doing paper work or paying bills (o):	A new finding from round 2, revealed Q1o paper work and paying bills can be a difficult question to answer when a respondent needs help to get to a place to pay the bills, for example the bank or post office. This situation arose once in round 2 with the implication that the respondent changed their answer from 1 to 2 because although he/she did not need help to pay bills or do paper work he/she did need help to get to the bank.

Final recommendations for Q1 and Q2

We would recommend retaining all Q1 and Q2 questions tested in round 2, and in the order tested for a long module. If a shorter module of questions is needed Q1 (about need) could be dropped and/ or the list of tasks asked about in Q1 and Q2 reduced, but this would need to be informed by the appropriate social care measures to ensure that the relevant tasks which feed into these measures are retained. If Q1 and Q2 are to be retained the following amendments would be needed.

- Improve the introduction to Q1 and Q2. A suggestion of how it could be improved is provided below.

E.g. INTERVIEWER READ OUT...“ The next few questions are about tasks that some people may need help with and about help that you may have received in the last month. Please think only about help you need because of long-term physical or mental ill-health, disability or problems relating to old age. For each task, I'd like you to tell me which option applies to you. Please include all help you received even if it was received for a short time or provided by your husband/wife or another family member but please don't think about help you have always received because of the way household responsibilities are divided in your home.

- As code 5 has not consistently captured help provided because of the division of labour in the home consider removing this code. To route out these respondents, consider adding a checking question that is asked only if the respondent has identified that they receive help with three or fewer of the following tasks which were identified in both rounds of cognitive testing as vulnerable to this problem. These being: shopping for food (a), preparing hot meals (b), doing routine housework (c), doing laundry (d), and doing paperwork or paying bills (o). We suggest asking this question for three or fewer tasks because respondents who receive help with more than three of these tasks even if it is because of the division of tasks in the home are likely to be needing help relating to ill-health or old age. Suggested wording for the check question is:

E.g. Is any of this help with [text fill of list of tasks in shortened form] received because of long standing physical or mental ill-health, disability or problems relating to old age? The answer codes for this question could be: Yes for some or all and No, none of this help is because long standing physical or mental ill-health, disability or problems relating to old age.

It is difficult to suggest a question that will work for everyone and ensure the correct respondents are routed to the rest of the receiver module of questions without making the question so complicated that it is difficult for everyone. Ideally, this re-wording should be cognitively tested. Those who answer no would then be routed past the detailed questions on provision and the derived variables on the incidence of need for help for each task can be adjusted accordingly.

- To assist respondents in understanding that the showcard at the bowel question is only providing examples and not a definition of the problem, consider amending the

text slightly with **this could result**. For consistency purposes, consider adding the same amendment to the bladder question.

E.g. BladProb SHOWCARD B

Do you suffer from problems with your bladder? By bladder problems we mean **this could result** in accidentally having wet pants, leaking urine, needing to go to the toilet frequently or urgently, sometimes not making it to the toilet in time, or using aids or appliances to manage bladder problems or incontinence. Please include problems with your bladder caused by any medicines that you take.

1. Yes
2. No
3. Prefer not to stay

E.g. BowProb SHOWCARD C

Do you suffer from problems with controlling your bowels? By problems controlling your bowels we mean **that this could result in** accidentally having soiled pants, leakage from the bowel, needing to go to the toilet frequently or urgently, sometimes not making it to the toilet in time, or using aids or appliances to manage bowel problems or incontinence. Please include problems with your bowel caused by any medicines that you take.

1. Yes
2. No
3. Prefer not to stay

- Consider adding **Not Applicable** to Q1m (stairs). Include the amendment intended after round 1: **'don't include the use of stair lifts'**.
- It is important that the interviewers are well briefed on the sensitivity of the module of questions and the nature of the respondents participating in the survey. For example, the interviewer may have to help respondents turn over the showcards and/ or read the showcards aloud. To make the interview appropriate for all respondents, consider providing showcards appropriate to the survey population. For example showcards could be presented in large print with text well spread out, easy to hold versions or providing a stand that the showcards can be rested against.

3.2 Who provides care (Q3a, Q3b, Q3c)

The questions in this section identify the informal and formal providers and their names. On the whole the questions in this section worked well. An exception was the new question introduced in round 2 to identify the number of different types of home help a respondent receives (Homehelp). This question was problematic. The findings for the individual questions are discussed below question by question.

{ASK FOR EACH ACTIVITY RECORDED AT Q2e - o (USED IN THE LAST MONTH) on a loop}

SHOWCARD E

Q3a. In the last month, who has helped you with [ACTIVITY]. I will show you **two** lists of people who may have helped you. First, please tell me about all of the people from this list who have helped you? Please only think about help received because of long-term physical or mental ill-health, disability or problems relating to old age.

CODE ALL THAT APPLY:

1. Partner/Spouse
2. Son (including step son, adopted son or son in law)
3. Daughter (including step daughter, adopted daughter or daughter in law)
4. Grandchild (including Great Grandchildren)
5. Brother / Sister (including step / adopted / in laws)
6. Niece / Nephew
7. Other family member
8. Friend
9. Neighbour
10. None of the above

{ASK FOR EACH ACTIVITY RECORDED AT Q2e - o (USED IN THE LAST MONTH) on a loop}

SHOWCARD F

Q3b. (In the last month, who has helped you with [ACTIVITY]). Now, please tell me about all of the people from this list who have helped you with [ACTIVITY]?

CODE ALL THAT APPLY:

1. Home care worker /Home help/Personal assistant (in round 1 personal assistance was a separate category)
2. Nurse (In round 1 four nurse categories tested: district nurse, health visitor and community nurse, community psychiatric nurse and other nurse)
3. Health visitor
4. A member of the reablement / intermediate care staff team
5. Occupational Therapist / Physiotherapist
6. Voluntary helper
7. Warden / Sheltered housing manager
8. Cleaner
9. Council's handyman
10. Other (please specify)
11. None of the above

{If 3b=14}

Q3c. Who has helped you?

OPEN RESPONSE: _____

Findings

Which informal and formal provider provides care for each task (Q3a, Q3b and Q3c)

Testing suggests that Q3a and Q3b worked well in identifying who provided help with a particular task even when the respondents did not receive any help from formal providers. However, on occasions these questions were burdensome for select individuals. The questions were found to be repetitive when a respondent received help from one carer with multiple tasks or received a lot of help from different people. Individuals in this group are obviously more vulnerable to the cognitive burden of answering a series of questions. This burden could have been felt more because of the probing and 'think-aloud' technique used in the cognitive interview at Q1 and Q2. On a rare occasion in round 2 a respondent did get annoyed to be asked the question because they had already provided this information during probing and think aloud at the earlier questions.

In both rounds of testing only answer codes 1 to 6 and 8 and 9 were used in Q3a and 1, 2, 5, 6,10,11 and 12 in Q3b. There was no ambiguity in the answer codes selected even if the answer code applied to two or more people such as two friends. These individuals were successfully identified in Q4.

We are unable to say anything about Question 3c as it was not tested in either round of cognitive testing. The findings in the rest of this section refer to Q3a and Q3b.

Home care worker / Home help/Personal assistants can also be friends

Testing revealed that a PA/Home help can also be viewed as a friend by a respondent. On occasions, deciding how to indicate this relationship was described as awkward. The implication was that a respondent could select friend **and** Home care worker/home help/personal assistant. Therefore, this problem results in over reporting of care received. Also, if a respondent's ex PA/Home help is now a friend who provides care in this role, the question was also described as awkward. In round 2, when this scenario arose, the respondent was not sure whether to select friend or home care worker/Home help/Personal assistant. The respondent decided to select Home care worker/home help/personal assistant because this is how the respondent first met the friend. The respondent therefore indicated that he or she was in receipt of formal help when in fact the respondent was in receipt of informal care.

Understanding of formal providers

Respondents who received formal social care were able to select an answer code from the showcard consciously deciding not to include the nurse because the nurse covered medical problems. Even when a respondent used the term carer throughout their think-aloud, they could easily select answer code 1 for Q3b i.e. Home care worker/ home help/personal assistant. This suggests that the 'home care worker/home help/personal assistant' code is successfully capturing who it should be.

The recommendation from round 1 to merge Home care worker and home care worker with personal assistant did not cause difficulties in round 2. All three terms were well understood in this round of testing. Occasionally respondents could not see the difference between home care worker and (intermediate) care staff team used in option 4. When this arose universally respondents correctly selected answer code 1 Home care worker/home help/personal assistant.

Division of household roles and responsibilities

Testing revealed that respondents who receive help with a task because they do not generally do them (notably cooking, cleaning and laundry), selected the informal carer who provided them with help. This question therefore incorrectly captured details of informal provider(s) who provides help due to the gender division of labour in the home rather than because of old age. These respondents should be routed out after the new check question being proposed to come after Q2.

Time reference

In round 1 the time reference was not easy for respondents to remember or they consciously decided it was irrelevant because they have a daily routine or kept asking the interviewer for confirmation that they should be thinking about the last month. When it was noted respondents were assisted by a particular event that defined the last month e.g. being ill. In round 2, the time reference was understood as intended with respondents correctly excluding help they receive from family and friends which was not received in the last month or deciding to include it because it did occur in the last month even if it was unusual or irregular help.

Administration

On an occasion in round 1, a respondent found Q3a and Q3b sensitive because the respondent thought the interviewer was thinking she ought to have this help. This reinforces the need to set the survey in context with a very good introduction so the respondent understands what the survey is about, why they are being asked to participate and how the data will be used.

Finally in both rounds; it was found that on a rare occasion a respondent found:

- It difficult to read down the list on the show cards to select an answer code preferring just to say who helps them or even just to say the name of the person who helps them leaving it for the interviewer to follow up and identify the relationship of the named individual.
- It difficult to work with two show cards.

Final Recommendations for Q3a, Q3b and Q3c

To address the issue of over-reporting of home helps who are also friends, consider inserting a check question. If friend and home help/home care worker selected for the same task consider inserting a new question to ask **you have said that your friend and**

your home help/home care worker/PA both help you with x task, can I just check that they are two different people. It cannot be assumed that asking for the name of these two people at Q4 and Q4b will be sufficient to distinguish this relationship because these two individuals could have the same name. If yes, then the two names should appear at WHPROV as it does currently. **If no, the interviewer should be instructed to go back and select only one option to describe the person.**

Consider removing nurse from the showcard at Q3b because nurses are unlikely to be providing social care and the 'nurse options' were occasionally used wrongly in round 1.

We would suggest retaining question 3c without modification as we do not have evidence about this question.

3.3 Identifying the different types of home care workers a respondent has (Homehelp)

This was a new question added to ascertain how many different types of home help a respondent receives. The aim of the question was to identify the different types of home help the respondent receives but also to allow routing of individual providers through subsequent sections (amount of care and payment) in the question module for respondents who receive help from different types of home care worker.

{IF Q3b=1}

Homehelp How many different types of home care worker/home help/personal assistants helped you in the last month?

Insert Number: _____

Findings

Only rarely was the question understood as intended and when it was the respondent easily answered the question. When it was not understood, the interpretation varied in four ways:

- Respondents thought they were asked to describe their home care workers. This was shown by the respondent describing their home care workers by gender or how nice they were; or,
- Respondents counted, and reported, the number of home care workers they have, which were either (1) the total number currently providing care and on occasions to also include the agency that provided the home care worker in the calculations or (2) the total number they have had for their long standing illness, disability or old age.
- Respondents counted the number of tasks that the home care worker helps the respondent with and gave this number as their answer.
- Respondents could not answer the question and this tended to be because they:
 - Did not know how to answer the question thinking about the 24 hours intensive care provided by the specialist home care worker. The supporter answered the question as one type; or,

- Did not know the answer because the complex the respondent lives in organises the respondent's care.

Final Recommendation for Homehelp

Consider amending the question wording to clarify understanding of types. Suggested wording is provided below:

Homehelp How many different home care workers/home help/personal assistants helped you in the **last month**? *If you get daily help with the same task but from different people each day of the week that would count as one home care worker/home help/personal assistant.*

Insert Number: _____

3.4 Identifying the name of information carers and the names of home help/home care worker/personal assistant (Q4a and Q4b)

Question 4 was retained without modification from round 1. Question 4b was a new question introduced in round 2. The aim of both questions was to find the names of the carers so the subsequent questions could be specifically worded to refer to the correct carer to ease respondents' understanding of the question and guide them through the rest of the questionnaire.

Q4. You have told me that your [INSERT WHO] helped you. Please tell me the first name of this person. If more than one [INSERT WHO] helped you, please tell me all of their names?

Partner/Spouse

1ST Son's name

2nd Son's name

1st Daughter's name

2nd Daughter's name

1st Grandchild's name

2nd Grandchild's name

1st Brother's name

2nd Brother's name

1st Sister's name

2nd Sister's name

Niece's name

Nephew's name

Other family member's name

Friend's name

Neighbour's name

{IF HomeHelp>1}

Q4b.

What do you call the first home care worker/home help/ personal assistant. Please give me their name or initials or the name of the organization they work for?

First home care worker/home help/personal assistant name: _____

Second home care worker/home help/personal assistant name: _____

Third home care worker/home help/personal assistant name: _____

INTERVIEWER: THE PURPOSE OF THIS QUESTION IS TO IDENTIFY INDIVIDUAL HOME CARE WORKERS TO ASSIST WITH ROUTING THROUGH THE QUESTIONNAIRE. ENTER A NAME WHICH YOU CAN USE TO REFER TO THIS HOME CARE WORKER DURING THE INTERVIEW.

Findings

Providing the name of the informal carer (Q4a)

Testing revealed that the question was generally easy and insensitive for respondents. At earlier questions respondents had naturally provided the name of the informal carer. This question captured the names of different informal carers who had the same relationship to the respondent in round 2. A slight concern with this question was indicated by a respondent in round 2. The respondent asked for confirmation that the data collected was private and just for statistics. The interviewer provided a comment at this question that the respondent had said that she trusted the interviewer that the information collected was private (Female 90 years old receives care).

Providing the name of the home help/ Home help/ personal assistant (Q4b)

This was a new question introduced after round 1 to identify the name of the home help. On the whole this question worked as intended and respondents found the question easy to answer; generally providing the first name or the name of the organisation that supplied the home help, or the name they use to refer to the home help/ home care worker or personal assistant.

Testing revealed, however, that this question can be complicated for respondents who receive a lot of help from different types of home care workers to answer and inevitably these respondents would feel the cognitive burden of taking part in any survey. However, these respondents could still answer the question.

Final Recommendations for Q4a and Q4b

We would suggest retaining both questions without modification.

4 Amount and Patterns of Care received

4.1 Whether provider lives in the household (Q3d)

In round 1 the question about whether provider lived in the household was not found to be problematic but it was decided that it would be most useful to ask the question for each provider individually. In the context of a household survey this could also be linked to the household grid (the means of doing this would depend on the set up of the survey). For the cognitive testing in round 2, the question was asked for each provider to assess whether respondents were able and willing to provide this information.

Round 1 asked once for all providers

{IF ANY HELP MENTIONED AT Q3a}

Q3d. You have told me that your [INSERT ALL WHO HELP] helped you. Can I just check, does this person/ do any of these people live in this household?

1. Yes
2. No

Round 2 asked for each provider separately

{IF ANY HELP MENTIONED AT Q3a/Q3b ask for each provider}

Q3d.

You have told me that [PERSON WHO HELPS] helped you. Can I just check, does [PERSON WHO HELPS] live in this household?

1. Yes
2. No

Findings

Round 2 showed that respondents were able to answer this question, though the following points were noted

- Respondent included her son staying temporarily (because of his personal difficulties) though she is registered as living alone and as a result she was worried it could affect her home care status and eligibility for care. It should be noted that some respondents might be reluctant to report their living arrangements and others staying in their home. Also in analysis one cannot assume someone living with a care receiver is providing extra help; they might need help themselves
- Respondent remarked that it is odd to be asked this about her husband
- Respondent reported carers who stay with her on shifts of 3 days (3* 24 hours) as living with her, when in fact they have their own homes and do not live permanently with her.

Final recommendation for Q3d

- Retain question but add note to explain what living in this household means/ clarification that should not include people who have another home.
- Consider only asking this question about informal carers. If we do not ask Q3d for formal carers we will still find out from following questions about whether the

respondent gets care round the clock, including at night. Although some carers may live with the respondent and not have any other residence (e.g. overseas workers as home care workers) this is probably not of prime importance for this study.

- If the questions are being administered in a survey including a household grid and a link is made to this, then the question should be asked about all providers.

4.2 Selection of providers for looping through detailed questions about care received (WHPROV)

During the cognitive interview, interviewers were instructed to ask detailed questions for up to three providers in round 1 and two providers in round 2. For round 1 interviewers were just instructed to make the selection. In round 2, in CAPI, an explicit question had to be set up. This was a new question introduced for the CAPI to allow interviewers to select which two providers to use for the remaining interview. The choice of providers was left at the interviewer's discretion for cognitive testing. For a main stage survey this would need to be automated – see below for recommendations on how this selection is done.

{IF R RECEIVES HELP FROM MORE THAN TWO PEOPLE FROM Q3b AND FROM Q4}

WHPROV

INTERVIEWER: PLEASE SELECT WHICH TWO PROVIDERS YOU WILL ASK THE RESPONDENT ABOUT. IF YOU ONLY HAVE TIME FOR ONE PROVIDER PLEASE SELECT ONE PROVIDER.

List two chosen:

Final Recommendations for WhoProv

After discussion of the options within the research team and examination of the impact of the choice of providers on interview routing and length, we recommend the following:

Q10 (which identifies the intensity of care in terms of hours in the last week) should be asked for all providers (see below for details). On the basis of intensity of care the following selection should be made, similar to that used in the GHS:

- Two providers which gave most care to respondent in the last week should be selected
- Where the second and third provider gave equal hours priority would be given to:
 - formal provider if one formal and one informal
 - a co-resident provider if both informal
 - provider helping with the most tasks if both formal

This relies on individual home care workers being identified correctly at Homehelp. If respondent records large numbers of individual home care workers each providing a small number of hours (because they have a different individual each day of the week, for example) this will adversely affect the selection of providers. Thus it is important that the amendments to that question are effective.

This selection would then be used for the following section on amount and pattern of care.

Once the payments section is reached the selection of the providers to be asked about would be different:

- all formal providers would be asked about, whether or not they were the selected provider; and
- questions on informal providers would only be asked about if they provided 20 or more hours of care in the last week and if the questionnaire has not already asked about three or more formal providers

4.3 Help provided remotely (Remote and Remoft)

Two new questions were introduced after round 1 in response to findings that respondents received assistance from people who were not present. The two reasons for including them were:

- to reflect these types of remote help in questionnaire; and,
- to make it clear these should not be considered when asking the main set of questions about receipt of care.

{ASKED OF UP TO TWO PROVIDERS IDENTIFIED AT WhProv or at Q3a/Q3b if only one provider}

SHOWCARD G

Remote

Does [PERSON WHO HELPS] help you in any of the ways shown on this card?

CODE ALL THAT APPLY:

1. Phones me every day or every other day
2. Is available for me to phone for help during day
3. Is available for me to phone for help during night
4. Is available for me to email for help
5. Orders shopping/ meals over the internet to be delivered to me
6. Makes phone calls on my behalf e.g. to make doctors appointments, to arrange for repair / service of boiler etc
7. None of these

{ASKED OF UP TO TWO PROVIDERS IDENTIFIED AT WhProv or at Q3a/Q3b if only one provider}

SHOWCARD H

Remoft

How often are you in contact with [PERSON WHO HELPS] by phone or email?"

1. More than once a day
2. Once a day/ everyday
3. Three to five times a week
4. Once or twice a week
5. Once a fortnight
6. Once a month
7. Less often than once a month
8. Never

Findings

Whether respondent receives help by phone or email (Remote)

This question did not work very well. Respondents who lived with their provider felt that the question was irrelevant and did not answer, chose Don't Know or coded redundant items like use of phone as internal intercom (which is not remote help).

More generally the following problems arose:

- respondents coded that people were available for help by phone or email when in fact they were only available in person (only read part of answer category)- this also affected some people getting help from those who did not live in household;
- respondents who understood correct meaning of question included the provider writing letters on their behalf at code 6;
- respondents who understood the meaning of question coded help that would be available even if not used;
- respondents ring carers for emotional support, not just when in need of help and it was not clear whether this should be included;
- The question did not work well for formal carers as they may not work everyday for the respondent.

Frequency of contact by phone or email (Remoft)

Respondents had difficulty with this question when:

- They coded the frequency of face to face contact (some understood contact to be in person);
- They coded DK, said 'just lives here', not applicable if only contact is in person;
- The frequency of contact varied and so was hard to code – chose DK or chose 2 answers;
- They were unsure whether to include frequency of social contact by phone – ringing for a chat, or speaking to someone who answers the phone (e.g. grandson) even if that is not who they rang;
- They commented the question was not good or awkward;
- They were unsure what to do if carer phoned the R, rather than the R phoning the carer.

Final Recommendations for Remote and Remoft

- Consider dropping Remote. It would be possible to incorporate code 5 (shopping and meals) at the Meals question, described in section 5.1. One could just include clarification about not including remote help at Q6 without needing Remote.
- Alternatively, if Remote is retained, consider the detailed purpose of it and simplify the question and only ask for informal carers who do not live with the respondent. Though people may be in phone contact with people who live with them, this is not relevant in this context.

- Drop Remoft because respondents considered it irrelevant. Those for whom the question was relevant experienced difficulty answering because how frequently they were in touch varied so much.
- If Remoft has to be included, only ask this question if Remote =1-6 (i.e. informal carer who does not live with R and does provide some kind of remote help).

4.4 Amount and patterns of help received by respondent (Q6, Q7, Q8 and Q9)

{ASKED OF UP TO TWO PROVIDERS IDENTIFIED AT WhProv or at Q3a/Q3b if only one provider}

SHOWCARD I

Q6.

Thinking only about help received in person (not by phone or internet). how often does [PERSON WHO HELPS] usually help you?

1. Every day
2. Four to six times a week
3. Two or three times a week
4. Once a week
5. Once a fortnight/ every two weeks
6. Once a month
7. Less than once a month

Round 1 with read out

Q7. On the days (the) {provider name } helps you, how many times a day does he/she help you. Is it usually...READ OUT

1. Once a day
2. Twice a day
3. Three or four times a day
4. or does he/she help you all the time or whenever you need help?

Round with showcard and extra category

{If Q6=1, 2 OR 3}

SHOWCARD IX

Q7.

On the days [PERSON WHO HELPS] helps you, how many times a day does he/she help you?

1. Once a day
2. Twice a day
3. Three or four times a day
4. All the time
5. Whenever I need it?

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b}

Q8. And does (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} usually help you....READ OUT...

1. During the day time only
2. During the night time only
3. Or both?

{ASKED OF UP TO TWO PROVIDERS IDENTIFIED AT WhProv or at Q3a/Q3b if only one provider}

SHOWCARD J

Q8.

And when does [PERSON WHO HELPS] usually help you?

4. During the day time only, until you go to bed
5. During the night time only, once you have gone to bed
6. Or both during the day time and at night after you have gone to bed

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b}

Q9. Does (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} usually help you....READ OUT...

1. on week days only
2. over the weekend only
3. or on weekdays and over the weekend?

Findings

How often the provider helps (Q6)

In round 1 the main problems which arose with Q6 were that:

1. Respondents were unsure whether to include help given remotely, for example over the phone
2. Respondent could receive different patterns of help from different members of a care team
3. Respondents found the question hard to answer when the pattern varied
4. Respondent was unsure whether they were receiving help or just having social contact

In round 2 the first two problems were not identified because the wording added as introduction clarified that help in person was intended (problem 1). The introduction of Homehelp (described earlier) also helped with the problem of multiple home care workers providing help in different patterns (problem 2).

The third problem related to answering the question when the pattern of help varies was still found in round 2 and was particularly problematic for informal providers. For formal providers with a set pattern, answering this question presented no problems to respondents. The fourth problem, concerning whether social contact should be included, was still a problem in round 2. Respondents considered social and emotional support to be very important.

How many times a day the provider helps (Q7)

Respondents remarked on this question being 'awkward' or a 'rubbish question', however this varied according to the pattern of care.

Round 1 and round 2 showed that this question was more problematic for informal than formal providers. If a formal provider visited on a set pattern each day respondents were able to answer the question, though at least two wrong answers were identified even for carer's who were aware of a regular visiting pattern. For formal providers on hand all the time, respondents chose 'whenever I need it' or selected a number of times per day.

For informal providers in round 1 respondents tended to choose the fourth category which covered receiving help all the time or whenever they needed help. As a result in round 2 these were split into two categories. In round 2 respondents chose 'whenever I need it' when the informal provider lived with the respondent, or where they do not live there but are on hand (live close by). Where the informal provider visited the respondent on a regular pattern the respondent would choose a frequency (codes 1-3).

The category 'helps me all the time' was not selected. However having it removed from the 'whenever I need help' category helped respondents to choose that category in round 2 as it was less wordy and seemed more appropriate.

Whether care received during the day time or night time (Q8)

In round 1, respondents felt that the question about whether help was received during the day, at night or both day and night made sense. A few problems occurred for respondents who had help 'on hand' but infrequently used. In addition, respondent definitions and understanding of what was included in the day and the night varied. As a result in round 2 the category wording was changed to define night and day whilst a showcard was introduced because the wording was too long and complicated to readout.

Round 2 did not identify any new problems with the question, apart from a sense among certain respondents that these questions were not relevant. There did not seem to be problems with inconsistent definitions of night and day, though interviewers did not probe on this to the extent they did in round 1.

The issue of whether to include emergency help and being potentially on call was also found in round 2.

Whether care received during week or weekend (Q9)

At round 1 the question about whether help was received during weekdays, weekend or both weekdays and weekends made sense to respondents and was not difficult to answer. As a result no changes were made to the question for round 2. In round 2 in most cases a coded answer was recorded and no notes were made. The issues noted were:

- continued increasing irritation when a respondent felt that the question was not relevant; and
- difficulty answering when care was flexible and could happen on any day of the week.

Final Recommendations: Q6, Q7, Q8, Q9

- Retain Q6 but consider whether such a detailed breakdown of categories is needed – collapse if possible (into three categories) to make the question easier to answer where the pattern varies. Alternatively retain the detailed categories but consider a follow-up question where R answers DK/ refuse which offers broader categories.
- Retain Q7 as it has value in understanding pattern of care needed (especially for formal providers). Consideration needs to be given, if we can ask Q7 just for formal providers (possibly only home help/ personal assistant) and not for informal or other types of formal providers. It is not that helpful to have mostly ‘whenever I need it’ as answers for informal providers. The question was really intended to identify how many times a day home care workers make visits to the respondent
- Retain Q8 for full module. Consider adding clarification, either in wording of question, or as interviewer note, only to include help given in person (to avoid people recording that emergency help is available remotely).
- Retain Q9 as worded for full module.
- As noted in the recommendations for Q11, this set of questions asked about usual patterns of help in contrast to Q10 which asked about help in the last week. One way of overcoming the problem of respondents saying that the pattern varies and it is hard to say is to ask them about what happened in the last week. Answers to Q10 show that respondents were not necessarily always thinking of the last week when answering that question, but if all the questions in the section covered the last week this could be emphasised at the beginning of the section and calendar referred to, to help the respondent think of the right time frame.
- Notwithstanding the recommendation to retain these questions, we suggest that in a short version of the module these questions are not included.

4.5 Intensity of care received (Q10 , Q10i and Q10a)

Round 1

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b}

SHOWCARD G

Q10. Now thinking about the last week, that is from last Monday to the Sunday just gone, how many hours did (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} help you in the last week?

1. No help in the last week
2. Less than one hour
3. 1-4 hours
4. 5-9 hours
5. 10-19 hours
6. 20-34 hours
7. 35-49 hours
8. 50 hours or more
9. 24 hours a day, 7 days a week

{If Q10= don't know or refusal}

Q10a . Can you tell me whether in the last week (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} helped you for:....READ OUT....

1. Less than 20 hours
2. 20-34 hours
3. Or for 35 hours or more?

Round 2 only

{ASKED OF UP TO TWO PROVIDERS IDENTIFIED AT WhProv or at Q3a/Q3b if only one provider}

SHOWCARD K

Q10i

Now thinking about the last week, that is from last Monday to the Sunday just gone, and thinking of all the time [PERSON WHO HELPS] was on hand to offer you the help you need, how many hours did [PERSON WHO HELPS] help you in the last week.

By this I mean time [PERSON WHO HELPS] had to be with you in case you needed help?

INTERVIEWER: WATCH OUT FOR ANSWERS GIVING A DAILY AMOUNT. IF YOU THINK THE ANSWER MAY BE A DAILY AMOUNT ASK 'SO THAT IS XXX HOURS IN THE LAST WEEK?' AND ALLOW RESPONDENT TO CHANGE ANSWER.

1. No help in the last week
2. Less than one hour
3. 1-4 hours
4. 5-9 hours
5. 10-19 hours
6. 20-34 hours
7. 35-40 hours
8. 50-99 hours
9. 100 hours or more

{Only ask if Q10i=DK or refusal}

Q10j

Thinking of the same type of help can you tell me whether **in the last week** [PERSON WHO HELPS] helped you for:....READ OUT....

1. Less than 20 hours
2. 20-34 hours
3. Or for 35 hours or more?

{ASKED OF UP TO TWO PROVIDERS IDENTIFIED AT WhProv or at Q3a/Q3b if only one provider}

SHOWCARD K

Q10.

Now thinking of the types of task and activities I have been asking you about, how many hours did [PERSON WHO HELPS] help you in the **last week**?

INTERVIEWER: IF MORE THAN ONE PROFESSIONAL CARER HELPS THE RESPONDENT, ASK THEM TO ADD UP THE TIME OF ALL THE HELPERS IN THAT CATEGORY, E.G. IF TWO DIFFERENT HOME CARERS HELP, ENTER TOTAL TIME FOR HELP PROVIDED BY THESE.

1. No help in the last week
2. Less than one hour
3. 1-4 hours
4. 5-9 hours
5. 10-19 hours
6. 20-34 hours
7. 35-49 hours
8. 50-99 hours
9. 100 hours or more

{If Q10= don't know or refusal}

Q10a

Thinking of the same type of help can you tell me whether **in the last week** [PERSON WHO HELPS] helped you for:....READ OUT....

1. Less than 20 hours
2. 20-34 hours
3. Or for 35 hours or more?

Findings

Hours of care received in the last week (Q10 and Q10a) (Round 1)

Round 1 found that most respondents were able to give an answer to Q10, even if it was not something they had thought about before. For individuals who answered 'don't know' to the overall hours of help for the various tasks, they were routed to Q10a which they could answer. Respondents used a wide variety of strategies for working out their answers to either question but on the basis of probing it seems that the answers generated were reasonably accurate.

The question was easier for formal providers giving care in a regular pattern. Problems were more likely to arise when the provider was around all the time and respondent could not say how much he or she actually helped – in this case the category 24 hours a day/ 7 days a week was available but this does not give very useful information to analysts.

As a result of findings from round 1 and subsequent discussions within the research team about the purpose of the questions, it was agreed that Q10 would be revised (new Q10i) to clarify that the question just enquired about the time the respondent received help with tasks from the provider – i.e. ‘active help’ and not the time they were available or there ‘on call’. This would be preceded by a question about time when the provider was with the respondent but not actively doing tasks. The question was worded to make it clear that it was about times when the provider **had** to be present fulfilling a care task. As opposed to times present because they live with the respondent or because they were visiting socially.

The category 24 hours a day/ 7 days a week was removed and a category for 100 or more hours added for both versions of Q10.

In round 1 there was some evidence of respondents providing a daily number hour rather than weekly. A note for interviewers to check this was included in round 2. There was no evidence in round 2 that respondents were providing daily amounts in error.

Time the provider ‘had’ to be with respondent in the last week (Q10i) (Round 2)

Q10i intended to capture times the carer was present with the respondent because the carer needed to be there, even if actual tasks were not being done. The question was not intended to capture social visits or the carers’ presence because they also lived in the same accommodations as the respondent.

The type of informal help respondents considered when answering this question

- Considered all the time in the last week/ daylight hours and took off time provider was out ‘doing his own thing’
- Excluding a ‘friendly outing’ and coded no help in last week
- Including an outing with son (to football, to RNLI presentation)
- Time when husband available to help if needed (in this case seems likely respondent did need husband to be present)
- Including times when the provider is in house watching television but does not really **have** to be there

Calculating time for formal providers

Approaches to answering for formal care included:

- Working out total hours and days per week from pattern, e.g. (7 days a week 30 mins in morning and 15 mins in evening) and picking a codeable answer based on hours e.g. 5-9 hours;
- Working out when his wife is at college and so needs formal care;
- Recording an answer based on the number of hours the carer is paid for;
- Describing pattern (40 mins in am, then dinner time, then put to bed at 6.00, should come back at 8.00 but don't, but being unable to work out an answer and so choosing DK;
- Respondent being unable to answer but daughter answering that R receives 98 hours in day and 7 hours in night making it 105 hours;
- Respondent confused and unable to answer but was able to provide the interviewer with his/her carer's time sheet. This allowed the interviewer to work out the answer.

Time frame

During round 2 respondents used the following approaches in relation to the time frame:

- Thinking about the last week;
- Thinking only about yesterday;
- Including an event 9 days ago;
- Thinking generally, rather than about any particular time period;
- Thinking about next weekend.

Time the provider 'had' to be with respondent in the last week using broader categories (Q10j) (Round 2)

Q10j was asked when a 'don't know' answer was received for Q10i. In these cases Q10j either generated another don't know or a coded answer. There was no evidence of increased respondent irritation or burden when asked Q10j.

Hours of 'active' help with tasks received in the last week (Q10) (Round 2)

The purpose of Q10 in round 2 was to capture help with specific tasks, rather than just time when the person was generally present. When the informal provider lived with the respondent there were two answer patterns:

- Same answer as at Q10i (no explanation)
- Longer hours than at Q10i (no explanation)

When the informal provider did not live with the respondent the following answer patterns were observed:

1. Same answer as at Q10i whether that was in hours, DK/ can't answer, or no help in last week, but no explanation for answer given by respondent;
2. Same answer as at Q10i because respondent says the answer is the same if you are talking about one task and one carer, i.e. respondent interpreting Q10i and Q10 to be the same;
3. Fewer hours than recorded at Q10i with no explanation;
4. Fewer hours than recorded at Q10i because respondents thought about particular tasks rather than times the carer is just present in the house;
5. Fewer hours than recorded at Q10i because the provider was there to move furniture s/he did not do any of tasks on list. The respondent was now only thinking about tasks on list, rather than tasks more generally;

6. More hours than recorded at Q10i because respondent had correctly understood Q10i to be about time someone had to be with here – chose no help in last week and then for Q10 chose number of hours received help with tasks.

The information above shows that in general the distinction between Q10i and Q10 was not understood by respondents. In the list above only patterns 4 and 6 show a correct understanding of the two questions. Patterns 2 and 5 indicate an incorrect interpretation. However, where patterns 1 and 3 is demonstrated we unfortunately do not have enough information to know whether respondents were answering correctly.

For formal providers there was not quite the same range of interpretations but the evidence gathered from respondents was either not enough to be sure that they were answering correctly or showed that the respondents did not understand the difference between the questions.

Hours of 'active' help with tasks received in the last week with broader categories (Q10a) (Round 2)

Little evidence was obtained about this question in round 2. There is no evidence that Q10a caused particular problems so we assume that this question has the potential to achieve its measurement aims if the respondent is unable to answer Q10.

Final recommendations for Q10, Q10a, Q10i, Q10j

- Retain Q10 and Q10a as worded in round 2 with slightly adjusted wording to clarify that help does not have to be received in terms of the specific tasks from Q1 and Q2. Instead establish that the respondent considers active help with tasks, excluding when the provider was readily available to help or present in the house because living arrangements or social visits.
- Encourage respondents to refer to a calendar (for informal provision) and/ or the care plan or care workers time sheet for formal providers to assist in recording an accurate answer.
- Drop Q10i and Q10j as the meaning was not understood consistently. Given that the module is very long, the questions should be dropped to collect the priority information.
- Although not a problem in the cognitive testing, it is not clear how a respondent who received 4.5 hours of care should answer – is this category 3 or 4? Respondents who calculate a series of short visits from formal providers may provide inaccurate answers that fail to reflect the number of completed hours. Interviewers should be given guidance on how to deal with this situation (e.g. told to include any time up to 5 hours in category 3).

4.6 Whether last week was a usual week (Q11)

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b}

Q11. And was last week a usual week or did (the) {person who helps} help you more than they usually do or less than they usually do?

1. It was a usual week
2. Helped more than they usually do
3. Helped less than they usually do

Findings

Whether last week was a usual week (Q11)

The evidence from round 1 did not show any particular problems with Q11. The question made sense to respondents; they understood it consistently; and were able to answer the question. The same question was included in round 2 and with less extensive probing. However the cognitive probes, for the most part, revealed no significant problems. Typically respondents thought about the usual tasks and/ or usual length of time spent by the provider.

Problems that surfaced included respondents selecting 'don't know' because it varies too much (son who does not live in household) and feeling her memory was being tested. Another respondent answered the question apparently without difficulty but was frustrated by probing process that may have resulted in feelings of confusion. However both of these problems are specific to the cognitive interview and are unlikely to occur in a main stage CAPI survey.

Final recommendations for Q11

This question did not pose problems in either round, providing useful additional information to help interpret findings about care in the last week. However, one should consider the importance of Q11 individually and the priority of Q11 in the context of the other survey questions to determine its inclusion in the main survey. Given that the survey may be too long, we recommend that the question is omitted from the final survey.

Notably the question about hours of help asks about the last week (and so the usual question relates to that), whereas other questions in the pattern and amount of care section ask for their usual patterns of help. To overcome respondents candidly reporting that the patterns vary, the question could be rephrased to alternatively ask respondents about the last week. If this approach adopted, there would be a stronger case for retaining Q11, at least in the long module.

5 Care services used

This section aims to provide information on the different types of care services used by people over 65. This section has changed since round 1 testing, the list of services asked about has decreased. In round 1, questions also asked about home helps and private domestic help (standard existing survey questions) but since these questions overlap with the new questions that take a task based approach, the former set were removed from round 2. Although the wording for the questions in round 1 is included in the section below for reference; more detailed findings about these two questions are presented in the round 1 key findings report.

5.1 How people over 65 have received food for their main meals over the last month (MEALS)

The introduction for the Care services used section has remained the same from round 1 cognitive testing. The Meals question is a new question added to round 2 testing. This question looks at how people over 65 got food for their main meals during the last month. In round 1 testing, this question only asked whether respondents had used meals on wheels in the last month. This question now covers a range of ways people may have received their food for main meals.

INTERVIEWER READ OUT... "I'm going to ask you about services that people can make use of. Some of them won't apply to you, but others may. Some of these questions will cover services you have already told me about. Please tell me about services you have used, even if you have already told me about them."

Round 1 only

Which of these services did you use in the last month, that is during [LAST COMPLETE CALENDAR MONTH]?

Home help: Local authority home help or home care worker?

Privhelp: Private domestic help?

Meals: Meals on Wheels?

1. Used in last month
2. Not used in last month

Round 2 only

{ASK ALL OVER 65}

SHOWCARD L

MEALS

In the last month (that is during LAST CALENDAR MONTH) did you get food for your main meals delivered to you by any of the following?

PLEASE CHOOSE ALL THAT APPLY

1. Council Meals on Wheels
2. Private frozen meal provider such as Wiltshire farm foods
3. Internet food delivery e.g. Tesco or Ocado
4. Milkman
5. Vegetable delivery company (e.g. Abel and Cole or Riverford)

6. [Family brought shopping to my house](#)
7. [Family brought me ready prepared meals](#)
8. [Other](#)
9. [None of the above](#)

Findings

On the whole, this new question (meals) was easy for respondents to answer compared to the old question which just asked about Meals on Wheels. However there were a few problems identified at round 2. Things included under 'other' were: Take away's such as a Chinese and a neighbour bringing fresh meals. It was questioned if the 'wet fish' man could be included under other. Respondents chose the answer code Milkman when the Milkman only brought them milk and not food for their main meals. Respondents excluded voluntary organisations that provided food shopping and a delivery from Sainsbury's, the respondent was unsure if the delivery from Sainsbury's was completed online so did not include this in his answer. Options 6: Family brought shopping to my house caused confusion because this was shopping for food which was not for the main meal.

Final Recommendations for MEALS

We suggest adding a clarification next to Milkman to specify the inclusion of food delivered by the Milkman, and not just milk. Consider removing internet food delivery when talking about Tesco and Ocado because respondents may not know the food is ordered over the internet. An interviewer suggested adding the answer category a neighbour brings me shopping, however, respondents could just code this as other or it could be included in the family category by amending the wording and the same would be true for category 7.

5.2 Frequency of meals on wheels in the last month (MWtimesc)

This question has not been changed since round 1. It measures how often respondents received meals on wheels within the last month.

{IF MEALS=1 (COUNCIL MEALS ON WHEELS)}

SHOWCARD M

MWtimesc

About how often did you have meals on wheels in the last month (that is during LAST CALENDAR MONTH)?

1. Every day or nearly every day
2. Two to three times a week
3. Once a week
4. Less often

Findings

This question was not fully tested. Only one respondent answered it but no comments on the question were reported.

Final Recommendations for MWtimesc

Assuming there is still an interest in meals on wheels, we recommend that this question is retained as currently worded.

5.3 Whether respondent has used a lunch club within the last month (LnchClub)

This question considers whether people aged 65 and over used a lunch club run by the council or a voluntary organisation in the last month. The question wording has not changed since round 1 but has been reordered to be the first question, whereas before it was the fourth question in this battery of questions.

INTERVIEWER READ OUT.....“Which of these services did you use in the last month that is during (LAST COMPLETE CALENDAR MONTH)”?

{ASK ALL OVER 65}

LnchClub

....A lunch club run by the council or a voluntary body?

1. Use in the last month
2. Not used in the last month

Findings

In round 2, respondents were sure of their answer if they had not used the service. Respondents answered No if they had been to private lunch club or lunch clubs run by a voluntary organisation held at a church. Confusion arose as respondents thought that the question was asking whether they had meals delivered by this service. One respondent had not heard of such clubs.

Final Recommendations for LunchClub

Assuming there is still an interest in lunch club attendance, we recommend that this question is retained with a slight modification to make it clear that it is asking about ‘attending a lunch club’.

5.4 Whether respondent has used a Day Centre in the last month (DayCen)

The DayCen question wording has not changed since round 1. instead of being in a long list of questions it is only one of two and is now second question asked instead of fifth.

...A Day Centre for the elderly? Please include groups or classes run by a day centre but not necessarily held at the building.

1. Use in the last month
2. Not used in the last month

Findings

In round 2 of testing, respondents were able to describe a day centre and where the nearest day centre was located. One respondent answered yes to the question but pays to attend the daycentre so was unsure whether this should be included. Respondents did not include attending a pensioner's centre with information and classes and a woman's health group that takes place at a day centre but are not run by the day centre.

Final Recommendations for DayCen

Retain this question as worded.

5.5 How often respondents have used lunch clubs in the last month (LCTimes)

This question had not been changed since round 1. It looks at the frequency of people using lunch clubs in the last month.

{IF LNCHCLUB=1}

SHOWCARD M

LCTimes

About how often did you have lunch at the lunch club(s) [last month / in the last month]?

1. Every day or nearly every day
2. Two to three times a week
3. Once a week
4. Less often

Findings

This question was not fully tested. Only three people answered this question in round 2 and no comments about the question were given. Only one respondent answered this in round 1. So no conclusions about this question can be drawn

5.6 How often respondents have used Day Centres in the last month (CenTimes)

This question was not changed from round 1 testing.

{IF DAYCEN=1}
SHOWCARD M
CenTimes
About how often did you go to the day centre, including attending classes or groups run by the day centre, [last month / in the last month]?
1. Every day or nearly every day
2. Two to three times a week
3. Once a week
4. Less often

Findings

This question was not fully tested. There were no specific comments given in either rounds to suggest that this question has not worked as intended.

5.7 Amount of time respondents spend at a Day Centre (CenDur)

This question aimed to measure the amount of time people attend day centres. Answer code two has been changed from round 1 because it overlapped with the first answer code.

IF DAYCEN=1}
CenDur
Each time that you have attended the day centre, including attending classes or groups run by the day centre, [last month / in the last month] about how many hours did you usually spend there? Was it...READ OUT
1. 1-3 hours
2. 4-6 hous
3. 6 or more hours

Findings

In round 2, respondents were able to estimate the time spent at the centre but could not automatically recall these periods. In one case, a respondent considered all the time out of the house. Her answer included travel time and did not exclusively specify the time present at the day centre.

Final Recommendations for CenDur

- Retain the question as worded. It is not clear how the wording could be modified to make it clearer that the refers to the time spent at the day centre.

6 Payments for Care

6.1 Overview of payments module

The structure of the payments for care section changed between round 1 and round 2 of testing. Since this module was totally new and not based on questions asked in previous surveys, feedback from round 1 and discussion about the objectives of the module led to substantial revisions in round 2.

Round 1 structure

For family and friends (informal providers) who helped them:

- Whether R paid or gave any money to any of them (Q12newa)
- Whether any other person or organisation paid any of the informal providers on R's behalf (Q12newb)

This was intended to avoid burdening respondents by asking about every informal provider individually if they pay none of them.

For every formal provider and for any informal providers used by respondents who they or someone else paid respondents were asked: (LOOP WITH QUESTION ASKED FOR EACH PROVIDER UP TO THREE):

- Whether R pays or gives any money to provider (Q12)
- *If they pay*, how much money they pay to provider (Q12b)
- Whether any other person or organisation pay the provider (family member, social services, other) (Q13)
- *If local authority/ social services pay anything*, what form that payment was made in –directly or through direct payment/ personal budget (Q14)
- *If LA pays in direct payment/ personal budget*, how much money is paid from direct payment or personal budget for that provider (Q15)
- *If R pays money for provider*, where money which R pays provider direct comes from (own income or direct payment/. Personal budget) (Q16)
- *If R pays provider*, what proportion of cost of that provider R pays from own money (Q17)
- *If family member pays for provider*, what proportion family member pays (Q18)
- *If no payment made by R or anyone else*, why there was no payment made to that provider (Q19)

Round 2 structure

For any formal providers, respondent was asked for each provider:

- Was the local authority or social services involved in providing you with this named provider (Q5a)?

Set of questions for providers arranged/ provided through the local authority (asked once for all formal providers arranged by LA as a package):

- Whether R has had an income assessment for any of the care arranged or provided by LA (IncAss)
- Whether R or their partner pays or gives any money to providers (Q12lump)
- *If they pay*, how much money they pay to providers (Q12blump)
- *If they pay*, reference period for payment to providers (Q12bfrlp)
- *If R does not answer*, Q12blump about amount, why they didn't give an answer (WhyNoQ)
- *If it's because someone else in household deals with payments*, ask whether this person can help with questions (*Finhelp*)
- *If R pays anything for providers*, whether this covers all or some of cost of help (Allcost).
- Whether any other person or organisation pay the provider (family member, social services, other) (Q13)
- *If R pays some or none of cost*, what form that payment by LA was made in – directly or through direct payment/ personal budget (Q14)
- *If LA pays in direct payment/ personal budget*, how much money is paid from direct payment or personal budget for that provider (Q15)
- *If they pay*, reference period for payment to provider (Q15freq)
- *If R pays money for provider*, where money which R pays provider direct comes from (own income or direct payment/. Personal budget) (Q16)
- *If no payment made by R or anyone else*, why no payment made to that provider (Q19)

For any informal providers (selected for detailed questions) and for formal providers not arranged through LA:

- Whether R or their partner pays or gives any money to provider (Q12)
- *If they pay*, how much money they pay to provider (Q12b)
- *If they pay*, reference period for payment to provider (Q12bfreq)
- *If R does not answer*, Q12blump about amount, why they didn't give an answer (WhyNoQ)
- *If it's because someone else in household deals with payments*, ask whether this person can help with questions (*Finhelp*)
- *If R pays anything for providers*, whether this covers all or some of cost of help (Allcost).
- Whether any other person or organisation pay the provider (family member, social services, other) (Q13)
- *If R pays some or none of cost*, what form that payment by LA was made in – directly or through direct payment/ personal budget (Q14)
- *If LA pays in direct payment/ personal budget*, how much money is paid from direct payment or personal budget for that provider (Q15)
- *If they pay*, reference period for payment to provider (Q15freq)
- *If R pays money for provider*, where money which R pays provider direct comes from (own income or direct payment/. Personal budget) (Q16)
- *If no payment made by R or anyone else*, why no payment made to that provider (Q19)

6.2 Local Authority involvement in arranging care (Q5a and IncAss)

{If R RECEIVES HELP FROM ANY FORMAL PROVIDER – ASKED ONCE FOR EACH FORMAL PROVIDER}

SHOWCARD N

Q5a. Was the local authority (council) or social services involved in providing you with this {FORMAL PROVIDER}?

1. No, I did not contact the local authority (council) or social services about this help
2. Yes, local authority (council) or social services arranged this help for me
3. Yes, local authority (council) or social services told me about the help but I arranged it myself or my family arranged it for me
4. Other

SECTION OF QUESTIONS FOR FORMAL PROVIDERS ARRANGED THROUGH LOCAL AUTHORITY

This set of questions are asked once to cover all providers for which the answer to Q5a was 2 or 3 (Local Authority arranged or directed R to care). This is because LA may arrange a package of care for which one charge is made.

{ASK FOLLOWING QUESTIONS ONCE}:

IncAss.

Have you had an assessment of what you can afford, sometimes called an income assessment, for any of the care arranged or suggested by the local authority [LIST OF RELEVANT FORMAL PROVIDERS]?

1. Yes
2. No
3. (Allow DK)

Findings

Whether Local Authority involved in arranging care (Q5a) (Round 2 only)

In round 1 local authority arranged care and other formal providers were asked about one by one in the payments section. Problems with obtaining information about payments for formal care and additional discussions about the objectives of the questions led to a new approach for round 2. In round 2, respondents were first asked for each formal provider whether it was arranged or provided through the local authority. This used Q5a which in round 1 had been included earlier in the questionnaire to ask about home care workers and personal assistants only (in round 1 these questions did not lead into any routing)

In round 2, in order to reflect the research team's understanding of how local authority provision is paid, respondents were then asked whether they had an income assessment for this package of provision. Respondents were asked subsequent questions about payments for all the LA arranged or provided care together.

Findings from round 2 which used this approach showed that it had mixed success. In answering Q5a problems arose when:

- A respondent does not deal directly with this and someone else would be better placed to answer (a general problem with the payments module and not specific to this question)
- The Local Authority (LA) initially arranged care but the respondent had subsequently changed provider or agency so the respondent was unsure which answer code provided the 'correct' answer.
- Interviewer felt this question was not relevant for a particular provider (e.g. warden at day centre visited twice a week) – this reflects a problem with the types of providers included and not a particular problem with this question.
- A respondent was unable to answer question and instead started talking about problems paying for care – it is clear from interviewer notes that for some respondents, discussion about payments for care raises strong feelings. Interviewers should be briefed to stick to the survey questions but allow respondents to 'let off steam' when necessary.

Whether respondent has had an income assessment (Incass) (Round 2 only)

In round 2, respondents were asked for the package of Local Authority care, whether they had an income assessment. Respondents varied in terms of whether they had the information needed to answer this question. There were several groups of respondents:

- Those who were clear about what an income assessment is answered 'yes' with no difficulty, sometimes additionally providing a clear description;
- Those who answered 'no' and there is no evidence from the interviews that this question was answered incorrectly;
- Those who said 'no' but other information in the interview suggests s/he may have had one – e.g. someone coming to check bank statements after brother died, social services asking R about needs and money;
- Those who answered that s/he doesn't know as someone else deals with it;
- Those who indicated a 'not applicable' answer. One N/A was recorded but probing indicates that the respondent did not understand the question.

Although not all respondents understood and were able to answer these questions, generally this originated from them not knowing the information, rather than not understanding the question. When respondents had the information they seemed able to answer the question. Therefore we recommend that these questions are retained. If possible, information should be sought from a proxy when the respondent does not deal with these financial matters themselves. For income assessments a more detailed description or examples could be given, but there is a risk that respondents may start including assessments which are not connected with the use of services, for example interviews with banks or financial advisors.

Final Recommendations for Q5a and Incass

Retain these questions and the approach of asking about local authority arranged and provided care as a package. Although there were some problems, as explained in subsequent sections, this still seems to be the best approach. Some of the problems observed related to problems with other questions (which will be fixed elsewhere in the questionnaire) or to the fact that respondents did not have the information.

Although payments may be made in different ways for different providers within the package, it is easier for respondents to add up separate pieces of information which they know, than to split up information when they only know an overall amount.

6.3 Whether respondent pays anything for care and how much

In round 1 this was asked for each provider individually, after first checking whether the respondent paid anything for their informal providers (to avoid asking about each informal provider individually when they didn't pay any of them). In round 2 respondents were asked about payments for Local Authority arranged providers, as a package, and then asked about individual formal care not arranged through the local authority and finally about payments for informal providers.

FOR INFORMAL PROVIDERS IN ROUND ONE

{ASK ONCE WITH REFERENCE TO EVERYONE IDENTIFIED AT Q3a IF MORE THAN ONE AT Q3a/Q4}

Q12newa. Do you pay or give any money to any of the family or friends {INSERT RELATIONSHIP AND NAME OR INITIAL OF ALL} for helping you,?

1. Yes
2. No
3. (don't know)

Q12newb. (And in addition to what you pay) As far as you are aware, does any person or organisation pay or give money to family or friends who help you { INSERT RELATIONSHIP AND NAME OR INITIAL OF ALL } for the care you receive - for example the council or a family member. Do not count any benefits such as Carers Allowance or Attendance Allowance?

INTERVIEWER CODE:

1. Yes, the council / local authority /social services
2. Yes, a family member (with their own money)
3. Yes, other
4. No

Questions asked of all types of provider in round 1/ non Local Authority arranged providers in round 2

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b}

Q12. Do you pay or give any money to (the) {INSERT WHO Q3b} / {INSERT RELATIONSHIP AND NAME OR Initial Q3a} for helping you?

1. Yes
2. No
3. (don't know)

Q12 (new version for round 2)

Do you or your partner pay or give any money for the help given by {NAME OF HOME CARE WORKER/ INFORMAL PROVIDER} for helping you?

1. Yes
2. No
3. (don't know)

INTERVIEWER: DO NOT INCLUDE GIFTS, TREATS OR OCCASIONAL PAYMENTS OF EXPENSES SUCH AS PETROL MONEY OR LUNCH.

(note that an error in the program led to the unnecessary words 'for helping you' at the end of the new version of the question.)

{IF RESPONDENT OR PARTNER PAYS}

Q12b. How much money do you pay (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} for helping you?

INTERVIEWER: RECORD AMOUNT AND REFERENCE PERIOD GIVEN BY RESPONDENT (pounds and pence).

Enter amount in pounds and pence on this screen.

Enter reference period for payment on next screen.

Q12b

INTERVIEWER: ENTER REFERENCE PERIOD FOR THE PAYMENT

Per visit

Per day

Per week

Per fortnight

Per four weeks

Per calendar month

Per year

Questions for package of formal providers arranged or provided by the local authority: round 2 only

Q12lump.

Do you or your partner pay or give any money to [LIST OF RELEVANT FORMAL PROVIDERS] for helping you?

4. Yes
5. No
6. (don't know)

{RESPONDENT OR PARTNER PAYS SOMETHING FOR ANY OF THIS CARE}

Q12blump.

How much money do you or your partner pay (LIST OF RELEVANT FORMAL PROVIDERS) for helping you?

INTERVIEWER: RECORD AMOUNT GIVEN BY RESPONDENT (pounds and pence).

INTERVIEWER: Record amount and reference period given by respondent.

Enter amount in pounds and pence on this screen.

Enter reference period for payment on next screen.

RESPONSE: _____

Q12bfrlp:

INTERVIEWER: ENTER REFERENCE PERIOD FOR THE PAYMENT

1. [Per visit](#)
2. [Per day](#)
3. [Per week](#)
4. [Per fortnight](#)
5. [Per four weeks](#)
6. [Per calendar month](#)
7. [Per year](#)

Findings

Whether respondent paid anything for any informal providers (Q12newa, Q12newb) (round 1 only)

In round 1, it was found that asking a question about whether the respondent pays any money for the informal care they receive (one question to ask about all informal providers), rather than asking about providers one by one was confusing. Therefore it was recommended that Q12newa and Q12newb (which were designed to reduce burden on respondents with two or more informal carers) should be dropped and instead each informal carer should be asked about separately. This was implemented in round 2; informal carers were asked about one by one.

Whether respondent paid anything for providers (Q12, Q12b, (for informal providers))

As a result of round 1 it was recommended that for Q12 and Q12b the question wording should be altered slightly to make it clear that the question doesn't just mean money paid directly to the carer but also money paid through council or through company providing care. In the question insert the word 'for' and amend wording slightly: "Do you pay or give any money **for the help given by** (the) {INSERT WHO Q3b} / {INSERT RELATIONSHIP AND NAME OR Initial Q3a}? This recommendation was incorporated in round 2 at Q12 (which asks whether the respondent pays anything), but with some of the old wording left in by mistake and was not included at Q12b. We recommend that this wording is retained as a recommended after round 1 for Q12, and that this is added to Q12b as well.

In both round 1 and 2 respondents were unclear about whether Q12b respondents should include payments made on a one off basis or in the form of treats for informal carers. In both rounds respondents varied in terms of whether they include such payments. After round 1 a clarification was made to Q12 "INTERVIEWER: DO NOT INCLUDE GIFTS, TREATS OR OCCASIONAL PAYMENTS OF EXPENSES SUCH AS PETROL MONEY OR LUNCH". Since the clarification was for interviewer (not to be read out to respondents as part of the question) the question still arose in respondents' minds but the correct answer was usually selected, presumably because interviewers read the note out when necessary. The clarification should be retained, but possibly in a form which is read out to respondents.

In both round 1 and round 2, respondents found it strange to be asked about whether they made a payment to an informal provider; a common feeling was that you do not pay relatives. Furthermore, in round 2 the wording was changed slightly to ask whether 'you or your partner pay'. This sounded particularly odd when asking about payments to the respondent's partner.

In a few cases payments were made to neighbours or family on a regular basis. Respondents differed in terms of whether they were then willing to give the amount. In contrast to the formal providers who did not answer due to not knowing the relevant information, informal providers did not specify an amount because monetary matters were deemed personal to the person paying and/or the person receiving the money.

Frequency or period for amount paid (Q12freq, Q12bfrlp)

In round 1 (on paper) there was no closed question for the frequency of payment, interviewers just recorded what the respondent said. For round 2 in CAPI it was necessary to introduce a closed question for frequency. As expected, respondents paid for care in a variety of different ways and it was easiest to answer for the frequency with which they paid or the frequency with which they quoted the price. The format of the amount and frequency questions worked well in CAPI but there was a missing category of 'per hour'.

Whether and how much respondent paid for local authority arranged care (Q12lump, Q12blump, Q12bfrlp)

For care provided or arranged through the local authority (as identified at Q5a) whether the respondent paid and how much they paid was asked once for the package of care. This approach had mixed success.

Although the wording recommended after round 1 to make it clear that payments did not have to be made directly to providers was added at Q12, it was not incorporated at Q12lump. In round 2 at least one respondent was confused by the wording and answered that they did not pay for care (just because they did not pay the provider directly), though others were not and recorded payments made via the council. This revised wording should be incorporated in Q12lump (or equivalent final question for formal providers).

Respondents who reached these questions, having successfully answered Q5a, were generally able to answer these questions about whether they paid and how much, or to enlist help of someone who could answer.

However the answer given showed the complexity of respondents' situations:

- Two or more people in the same household receiving care and sharing care providers. Each paying notionally for different hours, but it not being clear that they were receiving the hours paid for (e.g. daughter subsidising mother's care by paying for 10 hours of care for herself but making sure she doesn't use that much)
- Live in carers receiving board and lodging and respondent regarding this as a form of payment (even equating this to 3 hours of payment) but not clear whether this

has been calculated by council and is agreed as part of payment, or whether this is just what the respondent feels (respondent takes answer from invoice)

- Personal Assistant does extra hours privately for respondent and respondent pays from own pocket for extra hours (recorded at Q12lump and Q12blump)
- R knows about contribution made for one part of care package (day centre) but other main part is too complicated so just records the small amount for day centre, which would give misleading data.

Where respondents know this information and are willing to provide such details, respondents could answer the questions. The questions can be included in surveys, but it must be accepted that there will be a relatively high level of non-response. Where respondents had recently received invoice they tended to remember the amounts or could refer to the bills for information. Where possible, interviewers should ask to look at the invoice to check the amounts.

Final recommendations for Q12 and associated questions

- Question 12 concerning payments should only be asked to informal care providers of 20 or more hours care to the respondent in the last week (Q10) – this will reduce burden on respondents while still meeting analysts' needs (since the focus is on payments for formal care).
- For formal providers, Q12 or Q12lump (or equivalent) should be asked regardless of the hours of care provided.
- For Q12 the phrase 'or your partner' should be a textfill which only appears when respondent has a partner living with them and the informal provider being asked about is **not** the partner.
- The wording of Q12, Q12lump (or equivalent) for both formal and informal providers should be: Do you or your partner pay or give any money for the help given by {NAME OF HOME CARE WORKER/ INFORMAL PROVIDER}. Please include any payments made for this care, even if not made directly to the care provider?
- At Q12b equivalent wording should be provided "How much money do you pay for the help given by (the) {NAME OF HOME CARE WORKER/ INFORMAL PROVIDER}. Please include any payments made for this care, even if not made directly to the care provider?"
- For Q12 when asked of informal providers the following text should be included in the question, rather than just an interviewer note: "Do not include gifts, treats or occasional payments of expenses such as petrol money or lunch." This is not relevant for a question about formal providers. This recommendation should be tested in a pilot, to ensure that it is not making the core element of the question harder to understand or too wordy.
- For Q12freq and Q12bfrlp an additional category 'per hour' should be added as the first category. All other categories should remain the same.
- Include instructions for interviewers to refer to invoices or bills for care services to assist respondents in answering the questions. The wording and approach can be derived from FRS where similar requests are made.

- Interviewers will need training to interpret invoices and also to accept do not know answers either at times it is apparent that the respondent clearly does not know, there is no proxy available or any answer given could be misleading
- Analysts will need to be aware of high non-response from these data and the potential for incomplete or misleading information to be given by respondents

6.4 Obtaining proxy answers where respondent does not have the necessary information

Whynoq12

Why were you unable to give an answer to the previous question? Interviewer to code answer to categories (don't want code 1 shown to Rs as may affect answers to subsequent questions)

1. It is a personal matter and I don't wish to say
2. My spouse/ partner/ other person in household deals with this
3. Someone living outside the household deals with this
4. Other

If Whynoq12=2

Finhelp

INTERVIEWER: ASK RESPONDENT WHETHER THIS PERSON IS CURRENTLY AT HOME AND COULD ASSIST WITH THIS SECTION. USE DISCRETION TO DECIDE WHETHER THIS IS APPROPRIATE.

Findings

Whynoq12, Finhelp

In round 1 of testing it became apparent that some respondents did not have sufficient knowledge or information to answer questions about payments for providers. To allow proxy information to be obtained in a more systematic way two new questions were introduced to be asked when respondents said don't know to the questions about amount paid to formal and informal providers.

In round 2 these new questions were used and included after Q12. However, in some cases respondents declared that they did not know about these matters when asked the very first financial question (Q5a). This could lead to the helper being called in at that point and answering the questions. There was no way for it to be recorded in the CAPI that proxy answers were given. In another case, the interviewer persisted with the respondent, until they reached WhyNoq12, at which point they called in the assistance of a proxy and then had to go back over the preceding questions.

Final recommendations for WhyNoQ12 and Finhelp

Retain this approach but move these questions to the very start of the payments section. A question should also be included at the end of the section, which interviewers can use to indicate for all respondents, whether the respondent answered alone, with some help, with a great deal of help, answers given by proxy. The precise format of the questions

seeking assistance of family members will need to be decided on individual surveys as different surveys have different rules. This is something to discuss with HSE and ELSA.

In terms of a general recommendation of this social care module we would suggest that respondents answer at least questions 1 and 2 alone but that ideally help should be available for later questions, where possible.

6.5 What proportion of the cost of care respondent pays

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b} round 1 only

Q17. Thinking about the cost of (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} helping you, how much of your care do you pay from your own income, savings or pension?

Do you pay.. READ OUT...

1. All of it
2. Half or more but not all of it
3. Some of it, but less than half
4. Or none of it?

Those who paid something for care (from Q12) (Round 2 only)

Allcost

You said you pay (TEXTFILL FROM Q12B) for (CARER/NAME OR TYPE). Does this cover all the cost of this help or some of the cost of this help?

All

Some

Findings

Q17

On the basis that not everyone can provide amounts for the cost of care, it was agreed that respondents should be asked about what proportion of the cost of each provider they pay themselves. In round 1 respondents were presented with Q17, asking about whether they paid all of it, half or more but not all, some but less than half, or none of the cost of each provider. Findings showed that the question did not work and generated high levels of non-response. However answers to probing or think aloud showed that respondents paying tended to know whether they paid all or some of the cost.

Allcost

For round 2, Q17 was dropped and replaced by Allcost which was asked when the respondent paid anything for the care they received. Respondents were asked whether the amount paid covered all or some of the cost. In round 2 this was mainly tested on formal providers, since payments for informal providers were uncommon. This question did not have the same problem of non-response as Q17. Probing by interviewers was limited but the answers given to this question seemed in line with other information given in the payments section.

Final recommendations for Allcost

Retain Allcost as worded as respondents were able to answer this question. Given that many respondents will be unable or unwilling to provide information about detailed payment amounts, it is a valuable question for identifying whether respondent pays some or all of their care. The various versions of Q12 (depending on whether LA arranged or individually), allow analysts to identify those who pay for none of the care.

6.6 Collecting information about direct payments

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b in round 1, ask for package of LA arranged formal providers and for individual formal and informal providers in round 2 }

Q13. (And in addition to what you pay), as far as you are aware does anyone else or any organisation pay or give money to (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} for the care you receive - for example the council or a family member. Do not count any benefits such as Carers Allowance or Attendance Allowance?

INTERVIEWER CODE:

1. Yes, the council / local authority /social services
2. Yes, a family member (with their own money)
3. Yes, other
4. No

{IF Q13=3} ROUND 1 only

13b. Write in details of other organisation or person **TEXT 50**

(INTERVIEWER YOU DON'T NEED TO WRITE IN ANYTHING HERE)

{IF Q13=1 in round 1/ If R PAYS SOME OF THE COST OF CARE (ALLCOST) OR PAYS NONE OF COST (Q12LUMP=2 IN ROUND 2 }

SHOWCARD H

Q14. And did social services or the council pay (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} directly or was it through a sum of money paid to you by the council for you to spend on services. This sum of money can be called a Direct Payment or a Personal Budget?

INTERVIEWER CODE:

1. Social services or council paid directly
2. Paid through Direct Payments / Personal or Individual Budgets

INTERVIEWER READ OUT SHOWCARD H

Direct Payments is the option for you to purchase some or all of the services you are eligible for yourself, using a sum of money provided by the council, social services or the local authority.

This should not be confused with benefits paid directly into a bank account which may also be called direct payments.

A Personal Budget (also know as an Individual Budget) would be allocated to you following a "needs assessment". The council decides the amount or pot of money necessary to meet your social care needs and gives money to you. You can then use then money to buy services which you choose. The money could be paid to you as a Direct Payment

{ASK IF RESPONDENT PAYS ALL COST OF CARE THEMSELVES (ALLCOST=1)}.

Q16.

How do you usually pay or give money to (the) {LIST OF RELEVANT FORMAL PROVIDERS} for helping you?

CODE ALL THAT APPLY

SHOWCARD P

I use money from:

1. my own personal income, savings or pension
2. my Direct Payment/ Personal or Individual Budget from the council/ Social Services/ Local Authority
3. from another source

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b AND IF Q14=2 or Q16=2}

Q15. How much money is {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} paid from the direct payment for helping you?

INTERVIEWER: RECORD AMOUNT AND REFERENCE PERIOD GIVEN BY RESPONDENT.

Q15freq

Per visit

Per day

Per week

Per fortnight

Per four weeks

Per calendar month

Per year

Findings

Increasingly local authorities are moving towards direct payments and personal or individual budgets as a way for personal care service users to pay for their care. The use is being extended to older people. In round 1 of the testing our sample did not include sufficient cases to test questions about direct payments adequately so at round 2 the sample included people who we knew were receiving direct payments.

In both versions of the questionnaire, respondents were asked whether any other person or organisation paid for the care (mainly with the intention of identifying local authority contributions). Where the local authority contributed, respondents were asked whether these payments were made direct to providers, or via respondents as direct payments or personal budgets. Where payments are made directly, no further information was sought, but where the money was paid through direct payments or personal budgets, respondents were asked how much was paid. Respondents were also asked whether the amount they paid themselves was from their own income, savings, a direct payment or personal budget.

Whether other person or organisation paid for care (Q13)

In both rounds there were respondents who gave clear answers to this question without hesitation and think aloud revealed that they understood the question (for example, commenting that they received Attendance Allowance but understanding this was not covered by the question and choosing 'no').

There were respondents whose answers indicated possible confusion:

- Answer of 'no' – though R says assumes someone pays for the care and has already says she does not.
- Answer of 'Yes, LA' – though respondent is later confused with 'Disability Allowance' at Q15 and thought perhaps this would be a direct payment so not clear whether answer to this question is correct

Category 2 (family member) was chosen where the respondent's daughter was making a payment and was involved in the interview. The daughter spontaneously gave the amount.

Although it is hard to make firm conclusions about this, the impression gained from the cognitive testing is that this question was less problematic in round 2. Round 1 certainly included respondents who chose 'no' at this question when it was clear that the Local Authority makes some form of contribution. This may be because in round 2 it followed Allcost where respondent had been asked whether they paid for some or all of the care from the providers.

Whether LA payment made directly or by direct payment/ personal budget (Q14)

In both rounds there was confusion about direct payments and personal budgets. For respondents who had not heard of direct payments or personal budgets this was related to a lack of understanding or knowledge of the terms used and the arrangements being asked about. The only respondents who received direct payments or personal budgets were in round 2. However, these questions could be problematic even for those who were aware of such arrangements. For example, problems arose when:

- respondent was moving between payment systems and were not quite sure which system they were currently on,
- respondent had several types of formal care arranged by the local authority and some paid for directly by the local authority and some paid for by a direct payment (this related to the fact that respondents were asked about all local authority arranged care as a package)

In the context of a survey, it could be argued that few respondents will be between payment systems at any one time. On the other hand, the probing and think aloud revealed that care receivers could be in a relatively long term state of flux in relation to payments for or entitlement to care. As councils roll out direct payments and personal

budgets, it would be anticipated that care receivers will be moving between systems in large numbers.

It should also be noted that in some cases respondents may be on direct payments but the money is paid directly to the provider by the council – in this case the respondent selected direct payment but in other cases it could potentially cause confusion.

In both rounds, even respondents who were familiar with direct payments were unfamiliar with personal budgets. In addition there was some confusion after looking at the showcard, about whether respondents were asked about direct payments and personal budgets as a single category or whether they needed to decide between them. Q14 could be changed to separate out Direct Payments and Personal Budgets into two categories. However on balance we do not recommend separating the two, as respondents who were not entirely aware of personal budgets still seemed able to choose the correct code (2).

The questions were successful in identifying receipt of direct payments where the respondent's situation was not in a state of flux, and also identified receipt of a personal budget used by the respondent to pay for a cleaner (which had been picked up as a provider)

In both rounds of testing confusion between direct debits and direct payments was identified. It was recommended after round 1 that at Q14 a note: "DIRECT DEBITS USED TO PAY FOR CARE SHOULD NOT BE INCLUDED AT CODE 2" should be added but this was missed in error in round 2.

In the routing for Q14 during round 2, respondents were asked Q14 even if they said no to Q13. This was to ensure that as many questions got asked as possible to ensure we identified the best way of gathering the information. In a CAPI survey this inconsistency would need to be removed.

Whether respondent pays their contribution using direct payment/ personal budget (Q16)

Respondents who paid for all of the cost of the care themselves were asked about how they paid for their care. The intention of this was to identify those who receive direct payments and from that pay for all the care themselves.

In round 2, respondents who answered this question interpreted it in two different ways:

- How they make the payment – by cheque or direct debit (confusion between direct payment and direct debit) – a note saying "DIRECT DEBITS USED TO PAY FOR CARE SHOULD NOT BE INCLUDED AT CODE 2." had been added after round 1 – not clear whether this clarified or added to the confusion. – in both rounds respondents were nonetheless able to choose the correct answer but they were not really understanding the question in the way intended.

- Whether they pay using direct payment – the only case answering this question in this way had already had the direct payment captured through Q14 and Q15 so no new information was obtained

Amount and frequency of payment for direct payment/ personal budget (Q15, Q15freq)

In round 2, when asked about the amount paid to the provider from the direct payment or personal budget, respondents varied in terms of whether they:

- refused to give an amount – did not want to be asked about this;
- gave an amount without hesitation and without going through a calculation process; and,
- gave an answer but the process was difficult and involved complex calculations (e.g. different rates for day and night, hours of care vary, subtraction of care paid for by other means such as respite care, consideration of the fact that food and laundry are provided for carers)

It should be noted that some of these other ways of payments for care are not captured by this questionnaire (respite care, payment in kind). Their inclusion would add further complications. Nonetheless, analysts should be aware that the questionnaire only provides a partial picture.

One respondent indicated that she is taxed on the personal budget. This respondent refused to answer so it is not possible to know what the impact on the answer would have been.

Final Recommendations

- Q13 should be retained and asked for all providers and should directly follow Allcost.
- Q14 should be retained but the routing changed to avoid asking this question in contradictory context in relation to previous answers. Q14 should be asked when Allcost=some or Q12lump/ Q12=no or (allcost=all and Q13=1 (yes, LA)). In other words this means it should be asked when respondents:
 - pay for none of their care, or,
 - some of the care, or,
 - when they said they pay for all the care, but at Q13 record that the local authority pays something.
- This last scenario is not as contradictory as it may seem (respondent may pay all the cost themselves using a direct payment or personal budget received from the LA). If this routing is adopted for Q14, then Q16, which was not well understood, can be dropped. Q16 was designed for respondents paying for all the care themselves using a personal budget or direct payment. However with this re-routing, Q16 is not necessary now.

- Q14 should allow multiple codes for questions asking about the package of local authority provided care. This is necessary to allow for the fact that the local authority may arrange payments in different ways for different providers, while still accommodating the basic approach of the questionnaire in looking at packages of local authority arranged care.
- Q15 (amount and reference period) should be retained where Q14=2 (direct payment or personal budget). It should be noted that in cases where the respondent considers that they pay all the cost themselves using a contribution from the local authority in the form of a personal budget or direct payment, the amount given at Q15 could actually be a subset of the amount given at Q12 (as being paid by the respondent). Therefore there is a risk of double counting. However such cases can be identified from the data (allcost =all and Q13=1) and this could be taken account of in the analysis. Furthermore an additional question to check the respondent's answer could be included but this risks adding unnecessary confusion so is not recommended.
- Q15 should refer to personal budget as well as direct payment in the question wording. Consider whether clarification is needed (in a textfill) where there is a multi-code at Q14.
- Q15freq should have a new first category – 'per hour'.
- A later section of the report deals with recommendations on creating a short version of the module but it should be noted here, that we recommend excluding Q15 and Q15freq from a short module.
- Q16 should be dropped from the questionnaire

6.7 Payments made by family members (Q18)

Round 1 only

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b AND IF Q13=2 or Q14 =2}

Q18. Thinking about the cost of (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} helping you, how much of your care does your family member pay from their own income, savings or pension? Do they pay... READ OUT...

1. All of it
2. Some of it, but less than half
3. More than half but not all of it
4. Or none of it?

Findings

In round 1, when respondents indicated at Q13 that family members had contributed to their care they were asked a follow-up question to ask what proportion the family member paid. This question had the same problems as Q17. Since data collection prioritises

collecting information concerning respondent and local authority contributions, this question was dropped at round 2.

In round 2 it was evident that family members make contributions – sometimes in complex ways – for example paying the same provider for some care which the contributor does not use, or making payments directly (sometimes large sums – up to £1000 per month with significant impacts on the person paying). However, given the complexities of this question set, we continue to recommend that this element is not included in the module. It will be possible to identify whether the respondent receives contributions from family members towards their social care from Q13. Testing revealed that payments are made in other complex ways such as through respite care and payment in kind, often through family members and to try and amend the questionnaire to capture these would be too complicated.

Final recommendation for Q18

Do not include question about contribution made by family members.

6.8 Reasons for no payment being made for care (Q19)

{ASK FOR EVERYONE IDENTIFIED AT Q3a and Q3b AND IF Q10=5, 6, 7 OR 8 AND (Q12newa=2 and Q12newb=4) OR (Q12=No AND Q14=No)} ROUND 1

Q19. You have told me that no payment was made for (the) {INSERT WHO} / {INSERT RELATIONSHIP AND NAME OR INITIAL} helping you. Why was this?

UNPROMPTED RESPONSE:

1. They provided their help for free
2. They received payment in kind/ reciprocal help
3. There is no charge for the service
4. Other

IF NOTHING IS PAID FOR THE CARE - ROUND 2 ONLY

Q19.

You have told me that no payment was made for (the) {LIST OF RELEVANT FORMAL PROVIDERS} helping you. Why was this?

UNPROMPTED RESPONSE:

1. They provided their help for free/there is no charge for the service
2. Sometimes I give them money or gifts for the help they give me
3. Other

Findings

In round 1, Q19 about why no payment was made to a provider worked and was broadly understood as intended by respondents. There was an overlap between categories 1 and 2 and so these were merged for round 2. Reciprocal help could be understood more broadly than intended (by providing help to the community rather than to the provider) so at round 2 the nature of reciprocal help was made more explicit.

At round 2 Q19 appeared to be understood as intended and respondents were able and willing to answer the question. A situation arose when a respondent seemed keen to offer multiple answers for one provider, but this may be as a result of the conversational nature of the cognitive interview and could probably be avoided in a CAPI interview.

Final recommendations for Q19

Retain Q19 as used in round 2. This question should be asked to respondents not paying themselves or have not had payments made by other organisations. This question should not be asked for informal providers who provide less than 20 hours a week of care to respondents.

6.9 Feelings about being asked questions about payments and financial matters

Respondents had mixed feelings about being asked about payments and financial matters. There were two broad feelings:

- Financial matters are private and are the business of individuals (the respondent and or the person they are paying)
- These questions need to be asked as part of a survey and there is no problem discussing them.

Individuals could fall into both groups, depending on where they were in the payments section. The greatest sensitivity arose when discussing amounts (at Q12b, Q12blump and Q15). This was particularly the case where the payments were being made to informal providers, or to formal providers as a private arrangement. Respondents felt that the amount paid was personal to the recipient of the money, and were concerned that revealing the payment figures could impact on the benefits of those receiving the money.

Given the general attitude of giving friends and family money, Q12 indicated that payments most often occur when family and friends need the money (examples given in the interviews included being out of work or being a single mother). It is likely that these situations could be sensitive. By only asking about payments to informal carers who provide more than 20 hours of care, most of these cases will not be routed through these questions. Therefore reducing the problem of sensitivity and allowing the questions to capture the scenario of most interest (when respondents are paying previously informal providers, using personal budgets).

It should be noted that refusals to answer these questions, when combined with don't know answers from those who do not have the information needed to answer them, could lead to high levels of non-response. However we would recommend fielding the module in a pilot, without cognitive probing and using larger numbers in a more representative sample to assess this potential issue.

7 Aids and Equipment

A module of questions was designed to collect data about aids and equipment that has been used by people over the age of 65. The questions aim to find out the types of equipment people use, who provides this equipment, whether they have used a council's handyman service and what type of accommodation they live in. These sets of questions are asked to everyone over the age of 65 regardless of any type of care received. Here we present the questions that were tested in both rounds. The text in red shows either words or whole new questions which were added for round 2 based on problems or other findings identified in round 1.

7.1 Identifying whether respondents have a sensory alarm (SenAlarm)

This question examines whether people have sensory alarms which can be used to call for help. After round 1 of cognitive testing, an additional check was added to the optional read out for this question with the aim of screening out respondents who included smoke and burglar alarms when answering this question. When answering this question in round 1, respondents included smoke and burglar alarms when answering yes instead of just sensory alarms.

INTERVIEWER READ OUT...

"I've just asked you about payments for services that you receive but we are also interested in whether people have any aids or equipment to help them stay in their own homes"

{ASK ALL OVER 65}

Do you have an alarm which you can use to call for help. This could be worn round your neck or may be a button or pull cord in your home. Please tell me about any alarms you have even if you have not had to use them? INTERVIEWER IF NECESSARY: Please do not tell me about alarm clocks, timers, smoke or burglar alarms.

1. Yes
2. No

Findings

Testing from both rounds of cognitive testing showed that respondents found this question easy to answer. Respondents in both rounds correctly answered the question even if they had not used their alarms. In the second round of testing respondents were clear about the types of alarms they should be including in their answer. We cannot be sure whether the interviewers read out the extra clarification about smoke and burglar alarms because this was an optional read out but the correct types of alarms were captured in this question.

Final Recommendations for SenAlarm

This question seems to work well and capture the correct information. We suggest that this question wording is kept the same.

7.2 Identifying if respondents have equipment to help them with daily living (Equip2)

This question aims to find out what types of equipment people over 65 use to help with their daily living. This question has changed order for the second round of testing. In round 1 it was asked after Equip 1 and EquipX. In round 1, respondents were including similar types of equipment in both Equip 1 and Equip 2 and questioned if they were the same question. We have changed the ordering in hope that they would exclude smaller equipment in Equip 1. Also, the question wording has slightly changed from 'do you have' to 'have you used or received' any equipment. A note has been added to interviewers to only include equipment respondents have used themselves.

{ASK ALL OVER 65}

Equip2

Have you used or received any equipment to help you with daily living, such as grab rails, raised toilet seats or teapot tipper?

INTERVIEWER: PLEASE ONLY INCLUDE EQUIPMENT RESPONDENT HAS TO USE THEMSELVES.

1. Yes
2. No

Findings

Respondents in both rounds listed a range of different types of equipment they use. The examples given occasionally seemed to influence how respondents answered and what type of equipment they thought about, this applies to both rounds of testing. In rounds one and two, respondents did not include equipment if it was no longer being used but had been used in the past and if equipment had never been used. In round 2 a respondent questioned whether a time period was in the question because a piece of equipment had only been used for a short period of time, about a year ago, this piece of equipment was not included when answering. In both rounds of testing respondents questioned what was a teapot tipper. People in round 2 were still including some major adaptations which we would want to capture in the next question when answering Equip2.

Final Recommendations for Equip2

People are still including major adaptations at the question about minor equipment. Perhaps consider including a please do not include statement with a list of the examples of major adaptations given in Equip1.

7.3 Identifying who provided respondents with any equipment identified at Equip2 (Equipy)

If respondents answer yes to Equip2 then Equipy is asked. This question looks into who provided the equipment for the respondent. For round 2, this question was changed to a 'code all that apply' so the respondent can choose more than one answer code. The answers in round 2 were presented on a show card rather than read out; this is to facilitate the multi-code. An 'Other' code was added to this question for round 2 to incorporate voluntary bodies such as the Rowntree Foundation.

{If Equip2=YES}

SHOWCARD Q

Equipy

Who provided this equipment for you?

CODE ALL THAT APPLY

- 1 Provided through the Local Authority/council/social services
- 2 Provided through the NHS, i.e. your doctor or the hospital gave it to you
- 3 Bought it myself
- 4 Bought for me by my family or friends
- 5 In place already in my home
- 6 Other

Findings

In round 1, respondents occasionally wanted to choose multiple options when a piece of equipment was provided by two different bodies. In round 2 multi-codes were allowed and respondents chose multiple codes when different pieces of equipment were provided by different sources. One respondent in round 2 became confused because she was answering about equipment which was put in for her husband so originally chose the council (code 1) but then decided on code 5, 'in place already in my home' was a more appropriate answer. In round 2 some respondents did not know who provided the equipment.

Final Recommendations for Equipy

Consider adding a do not know option as a hidden code. This would mean that respondents can choose do not know but are not given it outright as an answer code so encouraging the respondent to think about who provided the equipment.

7.4 Identifying whether respondents have major adaptations to their homes to help with daily living (Equip1)

This question wording has been kept the same in round 2. After round 1 testing it was moved after Equip2 to try and stop respondents from including equipment they should have been thinking about in Equip2 in their Equip1 answers.

{ASK ALL OVER 65}

Equip1

Do you have any major adaptations to your home to help you with daily living, such as a stair lift, a walk-in shower or bath or a wheelchair ramp?

1. Yes
2. No

Findings

Respondents gave a variety of major adaptations in both rounds of testing. In round 2, equipment which was talked about at Equip2 was also included in Equip1 when answering yes. In round 2, one respondent included a stair-lift which had been installed for her husband which she did not use herself.

Final Recommendations for Equip1

Respondents in this round seemed to include less equipment which should be included in Equip2 than they did in round 1 although some equipment from EQUIP 2 was thought about in this question. We suggest including a short sentence to say please do not include any equipment thought about in EQUIP 2, although this might not work because they may have been thinking about major adaptations at EQUIP 2 and not include them in this question.

Alternatively consider removing the distinction between the questions and ask one question about all types of adaptation or equipment (combine Equip 1 and Equip2 as the distinction between them does not seem meaningful to respondents). This could be followed by a question which finds out more about the type of adaptation so it can be categorised as major or minor. Though if space is at a premium this question could be dropped.

7.5 Identifying who provided respondents with any major adaptations identified at Equip1 (Equipx)

If respondents answer yes to Equip1 then Equipx is asked. This question looks into who provided the equipment for the respondent. For round 2, this question was changed to a 'code all that apply' so the respondent can choose more than one answer code. The answers in round 2 were presented on a show card rather than read out to facilitate the multi-code. An 'Other' code was added to this question for round 2 to incorporate voluntary bodies such as the Rowntree Foundation.

{If Equip1=YES}

Equipx

Who provided this adaptation for you?

CODE ALL THAT APPLY

1. Provided through the Local Authority/council/social services
2. Provided through the NHS, i.e. your doctor or the hospital gave it to you
3. Bought it myself
4. Bought for me by my family or friends
5. In place already in my home
6. Other

Findings

In round 1 respondents wanted to choose multiple options. Because of the changes made for round 2, when different options applied to different adaptations respondents chose multiple answer codes. In round 2 testing, the cost of an adaptation was split 50/50 between two of the answer codes. The answer code 'Other' was chosen rather than listing the two parties involved. As in Equipy, in both rounds it was found that respondents may not know who provided the adaptations they had.

Final Recommendations for Equipx

Consider adding a 'do not know' code as a hidden code. This would mean that respondents can choose do not know but are not given it outright as an answer code discouraging this being used as a short cut.

7.6 Identifying if respondents have stair lifts in their home for their use (Stairlift)

This is a new question which was not tested in round 1. It aims to measure the number of people with stair lifts in their home which they use.

{ASK ALL OVER 65}

Stairlift

Do you have a stair lift for your use at home? Please include any stair lift which you use for getting up and down stairs on a regular basis, even if it was not installed for you.

1. Yes
2. No

Findings

Testing found that on the whole 'stair lifts' were described accurately by respondents. However there was an occasion where a respondent described it as a normal walk in lift. During the testing respondents suggested providing a 'not applicable' answer code for people who lived in types of accommodation which could not have a stair lift such as a bungalow or a ground floor flat.

Final Recommendations for Stairlift

Consideration could be made to add a 'not applicable' answer code so that respondents who live in accommodation where a stair lift is not needed could choose this code instead of having to select 'no'.

7.7 Identifying if respondents use equipment related to mobility (Mobility)

This is a new questions which was not tested in round 1. This question identifies the types of mobility equipment people over 65 are using.

{ASK ALL OVER 65}

SHOWCARD R

Mobility

Do you use any of the following?

CODE ALL THAT APPLY

1. A manual wheelchair
2. An electric wheelchair
3. Elbow crutches
4. Walking stick
5. Zimmer frame or other walking frame
6. Other
7. None of these
8. I don't need anything like this to get around.

Findings

Testing of this question showed that equipment which is not used often is still selected from the given list, such as using a walking stick which is only used in icy conditions outside. If a respondent uses a piece of equipment for a short period of time such as equipment used to recover from an operation, or have not used the item for a long period of time of more than a year, this equipment was not included in the answer given. Respondents questioned what the answer code 'Other' would include. Some of the things coded under other were:

- trolleys used to move about inside the home
- a hoist

Testing found that respondent's answers would change depending on whether they thought the question was referring to 'getting around' inside or outside their home/residence. For example saying they did not need anything to get around because inside they do not require assistance/ equipment but if the question asked about outside they would have chosen walking sticks.

Final Recommendations for Mobility

We suggest adding 'currently' to the question wording to assist respondents to think only about their present situation when answering this question. Consideration needs to be given to the issue of whether respondents should be answering based on getting around

outside only, inside only or both. Depending on the measurement aim of this question, the question could be clarified to assist respondents to answer the question as intended.

7.8 Identifying if respondents have used a council' Handy Man's service in the last three months (HandyMan)

This question aims to find out whether people over 65 have used the councils handy man's service in the last three months. After round 1, a clarification that this service is usually free was added to the question.

HandyMan

In the **last three months**, have you used or received the Local Authority/council's Handy man's service? This is usually a free service sometimes arranged through Age Concern or Help the Aged

1. Yes
2. No

Findings

The additional clarification about this being a free service etc. seems to have helped clarify this service for some R's. In round 1 the reference period of three months was noted, however in round 2 overall respondents did not think of the time period given and thought about whether they generally use the service. Testing in round 2 found that some respondents had never heard of the service. One respondent in round 2 focused on the end of the question and thought only of voluntary organisations as opposed to the local authority.

Final Recommendations for HandyMan

- Rethink time period reference in the question.
- Consider whether this question is high priority in the context of needing to cut module length

7.9 Identifying what type of accommodation respondents live in (SheltType)

This question looks at what type of accommodation people over 65 are living in. In round 1 testing respondents answered based on the type of accommodation he previously lived in so the word 'currently' was adding to the question wording from round 1. In addition some confusing about the meaning of residential care was identified to clarification was provided in round 2.

{ASK ALL OVER 65}

SHOWCARD S

SheltType

Please look at this card and tell me whether you currently live in any of these types of accommodation?

1. Warden maintained /sheltered accommodation
2. Housing with care / extra care housing / very sheltered accommodation
3. Residential care e.g. nursing home or care home
4. Other type of supported housing (Please specify)
5. None of the above

Findings

In both rounds of testing respondents who answered 'None of the above' found this question easy to answer and knew which answer code applied to them. The definition of 'other type of supported housing' and 'extra care housing/very sheltered' was questioned in round 2 but was not needed to be chosen as an answer code. When sheltered housing was chosen, it was questioned what the facility themselves would refer to themselves as. 'Currently' being added to the question wording was noted in round 2 as someone who had previously lived in residential care but now lived in his own home chose None of the Above. Respondents in round 2 suggested that 'I live in my own home' should be added to the answer codes.

Final Recommendations for SheltType

We suggest that the question wording remains the same. Testing suggests that the questions accurately record the types of accommodation where people live. We do not think 'I live in my own home' should be included as this answer code covers too many types of situations which is already included in the answer category 'None of the above.'

8 Provision of care

8.1 Identifying Providers of Care (Q61, Q61b and Q62)

A module of questions was designed to collect data about help or support that has been provided by the respondent to one or more people over the age of 65, but not in a professional capacity. We originally thought that all survey respondents would be asked two initial screening questions (Q61 and Q62) to establish whether or not they proceed through the rest of the module. A reference period of the last month was chosen to distinguish care that has ever been given from recently provided care. The aim of Q61 is to identify providers of care per se and is followed up with Q62, which specifies the age range of interest.

After one round of cognitive testing an additional check was added (Q61b) with the aim of screening out respondents who answer positively at Q61 but for reasons which do not match the measurement aims of the question. For example, people who provide help to others as a consequence of the way a relationship has always been (a man who drives his wife around because she has never learnt to drive), or because of the way a household, couple or other group of people divide up tasks (a woman who cooks a meal for her husband because she has always done the cooking). Here we present the questions that were tested in both rounds and the evidence which contextualises the approach or has shaped decisions that have been made. The underlined text in red shows either words or whole new questions which were added for round 2 based on problems or other findings identified in round 1. Both rounds of testing omitted an introduction to the provision module which we feel will be necessary when these questions are eventually fielded.

{ASK ALL}

Q61.

Have you (personally) provided help or support to anyone because they have long-term physical or mental ill-health, disability or problems relating to old age in **the last month**? Do not include help given in a professional capacity or as part of a job but include help or support given to your partner or spouse

INCLUDE HELP FOR WIFE/ HUSBAND/ PARTNER.

1. Yes
2. No → GO TO END.

{If Q61=1}

Q61b.

Can I just check, are you only including help or support that you give this person/these people because they have long-term physical or mental ill-health, disability or problems relating to old age, or were you thinking about how you have always helped each other and/or divided up tasks?

1. Yes, only help/support given because of health/old age
2. No, was only including how always helped each other/divided up tasks → GO TO END.

{If Q61=yes}

Q62. How many people aged 65 or over do you provide this type of help to?

UNPROMPTED RESPONSE:

ENTER NUMBER _____

Findings

Q61 (Whether provided help or support due to health problems or old age in the last month)

Both rounds of cognitive testing show that Q61 generally works well and mostly only screens in those who have provided help or support to someone in the last month, not in a professional capacity or as part of a job.

Findings from cognitive testing, particularly round 2, highlight that the question taps into a broad range of provision: from providing permanent help or being on-hand in case the person needs help to a small amount of friendly care for elderly friends and providing social support or company to somebody. On the other hand evidence was also found to suggest that certain kinds of 'low-level' help can be excluded (for example one-off lifts to appointments or picking up some food for a friend who can't get out themselves), even if it had occurred within the reference period stated.

Q61b (Follow up check to Q61 only included in round 2)

This check was added for round 2 as a means of reminding respondents to think only about help provided because of long-term physical or mental ill-health, disability or problems relating to old age. Although there were respondents for whom this question worked as intended, there were also respondents who found the question confusing, although this occurred rarely it is still worth noting nonetheless.

- If a respondent feels that the help or support that they provide is necessary because the person they care for is otherwise lonely and/or isolated, they may answer yes at Q61b (and it might not be clear whether the person also has health/old age related problems). If the intent of this question is to pick up on this type of help then this is fine but the current wording of Q61b did cause respondents in the sample for round 2 to question or make a comment about their response.
- If a respondent has cared for somebody else for a long time because they have always needed it, due to a disability for example, they too might answer yes to Q61b but find the current wording confusing. The question mentions 'how you have always helped each other and/or divided up tasks' but this could (also) be the case for a couple both over the age of 65 where one is caring for the other, but always has done because he/she is disabled. Both answer codes could apply and therefore lead to confusion.

Q62 (Number of people aged 65 and over provided help or support to)

Both rounds of cognitive testing provided evidence to suggest that this question works as intended and respondents are only counting those they help or support aged 65 or over.

Final Recommendations for Q61, Q61b and Q62

There is a need to clarify the measurement aims of Q61. As it is currently phrased, it draws in respondents who provide low-level and possibly even occasional help, as well as

those who provide more regular and intense help or support. There also needs to be agreement around the importance of social contact and support, and whether this should be considered as a form of 'social care'. The question may need to be revised based on where the interest lies. The instruction on an interviewer script, like the one suggested below, to introduce the module could help to clarify the intent of the module of questions:

"The next few questions are about help or support that is provided to others. We are only interested in help and support provided to people because they have long-term physical or mental ill-health, disability or problems relating to old age. Please think about all kinds of help or support that you have provided'.

Our current thinking is that Q61b should be retained as a follow up check question to Q61b but should be revised slightly:

Can I just check, are you only including help or support that you give this person/these people because they have long-term physical or mental ill-health, disability or problems relating to old age, or were you thinking about help more generally?

1. Yes, only help/support given because of health/old age
2. No, was thinking about help more generally → GO TO END.

8.2 Names of those aged 65 and over who are cared for (Q63)

There was a need to identify multiple people, aged 65 or over, who have been cared for in the last month and Q63 was included in the same format in both rounds of cognitive testing as a means of facilitating this. Due to time restrictions in the cognitive interviews, subsequent questions in this module were looped for up to three people, using the names provided here at Q63. For the purpose of administration in a survey however, a decision will need to be made around how many (cared for) people are looped through the subsequent questions and rules for making this decision (i.e. who goes through) will need to be added.

<p>{If Q61=1 AND Q62=1 OR MORE}</p> <p>Q63. You have told me that you provide help or support to {INSERT NUMBER} people/person aged 65 or over. Please tell me the name of the {1st, 2nd, 3rd ...} person?</p> <p>1ST PERSON'S NAME _____</p> <p>2ND PERSON'S NAME _____</p> <p>3RD PERSON'S NAME _____</p> <p>4TH PERSON'S NAME _____</p> <p>5TH PERSON'S NAME _____</p>

Findings

There is sufficient evidence from both rounds of cognitive testing to suggest that this question works as intended for both respondents who indicate that they provide help or support to one person as well as those who provided help or support to more than one person aged 65 or over. In both rounds respondents were happy to provide the names,

either in the form of a first name or an initial at the very least, and there was no reason to believe that the request for this information was sensitive in anyway.

Final Recommendations for Q63

For inclusion on a survey, it is likely that there will be time restrictions and therefore we are suggesting that each respondent is asked the rest of the module of questions about provision for a maximum of two (cared for) people. There will need to be rules in place for how CAPI makes this choice. One idea is bringing the hours cared question (Q67) forward and ask it directly after this one (Q63) so that the looping rules can be based on intensity of care provided (in a way which is consistent with the rules used in the receipt section of the questionnaire).

8.3 Whether those aged 65 and over who are cared for live in the same or a different household (Q64)

We were able to test this question with respondents who lived with the person/people for whom they provide care as well as care providers living in different households to the care recipients. The question did not change between rounds and as pointed out previously, this question was looped for up to three people cared for.

{If Q61=1 AND Q62=1 OR MORE. THIS QUESTION IS IN A LOOP FOR UP TO THREE PEOPLE}
Q64 Do you live in the same household as [1ST/2ND/3RD PERSON'S NAME] or do you live in a different household?
1. Same household
2. Different household

Findings

Cognitive testing of this question in both rounds suggests that it works as intended and correctly identifies whether the respondent lives in the same household as the person/the people they care for or a different household. There was no reported confusion and, although occasionally perceived as quite an obvious question if the person they cared for was the respondent's spouse, this question did not anger or cause upset.

Final Recommendations for Q64

Our recommendation is to retain this question as it is currently worded.

8.4 Relationship of those cared for to provider (Q65a)

This question was included as a means of gathering the relationship status of the provider to the person/people they help or support and did not undergo a revision between rounds of testing.

{If Q61=1 AND Q62=1 OR MORE THIS QUESTION IS IN A LOOP FOR UPTO THREE PEOPLE}

SHOWCARD L

Q65a What is your relationship to {1ST/2ND/3RD PERSON'S NAME}?

I am his or her:

1. Partner/Spouse
2. Son (including step son, adopted son or son in law)
3. Daughter (including step daughter, adopted daughter or daughter in law)
4. Grandchild (including Great Grandchildren)
5. Brother / Sister (including step / adopted / in laws)
6. Niece / Nephew
7. Other family member
8. Close friend
9. Neighbour
10. Professional care giver / Care staff (route out)
11. Voluntary helper (route out)
12. Other (PLEASE SPECIFY)

Findings

The two rounds suggest that Q65a was well understood and is easy enough to answer. Respondents in both rounds were able to choose a response from those provided, without getting confused by which way round they had to report the relationship to the person/the people they provided help to. In both rounds there were respondents who displayed a preference for the first category 'Partner/Spouse' to read 'Husband/Wife' however at no point did this hinder their ability to answer and respondents still used the code when answering. There was some evidence, in round 2, of answering thinking about the relationship to the person when the two people first met (i.e. the person was a neighbour who became a friend) however in the odd case where this occurred, the answer that was chosen was the initial relationship. It is worth highlighting the fact that codes 8 and 9 may overlap and we suspect that there will be respondents who now consider their neighbours as friends, possibly as a result of the care that has been provided.

Final Recommendations for Q65a

Our recommendation is to retain this question as it is currently worded.

8.5 Age of those cared for (Q65b)

The age of person cared for question was unchanged between rounds and, like the others in this module, was looped for up to three people.

{If Q61=1 AND Q62=1 OR MORE THIS QUESTION IS IN A LOOP FOR UPTO THREE PEOPLE}

Q65b

How old is {1ST/2ND/3RD PERSON'S NAME}?

Findings

In rounds one and two all respondents were happy to provide the ages of those they cared. If respondents could not provide the exact age, they were able to offer a good guess (for example one respondent in round 2 said “around 80-93”). All ages that were given at this question were 65 and over, verifying that the screening questions earlier in the module worked as intended.

Final Recommendations for Q65b

Our recommendation is to retain this question as it is currently worded.

8.6 Activities or tasks provider helps or supports with (Q66)

The list of tasks at Q66 evolved in parallel with the list of tasks in the receipt of care module (referred to in this report as Q1 & Q2 – items a-o). Here the respondent who provides care is asked to list the activities they help the person/people that they care for with. As a result of findings from testing these items in the receipt module in round 1, a clarification was added to the question stem and the order of the items on the card was changed. Additionally some of the items were revised. The table below shows the order of answer codes presented on the showcard in round 1 (column on the left) and then round 2 (column on the right). Again, the text in red and underlined shows additions or changes which were made for round 2.

{IF Q61=1 AND Q62=1 OR MORE. THIS QUESTION IS IN A LOOP FOR UP TO THREE PEOPLE}

SHOWCARD M

Q66

Which of the following activities do you help or support [1st/2nd/3rd PERSON'S NAME] with? Please think only of help or support given because of long-term physical or mental ill-health, disability or problems relating to old age.

CODE ALL THAT APPLY

ROUND ONE	ROUND TWO
1. Shopping for food	1. Getting the person in and out of bed
2. Preparing hot meals	2. Washing their face and hands
3. Doing routine housework or cleaning	3. Having a bath or shower, including getting in and out of the bath or shower
4. Doing laundry	4. Dressing or undressing, including putting on shoes and socks
5. Getting the person in and out of bed	
6. Washing their face and hands	

<ul style="list-style-type: none"> 7. Having a bath or shower, including getting in and out of the bath or shower 8. Dressing or undressing, including putting on shoes and socks 9. Using the toilet 10. Eating, including cutting up food 11. Taking the right amount of medicine at the right times 12. Getting around indoors 13. Getting up and down stairs 14. Going out, for example getting out of the house to go to the shops or visit a friend 15. Doing paperwork or bills 16. Other 	<ul style="list-style-type: none"> 5. Using the toilet <u>(for example getting to the toilet and using it)</u> 6. Eating, including cutting up food 7. Taking the right amount of medicine at the right times 8. Getting around indoors 9. Getting up and down stairs 10. Going out, for example getting out of the house to go <u>to the doctors</u> or visit a friend 11. Shopping for food <u>(for example getting to the shops, choosing the items, carrying the items home and then unpacking and putting the items away)</u> 12. Preparing hot meals 13. Doing routine housework or cleaning 14. Doing laundry <u>(including loading and unloading the washing machine, putting clothes out to dry and ironing)</u> 17. Doing paperwork or bills 15. Other
--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Findings

When the question was tested in round 1, several problems were aired during the cognitive interviews with providers of care. There was some evidence to suggest that respondents answered the question, and therefore choosing items from the list, thinking about mutual support and the division of labour within their partnerships/households (i.e. all part and parcel of being in a partnership). For round 2 the clarification 'Please think only of help or support given because of long-term physical or mental ill-health, disability or problems relating to old age' was added. Although we can only present findings from a small purposively selected sample, and cannot guarantee that the clarification has solved this problem, there was no evidence of the mutual support and division of labour kind of help in round 2.

The other problems round 1 shed light on related to four of the activities on the list. As shown in the table above, the four items were revised for round 2 as a result of the identification of these problems or issues. We describe the nature of the problems and what we did to resolve them below but first, it is worth noting an interesting finding from round 2. There was evidence in round 2 of respondents including tasks they always do, sometimes or occasionally do, as well as those the carer usually does but the respondent might 'step in' and do if the carer is not there when it needs to be done.

Shopping for food

A broad interpretation of 'shopping for food' in round 1, which included all of the different elements of a food shop, led us to revise this activity for round 2 to clarify what should be included here (namely getting to the shops, choosing the items, carrying the items home and then unpacking and putting the items away). In round 2 there was evidence of

respondents thinking about doing the shopping for someone as well as helping them with it (i.e. it captured the whole spectrum of the parts of the process).

Using the toilet

In round 1 'using the toilet' included taking the person to the toilet so this was added for round 2.

Going out for example, for example getting out of the house...

Cognitive interview respondents in round 1 thought about a wide range of outings such as driving someone around, taking the person for walks to give them fresh air to make them feel better, taking the person in the car to visit friends or relatives and taking the person to an appointment such as to the doctors or the dentist. As a result of a recommendation made after round 1 in the receipt of care module, a decision was made to replace the 'shops' with 'going to a doctor's'. This would also avoid overlap with the shopping activity. Round 2 respondents thought about taking someone out, to a funeral and to a doctor's or hospital appointment.

Doing laundry

Although there was no evidence from cognitive interviews at round 1, recommendations were made in the receipt of care module (following round 1) to add clarification of what should be included here – i.e. the whole spectrum of the process. The clarification was added to the laundry task here for round 2.

From both rounds of testing there were various issues that arose which we feel are worth pointing out here as some have implications for interpreting the results.

Taking the right amount of medicine at the right times

Care should be taken when interpreting this code during analysis as there was some evidence (although it was not entirely clear because of the lack of detail in some of the interviewers' notes) to suggest that reminding someone to take their medicine, and not necessarily administering it, is being counted here. There were respondents in round 2 who thought solely about contributing towards this task which was the responsibility of the carer. One respondent, for example, prepares the medicine for the carer so they know which medicine relates to which day. In this particular case, the carer actually administers the medicine.

Getting around in doors

Although we do not have a task which specifically states moving someone, and this is often a task which is used in indexes of disability, evidence from round 1 informed us that respondents were thinking about moving someone from their chair to another room as well as leading the person by their arm around the house and ensuring there are no obstacles in their way.

Preparing hot meals

Evidence from round 1 highlighted whether occasional meals that are cooked for someone, or taking over a take away to the person's house, should be included here.

Other

Respondents interviewed in round 1 included gardening, changing plugs and taking someone to the doctors (which we hope would now be included at new code 10: Getting out), at 'Other' and in round 2, cutting finger nails, washing someone's hair, providing company to someone, rubbing steroid cream into someone's back each day and other routine maintenance tasks were reported here.

Final Recommendations for Q66

Our recommendation is to retain this question as it is currently worded with the new wording used in round 2 and revised list of activities and tasks.

8.7 Remote help (RemoteP) and frequency of remote contact (RemOffP)

Two questions were added to round 2 for two main reasons. Firstly to reflect these types of remote help in the questionnaire, which were felt to have been omitted in the development for round 1 but would be important to cover in a question module about care provision. The second reason was to make it clear to respondents that remote help should be excluded from the questions which follow. Notably the hours of care provided question.

ROUND 2 QUESTION (ADDED FOR ROUND 2)

{THIS QUESTION IS IN A LOOP FOR UPTO TWO PEOPLE}

SHOWCARD V

RemoteP

Do you help [NAME OF PERSON] in any of the ways shown on this card?

CODE ALL THAT APPLY

1. I phone him/her every day or every other day
2. I'm available to phone for help during day
3. I'm available to phone for help during night
4. I'm available to email for help
5. I order shopping/ meals over the internet to be delivered to him/her
6. I make phone calls on his/her behalf e.g. to make doctors appointments, to arrange for repair / service of boiler etc.
7. None of these

ROUND 2 QUESTION (ADDED FOR ROUND 2)

{THIS QUESTION IS IN A LOOP FOR UPTO TWO PEOPLE}

SHOWCARD H

RemOffP

How often are you in contact with [NAME OF PERSON] by phone or email?

1. More than once a day
2. Once a day/ everyday
3. Three to five times a week
4. Once or twice a week
5. Once a fortnight
6. Once a month
7. Less often than once a month
8. Never

Findings (from round 2 testing only)

Remote help (RemoteP)

Respondents did not raise any major concerns with this question and were, on the whole, able to answer it and choose items from the list which best applied to their circumstances. There were a number of issues with some of the answer codes which we feel are important to note.

I'm available to phone for help during day (code 2)

Using an intercom within the same house as the person cared for was included here.

I'm available to phone for help during night (code 3)

This code caused confusion where a respondent considered that they were available to be phoned during the night but wondered whether the person they care for was aware of this.. This query raises the question of whether the remote help is from the perception of the provider and/or from the person cared for.

I order shopping/ meals over the internet to be delivered to him/her (code 5)

Ordering food over the phone was mentioned and included here, despite the omission in the answer category.

Frequency of remote contact (RemOffP)

Round two testing identified a number of issues with this question:

- It could give an unrealistic representation of intensity of contact if a respondent providing 'in person' care to somebody everyday, but only actually phones the person once or twice a week, chooses code 2 (once a day/ever day) probably as a result of confusing this type of help with the in person help.
- This question can seem a little odd to be asked if the provider of care lives in the same household as the person that they care for: "*I'm living with him 24/7. It's silly because the person I am caring for I live with*". (Female, caring for her husband).

Final Recommendations for RemoteP and RemOffP

Based on findings from testing equivalent questions in the receipt of care module which did not combine well and caused problems, we recommend here that these questions are dropped. As the version of Q67 which was used in round 2 specifies that the respondent should think only about the tasks and activities which have been asked about (i.e. the list at Q66), there should now be a focus on in-person active help, which was not necessarily achieved in the original version of Q67. See the discussion below.

8.8 Hours of provision (Q67i, Q67, Q68 and Q68b)

It was felt to be important to collect an equivalent measure of intensity of care to that collected in the receipt of care module and therefore a question was designed to ask respondents how many hours they helped the person in the last week (Q67). As a result of findings from cognitive interviews in round 1, in the receipt of care module, a new question was added for round 2 which aimed to deal with 'on-call' time the carer has to be around in case the person needs help (Q67i). The intention was that respondents would answer Q67i thinking about all of the time (in the last week) that they had to be there but were not necessarily helping with tasks, and then hours reported at Q67 would solely represent hours helped with tasks and activities. The first table below shows the questions which were used in the two rounds, with the round 1 question in the left hand column and the new question (Q67i), as well as the revised original hours question (Q67), in the right hand column. Below we show two versions of a question (Q68) that is asked if the respondent refuses or says they don't know at Q67. We also show the question (Q68b) that is asked, and was the same wording in both rounds, if the respondent reports no help in the last week. Again red and underlined text has been used to show newly added words and/or questions but in this case, the whole approach was changed.

<p><i>{THIS QUESTION IS IN A LOOP FOR UPTO THREE PEOPLE}</i></p> <p>Q67.</p> <p>Now thinking about the last week, that is from last Monday to the Sunday just gone. How many hours did you help [1ST/2ND/3RD PERSON'S NAME] last week?</p> <p>SHOWCARD G</p> <ol style="list-style-type: none"> 1. No help in the last week 2. Less than one hour 3. 1-4 hours 4. 5-9 hours 5. 10-19 hours 6. 20-34 hours 7. 35-49 hours 8. 50 hours or more 9. 24 hours a day, 7 days a week 	<p><u><i>{THIS QUESTION IS IN A LOOP FOR UPTO TWO PEOPLE}</i></u></p> <p><u>SHOWCARD W</u></p> <p><u>Q67i.</u></p> <p><u>Thinking only about help received in person (not by phone or internet). In the last week, that is from last Monday to the Sunday just gone, how many hours did you help [NAME OF PERSON] last week? By this I mean time you had to be with him/her in case he/she needed help?</u></p> <p><u>INTERVIEWER: Watch out for answers giving a daily amount. If you think the answer may be a daily amount ask 'So that is xxx hours in the last week?' and allow respondent to change answer."</u></p> <ol style="list-style-type: none"> 1. <u>No help in the last week</u> 2. <u>Less than one hour</u> 3. <u>1-4 hours</u> 4. <u>5-9 hours</u> 5. <u>10-19 hours</u> 6. <u>20-34 hours</u> 7. <u>35-49 hours</u> 8. <u>50-99 hours</u> 9. <u>100 hours or more</u> <p><u>ROUND 2 QUESTION (ADDED FOR ROUND 2)</u></p> <p><u><i>{THIS QUESTION IS IN A LOOP FOR UPTO TWO PEOPLE}</i></u></p> <p><u>SHOWCARD W</u></p>
---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

	<p><u>{If Q61=1 AND Q62=1 OR MORE. THIS QUESTION IS IN A LOOP FOR UPTO TWO PEOPLE}</u></p> <p><u>Q67.</u></p> <p><u>Now thinking about just these types of tasks and activities I have been asking you about, how many hours did you spend helping {NAME of PERSON} with those in the last week?</u></p> <ol style="list-style-type: none"> 1. <u>No help in the last week</u> 2. <u>Less than one hour</u> 3. <u>1-4 hours</u> 4. <u>5-9 hours</u> 5. <u>10-19 hours</u> 6. <u>20-34 hours</u> 7. <u>35-49 hours</u> 8. <u>50-99 hours</u> 9. <u>100 hours or more</u>
--	-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

<p><u>{If Q67= don't know or refusal THIS QUESTION IS IN A LOOP FOR UPTO THREE PEOPLE}</u></p> <p>Q68. Can you tell me whether in the last week you helped [1ST/2ND/3RD PERSON'S NAME] for: READ OUT....</p> <ol style="list-style-type: none"> 1. Less than 20 hours 2. 20-34 hours 3. Or for 35 hours or more? 	<p><u>ROUND 2 QUESTION (ADDED FOR ROUND 2)</u></p> <p><u>{If Q67= don't know or refusal THIS QUESTION IS IN A LOOP FOR UPTO TWO PEOPLE}</u></p> <p><u>Q68.</u> Thinking of the same type of help you give {NAME OF PERSON BEING CARED FOR} can you tell me whether in the last week you helped [NAME OF PERSON]:....READ OUT....</p> <ol style="list-style-type: none"> 1. <u>Less than 20 hours</u> 2. <u>20-34 hours</u> 3. <u>Or for 35 hours or more?</u>
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

<p><u>{If Q67= 1 (no help in the last week) THIS QUESTION IS IN A LOOP FOR UPTO THREE PEOPLE}</u></p> <p><u>SHOWCARD N</u></p> <p>Q68b. How many hours do you help [1ST/2ND/3RD PERSON'S NAME] in an average week?</p> <ol style="list-style-type: none"> 1. <u>Less than one hour per week</u> 2. <u>1-4 hours per week</u> 3. <u>5-9 hours per week</u> 4. <u>10-19 hours per week</u> 5. <u>20-34 hours per week</u> 6. <u>35-49 hours per week</u> 7. <u>50 hours or more per week</u> 8. <u>100 hours or more per week</u>

Findings

On-hand vs. Active help (Q67i and Q67)

When the original question (shown in the left hand column of the table above) was tested with respondents in round 1, there were difficulties which arose for certain kinds of respondents, notably respondents who:

- helped or supported someone but it was not their sole activity, for example they also work;
- helped or supported someone who also had a carer/carers and therefore the level of input from the respondent would vary;
- were thinking about mutual support and/or the division of labour (discussed earlier in this report) and therefore found this question pointless to be asked; and,
- live with the person that they care for. One respondent for example found this difficult to answer, chose '50 hours or more' but said he helps his wife most of the time. This respondent said he was 'on call' for her 24/7 but in-between helping her, he did his own thing (hence why he did not answer 24 hours a day, 7 days a week).

The addition of the new question (Q67i) for round 2, which was asked before Q67 to weed out time the provider was there but not actively helping, did not work. Q67 tended to be easier to answer as it was more specific than Q67i, which was perceived as vague and problematic as we will now discuss.

There were two main kinds of respondents who found Q67i confusing and especially difficult to answer:

- Those who lived and cared for their spouse, i.e. they are always there but not because they *have* to be; and,
- Those who often spent time in the cared for person's company for social reasons, either because they were a friend or because they wanted to provide the person with company (they are there socially, for example to have a cup of tea). One R said this was a "*grey area*" and that it was just a matter of being there for somebody, thinking purely about the companionship aspect.

Findings from cognitive interviews in round 2 provide evidence that the wording 'had to be there in case they needed help' does not make sense in the context of informal care, a friend visiting a friend for example. One respondent said she never feels like she is there because she *has* to be.

There was variety in how respondents tackled the two (new) questions in round 2 and consequently time reported at Q67i was either more than time reported at Q67 (which you would expect), it was the same amount of time or less time was reported at Q67 (for example one respondent reported fewer hours at Q67 and commented that she did not count the social aspect). There were respondents who did not hear the difference between the two questions and as a result failed to differentiate between 'on-hand help' and 'active help'. As in round 1, respondents who lived with the person they cared for occasionally found the two questions difficult.

Finally a mistake was noted in the question wording for round 2. The question should read 'thinking only about help *provided* in person', not *received*.

Banded version of active help question (Q68)

Very few respondents were asked this question and as a result very little can be said about its performance.

Hours help in an average week (Q68b)

Very few respondents were asked this question (which was only asked for those who provided no help in the last week) and as a result very little can be said about its performance.

Final Recommendations for Q67i, Q67, Q68 and Q68b

Round two clearly showed that the addition of a question about 'on-hand' help (Q67i) introduces problems and we therefore strongly advise that 'on-hand' help is dropped. We feel that retaining Q67 and asking it alone will work well. We are confident that the revised question, which now refers to the tasks which have been asked about previously, will focus respondents to think only about 'active help' that they provide. The first time this question is included in a field pilot, a respondent de-briefing question could be included as a means on checking, on a much larger scale than could ever be achieved in round of cognitive interviews, what type of 'help' is being counted in reports of hours.

If a decision is made to drop Q67i and retain Q67 as it is currently worded, which is our suggestion, consideration needs to be given to the importance of social contact and support as a form of social care. There were respondents, especially in round 2, who mentioned this type of help.

We recommend that Q68 and Q68b are retained as they are currently both worded, along with Q67. If the intensity of care given is used in the rules for which people are looped for the rest of this module, these questions may have to come earlier.

To be consistent with the receipt section where, if not care is received in the last week, no further information is gathered, Q68b could be dropped to shorten the module.

Also, with reference to the recommendation for Q73, Q67 could be adjusted to ask about all people who the respondent provides cares for rather than asking about each recipient individually.

8.9 Receipt of money for the help provided (Q69)

It was felt to be important to collect data on whether the respondent receives any payment for the help or support that they provide. Informal carers can be employed by the person being cared for, and paid through the direct payment and/or personal budget, or they can be paid via other sources. A question was included (Q69) which remained unchanged for the round 2 to ascertain this data. An additional question was then asked if a positive response is given at Q69. For round 1 the amount (i.e. Q70) was collected in the form of an open question but for round 2 an unprompted code frame was devised. The additional interviewer instruction and code frame used in the question at round 2 is shown in red text, underlined, in the box below. As far as the respondent was aware, Q70 remained the same in round 1 and 2.

***{If Q61=1 AND Q62=1 OR MORE. THIS QUESTION IS IN A LOOP FOR UPTO THREE PEOPLE}
SHOWCARD O***

Q69. Do you receive any money for helping [1ST/2ND/3RD PERSON'S NAME]?

CODE ALL THAT APPLY

1. Yes, this person pays me from their own income, pensions or savings
2. Yes, the person pays me from a personal budget or direct payment
3. Yes, I receive a carer's allowance
4. Yes, I receive money in another way
5. No, I receive no money for helping this person.

{IF Q69=1,2,3 or 4}

Q70.

How much do you receive?

INTERVIEWER: RECORD AMOUNT AND REFERENCE PERIOD GIVEN BY RESPONDENT.

OPEN RESPONSE: _____

INTERVIEWER: ENTER REFERENCE PERIOD FOR THE PAYMENT

1. Per visit
2. Per day
3. Per week
4. Per fortnight
5. Per four weeks
6. Per calendar month
7. Per year

Findings

There were few respondents who answered yes at Q69, in both rounds, so little can be said with regards to whether the answer codes cover the range of ways in which a person could receive money. Although there were respondents who correctly excluded gifts and one off amounts of money, there was evidence (in round 2) of the inclusion of very irregular payments at Q69. There were also respondents (in round 2) who possibly should (depending on the measurement aims) have reported the irregular amounts of money they had received for petrol and rail tickets but did not include these forms of payments.

Respondents who did not receive any money and therefore answered NO, in both rounds of testing, faced no major problems when answering this question. Although the question did not cause any offence, there were respondents who were either caring for their spouses or caring for other relatives that they would never expect to be paid for the support they provided and they would not dream of taking any money from a family member or friend.

Very little can be said with regards to how able respondents would answer Q70 as just one respondent in each round answered the question. There was a respondent from round 1, who cared for his father. He was unable to provide an exact figure because the care he provided varied too much. A female caring for her mother, in round 2, could not provide an amount and a reference period at Q70 as her mother gives her irregular, or “occasional”, amounts of money and gifts.

Final Recommendations for Q69 and Q70

If these questions are to be retained, there needs to be some clarification added to deal with occasional or irregular amounts of money. The addition of the clarification about occasional payments which was included in the payments section of the receipt module could be incorporated here: “INTERVIEWER: DO NOT INCLUDE GIFTS, TREATS OR OCCASIONAL PAYMENTS OF EXPENSES SUCH AS PETROL MONEY OR LUNCH.”

An additional code should be added to Q70: ‘per hour’.

When it is first introduced into a pilot, it would be worth gaining feedback from interviewers around how these two questions work in practice.

8.10 Support received for caring (Q71)

A question was included in the module to ascertain whether the person providing care (i.e. the respondent) receives any support as a result of their caring responsibilities. As a result of a problem which arose in the cognitive interviews in round 1, a clarification was added to the question stem for round 2. This can be seen in red underlined text in the box below.

<p>{If Q61=1 AND Q62=1 OR MORE. THIS QUESTION IS IN A LOOP FOR UPTO THREE PEOPLE}</p> <p>SHOWCARD P</p> <p>Q71. Do you receive any of these types of support in caring for [1ST/2ND/3RD PERSON'S NAME]? <u>Please think only about help or support given directly to you.</u></p> <p>CODE ALL THAT APPLY</p> <ol style="list-style-type: none">1. Help from GP or nurse2. Access to respite care3. Help from professional care staff4. Help from carer's organisation or charity5. Help from other family members6. Advice from local authority/ social services7. Help from friends/neighbours8. No, I don't receive any of these

Findings

When this question was tested in round 1, respondents thought about physically receiving help from others to assist in caring for the older person, for example carers and/or other family members (as opposed to thinking about support they received personally as a result of the help or support they gave). Even with the clarification added to round 2, there was evidence of respondents answering about help the care recipient receives, not help they personally receive. This is clearly a grey area, especially given that some of the answer codes could be seen as external input which could benefit both parties.

Final Recommendations for Q71

The placement of this question requires some thought. One idea is to move it so that it is asked up-front, or at least with some other questions about the respondent. The current location of this question muddles it with questions about the cared for person and it is clearly too difficult for respondents (i.e. 'carers') to think about themselves when they are being questioned about somebody else. One interviewer suggested asking Q72 before Q71 so that you collect the help for the cared for person and then ask about help/support received by the carer. This question could be cut in a short module of questions.

8.11 Whether person cared for receives support (Q72)

This question remained the same for both rounds and was used as a means of collecting information about (other) support received by the person being cared.

{If Q61=1 AND Q62=1 OR MORE. THIS QUESTION IS IN A LOOP FOR UPTO THREE PEOPLE}

SHOWCARD Q

Q72. Does [1ST/2ND/3RD PERSON'S NAME] receive any of these types of support?

CODE ALL THAT APPLY

This person:

1. Attends a day centre or lunch club
2. Receives help from professional care staff (e.g. home help/care worker)
3. Receives meals on wheels
4. Receives help from a Nurse or Health Visitor
5. Lives in sheltered or very sheltered housing
6. No, none of these

Findings

There was very little cognitive interview data that could be used to assess how this question worked from round 1. However the round 2 cognitive interviews can be used to shed some light on its performance. The question was understood as intended and there were no problems with lack of knowledge. There were a few issues aired relating to the answer codes. At code 2, professional care from a support group especially for people with disability was included, whilst a private home help was excluded on the basis that they had not come through the council. There was uncertainty around whether a Physiotherapist would be included at code 4 (incidentally it was excluded) and there was one option which was felt to be missing from the list: A volunteering service which provides a car to get to the hospital.

Final Recommendations for Q72

We suggest that this question is retained as it is currently worded, with the addition of a category for 'Other types of support'. This question could be cut in a short module of questions.

8.12 Total time spent caring for all people, aged 65 or over, cared for (Q73)

A question was designed to collect reports on the total time spent caring for all people aged 65 and over. The question changed between rounds but all that was changed was the answer code frame (codes 7 and 8) and the routing instructions (question only asked if more than one person is cared for).

<p>{ASK ONCE} {If Q61=1 AND Q62=1 OR MORE} SHOWCARD N Q73.Thinking about the total time you spend providing support or help to all of the people aged 65 or over that you care for, about how many hours altogether do you spend each week looking after or helping them?</p> <ol style="list-style-type: none">1. Less than one hour per week2. 1-4 hours per week3. 5-9 hours per week4. 10-19 hours per week5. 20-34 hours per week6. 35-49 hours per week7. 50 hours or more per week8. 24 hours a day, 7 days a week	<p><u>{ASK ONCE IF Q62=2 OR MORE -NOT IN LOOP}</u> <u>SHOWCARD X</u> <u>Q73.</u> <u>Thinking about the total time you spend providing support or help to all of the people aged 65 or over that you care for, about how many hours altogether do you spend in an average week looking after or helping them?</u></p> <ol style="list-style-type: none">1. <u>Less than one hour per week</u>2. <u>1-4 hour per week</u>3. <u>5-9 hours per week</u>4. <u>10-19 hours per week</u>5. <u>20-34 hours per week</u>6. <u>35-49 hours per week</u>7. <u>50-99 hours per week</u>8. <u>100 hours or more per week</u>
------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

Findings

During both rounds of testing a number of problems with this question were identified. Firstly, there were respondents who reported the same amount of time they had at Q67, but this was not universal. Secondly, and this problem was exclusive to round 1, this question was unsurprisingly difficult to answer for respondent's who had (for the whole question module) been thinking in terms of mutual support and the division of labour between themselves and their spouses. Finally, as with Q67, this question could be difficult to answer if the respondent lived with, and was the partner of the person they helped or supported. Additionally, from round 2 only, there was evidence of rough estimates and averaging over a month and also of respondents only thinking about the time they spend with one person, and not the others/the rest.

Final Recommendations for Q73

As this question stands, it does not necessarily collect accurate data on the total number of hours spent caring and therefore this raises a question over whether it should be asked at all. Our recommendation is to drop this question and use the current Q67, which could instead be asked for all cared for (aged 65 and over) as a means of collecting total time spent caring, rather than asking for each person cared for individually.

8.13 Health effects of caring (Q74 and Q75)

This question was included, and kept the same for both rounds, as a means of identifying a number of health related problems which arise as a result of care that people give.

{ASK ONCE}

{ASK ALL WHO CARE FOR SOMEONE AGED 65 AND OVER: Q61=1 AND Q62=1 OR MORE}

SHOWCARD R

Q74. In the **last three months**, has your own health been affected, in any of the ways listed on this card, by the help or support that you give the [person/people] aged 65 or over that you care for?

CODE ALL THAT APPLY

- 1 Feeling tired
- 2 Feeling depressed
- 3 Loss of appetite
- 4 Disturbed sleep
- 5 General feeling of stress
- 6 Physical strain
- 7 Short tempered
- 9 Developed my own health condition
- 10 Made an existing condition worse
- 11 Other
- 12 No, none of these

{If Q74=1 -11}

Q75: Have you seen your GP due to your health being affected?

1. Yes
2. No

Findings

On the whole this question appears to work quite well and was straightforward and easy enough to answer. In round 1 there were respondents who were unable or experience difficulty providing an answer at this question because they struggled to distinguish between the effects of caring and other external influences such as work-related stress, stress incurred from caring for others and the stress and upset some bad news in the family had caused. The round 1 interviews also highlighted that this question may be sensitive to ask in the presence of other household members, especially if they are the people receiving care. One interviewer, for example, decided to skip this question on the basis that she felt her respondent was very tense in the presence of her husband who she cared, and there was another respondent who was reluctant to say that his answers (feeling tired and general feeling of stress) were a result of caring for his wife. The wife

was present and said she would answer this question honestly as she had seen how the effects of caring for her had taken their toll on his health.

When this question was tested again in round 2, no major additional problems were revealed. Interestingly, one respondent chose 'Other' for feeling upset and sad because of the loneliness of their (people she cares for) lives. She chose not to count this under code 2, though questioned whether she should have done.

Final Recommendations for Q74 and Q75

We recommend that this question is retained as it is currently worded but that recommendations made at round 1, which by omission were not implemented, are taken on board if programming allows them to be.

IF Q61=1

In the **last three months**, has your own health been affected, in any of the ways listed on this card, by the help or support that you give to **[INSERT NAME]**?

IF Q61=2 OR MORE

In the **last three months**, has your own health been affected, in any of the ways listed on this card, by the help or support that you give **the people** aged 65 or over that you care for?

We also suggest that Q75 is revised based on recommendations made at round 1, but unfortunately omitted for round 2:

IF Q61=1

'Have you seen your GP due to your health being affected by the support you give to **[INSERT NAME]**?'

IF Q61=2 OR MORE

'Have you seen your GP due to your health being affected by the support you give to the people aged 65 or over that you care for?'

These questions could be cut from a short version of the module.

8.14 Affect of caring on ability to stay in employment (Q76)

The following question was included in both rounds using the same wording (i.e. it did not change between rounds). The question was designed to be asked of respondents who were aged 64 or under.

{ASK IF 64 OR UNDER AND CARE FOR SOMEONE AGED 65 OR OVER: Q61=1 AND Q62=1 OR MORE}

SHOWCARD S

Q76. Has your ability to take up or stay in employment been affected, in any of the ways listed on this card, by the help or support that you give the [person/people] aged 65 or over that you care for?

CODE ALL THAT APPLY

1. Left employment altogether
2. Took new job
3. Worked fewer hours
4. Reduced responsibility at work
5. Flexible employment agreed
6. Changed to work at home
7. Other
8. No, employment not affected

Findings

As very few respondents in both of the rounds were asked this, we are limited in what we can report with regards to the question's performance. No specific problems were noted however it was felt to be missing an answer category for 'retired'.

Final Recommendations for Q76

It is our recommendation that this question is retained as it is currently worded, with the addition of an extra answer category for 'retired'. However it could be cut from a short version of the module.

8.15 Whether received a carer's assessment (Q77)

Q77 was included in both rounds and no changes were made to it between rounds.

{ASK ALL WHO CARE FOR SOMEONE: Q61=1 AND Q62=1 OR MORE}

Q77. Have the Local Authority (council) carried out a carer's assessment as a result of the help or support that you provide to this [person/people] aged 65 or over?

1. Yes
2. No
3. Don't know

Findings

In both rounds of testing there were respondents who were unaware or had not heard of a carer's assessment. Occasionally a respondent commented that they could imagine what a carer's assessment would entail: someone to come along and ask the carer what they can and can't do and what help they might need (as one female, aged 60-64 put it). The question seemed to work as those who knew they had not received a carer's assessment answered NO and those who had received an assessment know so and answered YES.

Final Recommendations for Q77

It is our recommendation that this question is retained as it is currently worded.

9 Shortening the questionnaire

The experience of the cognitive testing and subsequent in house testing of the questionnaire without probing has revealed that it is too long. Interviews for receivers of care (moderate and heavy users) took 28 and 35 minutes respectively, running through the questionnaire with no probing. Obviously the average length will be much shorter as many respondents will only be asked Q1 and Q2. However it should be noted that Q1 and Q2 together took 7 to 9 minutes to administer (on a run through in the office). In addition, for surveys such as HSE and ELSA when considering questionnaire length, it is not just average length which matters but also maximum length.

The timings in the table below only come from practice runs in the office but demonstrate that the module is too long and needs significant cuts for inclusion in survey questionnaires.

Table 9 Questionnaire length on run through in office

Section	Time (hh:mm:ss)	
	Heavy user/ receiver	Moderate user
Q1 and Q2	00:09:09	00:07:52
Q3a and Q3b	00:06:48	00:07:38
Homehelp and Q4	00:02:47	00:00:56
Q3d	00:00:50	00:01:05
A3 - pattern of help	00:07:09	00:06:02
A5 - Services	00:01:18	00:01:46
A4 -Payments - Formal	00:03:56	00:02:45
A4 -Payments - Informal	00:00:56	00:00:30
A6 - Equipment	00:02:03	00:01:56
B: Provider questions	00:00:31	00:00:29
TOTAL DURATION	00:35:27	00:28:59

There are a number of ways that we feel the module could be shortened. For example, it could be possible to:

1. Cut down the number of tasks asked about at Q1 and Q2 from 15, after consideration is given to what tasks are specifically needed to inform the various indices of interest in this area. This method of shortening the questionnaire can only be done for the questionnaire as a whole and cannot be used to create a short module because of comparability problems.
2. Drop Question 1 about need. This is not an ideal situation, because there is an interest for information on unmet need but as shown above Q1 and Q2 together take 7-8 minutes. There will also be potential issues with comparability if Q1 is included only in a long version of the module.
3. Not ask about payments for informal providers providing less than 20 hours a week.
4. Drop Q10i and Q10j about time when provider 'had' to be around and instead focus on hours of help with tasks (Q10).

5. Drop questions about remote help in receipt and provider section.
6. Drop Q16 and Q18 in payments section.
7. Drop Q67i about provision of help when provider 'had' to be there.
8. Drop Q73 about total time spent helping all people helped and instead cover with an amended Q67.

Possible questions which could be removed from a short module are:

- Q1 entirely (on help with tasks needed) but we would advise retaining Q2 on help received. However, retaining Q1 on the long module as mentioned above raise issues of comparability. It may be sensible to drop this question completely therefore.
- Questions on pattern of care receipt (Q6, Q7, Q8, Q9).
- Questions on services (meals on wheels, day centres etc).
- Aids and equipment section (except alarms) – or drop from long module too.
- Questions on amounts of payments (Q12 and associated questions, and Q15 and associated questions).
- Impacts of caring on providers and support received (Q71, Q72, Q74, Q75, Q76, Q77).

In order to reduce the 'long' version of the module to an acceptable length some of the suggestions for cuts to create a short module may need to be taken up even for the long module.

The questionnaire can also be made more acceptable, simpler for respondents and shorter by only asking certain questions where really relevant – e.g. some frequency questions only apply to formal providers, and only ask Q14 where relevant. Where cuts can be made this way, they are indicated in the relevant section of the report. The problem with this questionnaire structure is that it assumes answers/ relevance for certain types of provider. This would need to be made very clear in analysis.

Technical Appendix

This appendix describes in further detail the design and conduct of the cognitive testing.

Study Design

This project was designed to test the new questions in a CAPI interview. The questions measure different aspects of receipt and provision of social care for people aged 65 or over. Two rounds of cognitive testing were conducted, testing questions developed by the QDT Hub in consultation with academic colleagues. Thirty face-to-face cognitive interviews were conducted in round 1 and twenty-six interviews in round 2. In round 1 the interviewers used a paper questionnaire and in round 2 the interviewers administered a computer assisted personal interview (CAPI). The CAPI was administered in round 2 to replicate how the questions would actually be administered in a real survey.

Cognitive Methods

Cognitive interviewing methods, which are derived from cognitive psychology, enable researchers to examine (in great detail) the question and answer process. This form of testing helps to identify problems with questions and also helps to illuminate possible solutions to these problems. Cognitive interviewing techniques focus on four main processes:

- how respondents understand and interpret questions;
- how respondents recall the information required to answer questions;
- the judgements respondents make as to what information to use when formulating their answers; and
- how respondents respond to the questions.

The two most frequently used cognitive interviewing techniques are think aloud and probing. In this study both techniques were used. In the think aloud technique, respondents are asked to verbally communicate their thoughts as answer the question. For example, respondents are encouraged to articulate the question meaning, specify information drawn to answer the question and state the decisions made in providing their (final) answer to the question

In the probing technique the interviewer asks specific questions which provide information on how respondents interpret question wording and what processes they go through when deciding how to answer. The probes used are partly pre-scripted and provide a guide to the topics covered in the cognitive interview. However, as cognitive interviews are qualitative in nature, interviewers also have the freedom to probe on an issue that may be unique to the respondent that may not have been foreseen in advance. Probing was carried out concurrently, once the respondent had answered one or a number of survey questions. A copy of the test questionnaire and probes used can be found in Appendix B.

Sample and Recruitment

Cognitive interviews are qualitative in nature and so the samples are purposive and designed to reflect the range and diversity of the population of interest, rather than to be statistically representative. For both rounds of testing we recruited three types of respondents (shown below).

Type 1: Were people aged 65 or over who received social care either from a formal provider, informal carer or both; and or,

Type 2: Informal carers aged 18 or over who provide care to someone aged 65+; or,

Type 3: Were people aged 65 or over who neither received nor provided care to someone aged 65 or over.

In total fifty-six interviews were conducted for this project, thirty interviews in round 1 and twenty-six interviews in round 2.

For round 1, we recruited respondents who had taken part in the Health Survey for England in 2005 and agreed to be re-contacted to take part in future research. For round 2, we wanted to recruit sufficient respondents who had received direct payments or personal budgets (also known as individual budgets) to pay for the social care they had received. We therefore adopted four recruitment strategies for this round of testing.

1. We contacted individuals who are currently taking part in the English Longitudinal Survey for Ageing (ELSA) and had given their permission to be contacted again.
2. We advertised this study with the help of Local Authorities and Age Concern and asked anyone interested in the study to contact the research team.
3. We asked interviewers to help with advertising the study in their areas and ask anyone interested in the study to contact the research team.
4. We contacted respondents who took part in the Health Survey for England in 2005 and who had not been contacted in round 1 because quotas had already been met.

An opt out letter was sent to everyone identified in the ELSA sample and the HSE sample who were considered suitable to take part in the study. Recipients of the letter were asked to contact the research team to say they were not interested in taking part.

Irrespective of which recruitment strategy was used, all prospective respondents were screened in the study using a telephone screening questionnaire to identify suitable respondents. Suitable respondents were those who fitted our quotas to reflect the range and diversity of the population of interest.

To help us to achieve a diverse sample in each round, quotas were designed to allow the questions to be tested on all relevant groups. Quotas were interlocked to ensure that respondents with specific combinations of characteristics were included. So in round 1, we included men and women in three different age groups who received care and two different age groups who provided care informally (see Quota Tables on the next page). In round 2, we included two types of receivers of care, those who receive informal care and those who receive formal home help such as support from a personal assistant or home care worker; as well as the two types of providers of care that we tested the questions on in round 1 (see Quota Tables). The tables below illustrate the quotas used in both rounds and the number of respondents we aspired to recruit in these quotas.

Quota Tables for round 1 Cognitive Testing

	Type 1: Receivers of Care		
Age Group/Gender	65-74	75-84	85+
Men	4	4	4
Women	4	4	4
Total	8	8	8

Type 2: Only providers of Care		Type 3: Don't Provide or Receive Care
64 or under	65 or over	65 or over
3	3	2

Quota Tables for round 2 Cognitive Testing

Type 1: Receivers of Care		Type 2: Only providers of Care		Type 3: Don't Provide or Receive Care
Informal carers	Formal Home Help	64 or under	65 or over	65 or over
2	15	3	3	2

In addition to the above quotas, the recruitment was designed to include respondents in different areas in England. The areas in which interviews took place were:

- London,
- South East,
- Grantham and Nottingham
- Lancashire, and
- Leeds and West Yorkshire

Conduct of Interviews

The interviews for round 1 were conducted in November and December 2009 and the interviews for round 2 were conducted in February and March 2010. All the interviews were conducted face-to-face at a time place convenient to the respondent. Each interview lasted approximately one hour, although interviews with those who receive care and those who receive and provide care were slightly longer. Interviews were digitally audio-recorded with respondents' consent. Respondents were given a £20 High Street voucher as a token of our appreciation for taking part in the interview. Confidentiality and anonymity were assured throughout.

Analysis

All the interviewers made detailed notes on each of their cognitive interviews in a structured 'notes-template' document, based on listening to the recording of the interview. The notes template is organised by test question and the key measurement issues to be explored i.e. the aims of the test. All notes contained verbatim references to the original interview recordings. These notes, the recordings of the interviews and the completed test questionnaires were reviewed as part of the analysis process.

Notes were analysed using a content analysis in Framework. This approach uses the analytic tool developed by the former Qualitative Research Unit at NatCen. A matrix was set up, which listed the areas under investigation *across* the page and cases *down* the page. The matrix also included a summary of the characteristics of each respondent; such as their whether they were a provider of social care, receiver of social care or neither, gender and age. Thus data could be read horizontally, as a complete case record for an individual, or vertically, by question area under investigation looking across all cases.

Once the matrix was completed the data were reviewed. In reviewing the matrix the full range of problems with the question were explored and appropriate recommendations for improving the questions made.