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Carers' Experience Survey 2009-2010: Survey Development Project

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PSSRU Discussion Paper 2643
June 2009

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Contents

Contents.....	2
Acknowledgements	5
Glossary	6
Summary	7
1. Background	8
2. Aim	10
3. Method	10
3.1 Previous work	10
3.2 Consultation	11
3.3 Questionnaire development	11
3.3.1 Heterogeneity of the sample population.....	11
3.3.2 Implications of using a self-completion format	12
3.3.3 Dual focus of carer and cared for person.....	12
3.3.4 Structure	13
3.4 Cognitive interviews	16
4. Findings	18
Recommended questions	19
Question 1	21
Question 2	21
Question 3	21
Question 4	22
Question 5	22
Question 6	23
Question 7	23
Question 8 – OPTIONAL QUESTION	24
Question 9 – OPTIONAL QUESTION	25
Question 10 – OPTIONAL QUESTION	25
Question 11 – OPTIONAL QUESTION	26
Question 12	26
Question 13	27
Question 14	27
Question 15	28

Question 16	28
Question 17	29
Question 18	29
Question 19 – OPTIONAL QUESTION	30
Question 20	30
Question 21	31
Question 22	31
Question 23	32
Question 24	32
Question 25	33
Question 26	33
Question 27	34
Question 28	34
Question 29	35
Question 30	35
Question 31	36
Question 32	36
Question 33 – OPTIONAL QUESTION	37
Question 34	37
Question 35 – OPTIONAL QUESTION	38
Question 36 – OPTIONAL QUESTION	38
Question 37	39
Question 38 – OPTIONAL QUESTION	39
Question 39 – OPTIONAL QUESTION	40
Question 40 – OPTIONAL QUESTION	40
Question 41 – OPTIONAL QUESTION	41
Question 42	41
Question 43	42
Question 44	42
Question 45	43
Question 46	43
Question 47 – OPTIONAL QUESTION	44
Question 48	44
Question 49	45
Question 50	46

Question 51 – OPTIONAL QUESTION	47
Question 52	48
Question 53	48
Question 54	49
Question 55	49
Question 56	50
Question 57 – OPTIONAL QUESTION	50
Question 58 – OPTIONAL QUESTION	50
5. Conclusion.....	51
References.....	52
Appendix A – Recommended questionnaire	54
Appendix B –Additional questions	78
Open questions.....	78
Other additional questions	80
Appendix C – Excluded variables.....	81
Appendix D - Cognitive interviewing.....	82

Acknowledgements

This project was funded by the Department of Health. We would like to thank the Department of Health Carers Policy Team and the NHS Information Centre for Health and Social Care for their guidance during the project. Input from stakeholders was crucial in developing the questionnaire and we would like to thank the following for their contributions:

- The members of the Social Services User Survey Group (SSUSG)
- The members of Strategic Information Group on Adult Social Care (SIGASC)
- The Healthcare Commission
- Crossroads
- Carers UK
- The Princess Royal Trust for Carers

Our thanks are also due to Sue Williams and Richard Benjamin at Kent County Council, Ben Collier at Manchester City Council and the staff at Manchester Carers Centre for their help putting us in touch with carers. Our warmest thanks go to those carers who gave their time to take part in the interviews.

Glossary

CQC	Care Quality Commission is the independent regulator of health and social care in England.
CASSR	Council's with Adult Social Services Responsibilities.
IC	The NHS Information Centre for Health and Social Care is England's central and authoritative source of health and social care information.
KCC	Kent County Council.
PSSRU	Personal Social Services Research Unit is an academic organisation with branches at three universities; the University of Kent, the University of Manchester and the London School of Economics. PSSRU aims to conduct high quality research on health and social care to inform and influence policy, practice and theory.
SIGASC	The Strategic Information Group on Adult Social Care is group that meets at least twice a year to strategically plan and monitor the collection of health and social care information. The group consists of representatives from the following organisations: <ul style="list-style-type: none">• Councils with Adult Social Services Responsibilities (CASSRs)• Information Centre for health and social care (IC)• Department of Health (DH)• Care Quality Commission (CQC)• Healthcare Commission• Audit Commission• Chartered Institute of Public Finance and Accountancy (CIPFA)• Department for Communities and Local Government
SSUSG	A group that meets at least 4 times a year to discuss how best to collect information about people's experiences of health and social care services. The group consists of representatives from the following organisations: <ul style="list-style-type: none">• CASSRs• The NHS Information Centre for health and social care• Department of Health• Care Quality Commission• PSSRU• Other relevant groups (eg. Carers UK when carrying out a survey of carers)
RAP	The Referrals, Assessments and Packages of Care Project is carried out by the NHS Information Centre for Health and Social Care (IC). It was developed to provide a coherent set of National Statistics on adult community care.
UES	User Experience Survey is a survey to collect the views of people who have experience of using health and social care services.

Summary

Around 4.9 million people in England provide unpaid care to support family members, friends or neighbours. Caring can be associated with lower income, poorer health and reduced access to leisure opportunities. The government's strategy on carers identified four key outcomes to be achieved by 2018:

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

The Department of Health plans to monitor the impact of the new strategy on carers' experiences and outcomes over time. A self-completion survey of a sample of carers known to local authority social services departments will be carried out in 2009-2010 to help do this. The survey will provide useful baseline information about carers' experiences and could be repeated at regular intervals over the next 10 years.

This report describes the development and testing of the Carers' Experience Survey 2009-2010 questionnaire. It contains details about the rationale of the design of the questionnaire and highlights any issues in relation to particular questions in order to aid interpretation of the survey results. In addition, this document contains examples of question-wordings which carers found confusing, meaning that it is a useful resource on what to avoid for future survey design.

1. Background

In recent years, government policy has increasingly recognised the valuable contribution made by unpaid carers in helping ill or vulnerable people to live in the community. Estimated figures (Office for National Statistics, 2001) show that 4.9 million people in England provide unpaid care to support family members, friends or neighbours. Caring can be associated with a lower income (Heitmueller & Inglis, 2007) and poorer mental health (Maher & Green, 2002). In addition, the time spent caring can limit carers' opportunities to engage in leisure pursuits, which evidence suggests can mitigate the effects of stress (Iwasaki, 2006).

In 2008, the government published their strategy for carers (Department of Health, 2008) which identified four key outcomes to be achieved by 2018:

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

The Department of Health plans to monitor the impact of the new strategy using a variety of methods. One approach being taken is the collection of baseline information about carers' experiences and outcomes using a survey. Repeating the survey at intervals in the future would help to monitor the impact of the strategy over time although future repeats of the survey will be dependent on the success of the first survey and future funding being available.

Since 2001, councils with adult social services responsibilities (CASSRs) in England have been required to conduct surveys of users' experience of social services. User experience surveys (UESs) offer councils information about how users perceive the services they receive and how they might improve local services. They form an important part of the performance framework for social care. The quality of services provided to service users has both direct and indirect impacts on the lives of carers. Legislative changes over the last 15 years (Carers (Recognition and Services) Act, 1995; Carers and Disabled Children Act, 2000; Carers (Equal Opportunities) Act 2004; Work and Families Act, 2006) and central government policy initiatives over the last 10 years (Department of Health 1999a; Department of Health, 1999b; Department of Health, 2000; Department of Health, 2001) have increasingly prioritised the role of CASSRs in providing or commissioning support and services specifically for carers. Until now, carers' views have been sought only as an adjunct to those of service users, meaning that a UES for carers in their own right is now timely.

In 2009/2010, CASSRs in England will, on a voluntary basis, post a self-completion survey to a randomly selected sample of carers. The aims of the survey are:

- To provide baseline information from which to monitor the impact of the carers strategy
- To provide information for CASSRs on service quality from the perspective of carers.
- To provide data about carers which aid interpretation of the survey results and complement other datasets.

The sample will be selected from social services records of carers aged 18 or over, who are helping or looking after someone aged 18 or over and who meet the following criteria:

- Carers who have received a carers assessment in the last 12 months
- Carers of service users who have received an assessment or review in the last 12 months.

It is important to note that the method of sampling carers via CASSRs means the views of carers who are not in contact with social services themselves or via the person they care for, will not be captured. The term 'hidden carers' has been used to describe those carers who are not in touch with services or those who do not view themselves as being carers. The very nature of this group of carers being 'hidden' from CASSRs means it is not possible to contact them to take part in this particular survey. Adult carers of someone below the age of 18 will not be included in the sample as some of the participating CASSRs do not have responsibility for providing or commissioning services for ill or disabled children. Carers below the age of 18 will not be included in the sample because gathering the views of young carers would require a different methodological approach and a range of age-appropriate questionnaires.

The survey data collected by the volunteer CASSRs will be collated and analysed by the NHS Information Centre for Health and Social Care (IC)¹ and will provide useful information about carers' recent experience of health and social care services.

¹ The IC are currently carrying out a pilot study with 25 CASSRs to test the process of administering the Carer Experience Survey and the results will be published as a working paper for the meeting of SSUSG on 16 July 2009 (<http://www.ic.nhs.uk/services/social-care/review-approval-and-development/ssusg/ssusg-papers--16-july-2009>)

2. Aim

The aim of this project was to develop and test a self-completion user experience survey for carers, to be distributed by volunteer CASSRs in 2009/10.

3. Method

The development of the Carers' Experience Survey was carried out in four inter-related stages: a review of previous work; consultation; questionnaire development and cognitive testing.

3.1 Previous work

The Carers' Experience Survey builds upon previous work carried out by Personal Social Services Research Unit (PSSRU). In 2007, Kent County Council (KCC) and the Department of Health commissioned the PSSRU to design a self-completion carers' survey for local use in Kent. The development of KCC carers' survey involved four stages: appraisal of existing research; focus groups; survey design and cognitive testing.

Previous research on carers' needs and outcomes² was appraised and the key literature fed into the survey design along with the findings from six focus groups. Four focus groups were conducted with a range of carers recruited via voluntary organisations in Kent and two focus groups were conducted with care managers. The aim of the focus groups was to establish the key aspects of quality, domains of outcome³ and other process and contextual factors associated with quality variation in services for carers. Survey questions were designed based upon the focus group findings and previous research. The questions were cognitively tested (see Appendix D for a description of the method) with 25 carers and the questionnaire was refined in the light of the findings. The resultant KCC carers' survey was completed and returned by 1750 carers living in Kent. Analysis of the returned questionnaires helped to identify any problematic questions which informed the design and development of the Carers' Experience Survey.

² Outcomes - the impact of social care on people's lives.

³ Domains of outcome – refers to the different aspects of individuals' lives affected by social care such as social participation and control over daily life.

3.2 Consultation

A review of recent policy priorities, research literature and the development work undertaken by PSSRU for the KCC carers' survey identified a vast number of topic areas (variables) that potentially could be included in the 2009/2010 Carers' Experience Survey. A consultation exercise was carried out aiming to identify which topics were considered the most important. In November 2008, a consultation document containing a list of variables was circulated to stakeholders including policymakers, representatives from carers' voluntary organisations and CASSRs. Stakeholders were asked to rate the importance of variables according to their priorities. The results of the stakeholder ratings were collated and the topic areas considered a low priority were not developed any further (see Appendix C for excluded variables).

Throughout the questionnaire development process, regular meetings with the Department of Health Carer Policy Team and the NHS Information Centre served to clarify the preferred focus of particular questions. In addition, feedback offered by members of the Strategic Information Group on Adult Social Care (SIGASC) and the Social Services User Survey Group (SSUSG) fed into the development of the survey.

3.3 Questionnaire development

The topic areas considered to be of high or medium priority, as a result of the consultation exercise, were taken forward to be developed into survey questions. The topics taken forward represented a very broad remit and included variables looking at the impact of caring on employment; finances; health; quality of life as well as carers' views on the quality of information, advice and services. In addition to the broad remit, prior to designing the survey it was important to consider: the heterogeneity of the sample population; the implications of using a self-completion format; and the dual focus of carer and cared for person.

3.3.1 Heterogeneity of the sample population

The design of the survey needed to be responsive to the likelihood that the experiences and needs of carers are likely to differ considerably, depending on the characteristics of both the cared for person (their age, disability or illness, and levels of dependency) and the characteristics of the carer (for example, their age and place in the life cycle will influence whether they are combining paid work, other home commitments such as supporting children, and informal care). The heterogeneity of the eligible sample population of carers requires that very specific questions should be avoided. Questions focusing on a narrow area risk disenfranchising those respondents to whom the questions are not relevant.

3.3.2 Implications of using a self-completion format

Self-completion questionnaires are subject to more constraints in terms of question design; routing and filtering questions; depth; and topic area compared with questionnaires administered by an interviewer. The use of routing to skip 'not applicable' questions is common in interviewer administered surveys but in self-completion surveys, respondents can find routing confusing. The Carers' Experience Survey does not use routing; meaning respondents are required to answer every question.

A self-completion format necessitates a trade-off between breadth and depth. For example, the extent to which questions can ask specifically about different types of service provider is limited, particularly as social care provision is becoming increasingly complex. In addition, results from cognitive interviews carried out during the development of the KCC carers survey suggested that respondents often find it difficult to distinguish which provider is responsible for a particular part of a care package. The questions in the Carers' Experience Survey are therefore phrased in a more general way to accommodate carers' varied experiences of social care services and the complexity of service provision.

Some topic areas are more difficult to explore using a self-completion format. Where there is likely to be uncertainty about terms or concepts, there is no opportunity for respondents to seek clarification as they would if the survey was administered by an interviewer. Examples of this were two proposed questions; one asking carers whether they had undergone a carers' assessment and another asking whether they received any information or services as a result of a carers' assessment. Cognitive testing revealed that participants, when considering their answer to this question, thought about various discussions with professionals, but were unsure whether their needs had been formally assessed. This finding concurs with data from a survey conducted by Hertfordshire County Council (Tim Anfiligoff, personal communication, February 2009) which also showed that carers are often unsure whether or not they have undergone a carer's assessment. Carers' uncertainty about this means an alternative method of collecting this information is required. The participating CASSRs will be asked to extract this data from their information systems which they already collect routinely for the Referrals, Assessments and Packages of Care Project (RAP).

3.3.3 Dual focus of carer and cared for person

The dyadic nature of the caring relationship means that the quality of the services experienced by the cared for person will have an impact on the life of the carer. The Carers' Experience Survey explores carers' views of the services experienced by the person they care for, in addition to their experiences of carer-specific services. The dual focus of carer and cared for person means that instructions and question wording need to be very clear.

Sometimes, carers are asked to answer in relation to the person they care for, sometimes in relation to themselves and for some questions, as a pair. Taking account of the dual focus necessary for a Carer Experience Survey has implications for the length of the questionnaire.

The broad remit, the heterogeneity of the sample population; the implications of using a self-completion format; and the dual focus, all have implications for the length of the survey. Attempts to reduce survey length without losing valuable information proved difficult. Information will be collected from CASSRs information systems where possible in order to reduce survey length. For example, CASSRs will be asked to extract data on individual budgets and direct payments because these are complex topic areas which require multiple questions. In addition, where CASSRs can provide demographic data reliably, the corresponding questions can be deleted from the survey.

3.3.4 Structure

There are some broad rules underpinning the structure of the questionnaire relating to question types; ordering and dealing with 'not applicable' which are described below.

The questions of the survey cover the following broad topics:

- Characteristics of the cared for person
- Characteristics of the carer
- Use of social care support and services
- Satisfaction with social care support and services
- Views about aspects of service quality
- Views about quality of life (outcomes)

Questions measuring satisfaction use a 7-point scale. A 7-point scale elicits more variation particularly where respondents are likely to give socially desirable responses. Previous UES work undertaken by PSSRU (Smith & Netten, 2009) found that older people are reluctant to use the negative end of satisfaction scales meaning that results can erroneously show high levels of satisfaction. Lengthening the scale allows respondents to express their dissatisfaction without choosing a negatively phrased category. It is likely that a large proportion of the sample of the Carers' Experience Survey will be aged over 65, meaning that a longer scale is especially appropriate.

Questions measuring service quality are designed with four response categories, each reflecting the degree to which quality standards are met. Quality standards are usually reported at four levels:

- Exceeded
- Met
- Almost met
- Not met

The approach taken to measuring outcomes is based on previous work undertaken by PSSRU (Netten et al, 2005, Netten et al, 2006). The outcomes questions have three response categories to reflect different levels of need as follows:

- Preferred situation – where needs are met to the desired level.
- Low level needs – where there are needs but these do not have an immediate or longer term health implication.
- High level needs – where there are needs and these have an immediate or longer term health implication.

The ordering of the questions follows several broad 'rules of thumb'. General questions are positioned before the more detailed and specific. Questions identifying the types support and services used by the cared for person and their carers are placed near the front of the survey, in order to provide a context for the respondents. The majority of the questions relating to the person cared for are also positioned near the front. Cognitive testing carried out during the KCC carer survey revealed that carers tend to answer questions in relation to the cared for person, rather than themselves unless a shift of emphasis is made explicit. Easier demographic questions are placed at the end in anticipation of fatigue (however there is no evidence from the analysis of the KCC carers' survey that respondents were less likely to answer questions positioned near end of the survey).

There remains debate in survey design literature about the optimum placing of 'not applicable' response categories in surveys. For this survey, most of the 'not applicable' options are placed at the top of the response category list. This allows respondents to quickly move on, if the current question does not apply to their circumstances. The exceptions to this general rule are questions 28 and 53 (see appendix A for questionnaire) which both ask about the carers' health and have the 'not applicable' option at the bottom of the list. For these questions it is important respondents read the entire response category list before responding because they use a 'tick all that apply' format.

Tourangeau et al (2004) found that respondents tend to use the visual midpoint of a scale as a reference point for choosing their answer. They found evidence that survey results are skewed when 'not applicable' options alter the visual midpoint of a scale. In addition, feedback from participants in previous research (Malley et al, 2006) showed a preference for 'not applicable' options to be separated from the rest of the response categories because it aids the selection of the correct response. In the light of the evidence outlined above, dotted lines were introduced to the Carers' Experience Survey to visually separate the 'not applicable' options from the main response categories.

3.4 Cognitive interviews

Cognitive interviews (see Appendix D for details of the method) were carried out in order to test the developed questions. The questions were tested to see whether they are easy to understand and answer and to ensure they are relevant from the point of view of carers. The interviews were conducted with a purposive sample of 30 carers from two local authority areas, one Northern and urban and one Southern and rural. The interviews were carried out in three 'rounds'. Participants for the first two rounds of cognitive testing were recruited via local authority contacts from a sample of carers that had agreed to being contacted for future research during an earlier study. Participants for the third round of cognitive testing were recruited via the local authority and a voluntary organisation. To ensure that the sample included as wide a variety of carers as possible, local authority and voluntary organisation contacts were asked to invite carers who were looking after people with a range of needs including:

- Dementia
- Problems connected to ageing
- Learning disability or difficulty
- Physical impairment
- Sensory impairment
- Mental illness
- Difficulties with drugs or alcohol
- A terminal illness
- A longstanding illness

These criteria were chosen on the basis that the different needs of the cared for person may influence carers' experiences of social care services and subsequently their views on service quality.

A total of 94 carers were invited to participate. Positive responses were received from 38 (40%). A further 8 carers (8%) were unable to participate for various reasons including bereavement, deterioration in the health of the cared for person and carer's own poor health. The 30 carers interviewed represented a range of characteristics in terms of their caring circumstances and demographics (see Table 1). Interviews were audio-taped and conducted face-to-face in the participant's home or in a hired room at the venue of the voluntary organisation. All participants were given a £20 high street voucher and those attending the venue of the voluntary organisation were offered travel and care replacement costs. After each interview the digital audio recordings were reviewed to establish whether amendments to any of the questions were necessary. Where there were major changes to questions, the re-written questions were tested in subsequent rounds of cognitive interviews.

Table 1: Characteristics of the participants

	<i>Number</i>	<i>%⁴</i>
<i>Gender of carer</i>		
Male	6	20
Female	24	80
<i>Age of carer</i>		
35-44	2	7
45-54	12	40
55-64	5	17
65-74	5	17
75 and over	6	20
<i>Ethnic background of carer</i>		
White	27	90
Mixed	1	3
Asian or Asian British	1	3
Black or Black British	1	3
<i>Paid employment status of carer</i>		
In paid work	7	23
Not in paid work	23	77
<i>Relationship of cared for person to carer</i>		
Spouse/partner	15	50
Parent	6	20
Child	9	30
<i>Co-residency with the cared for person</i>		
Co-resident	26	87
Not co-resident	4	13

⁴ Figures may not always total 100% due to rounding.

4. Findings

The detailed findings on each question are presented in the tables starting on page 21; however there are some general points to make about the questionnaire as a whole. The key finding is that the outcomes questions were considered by carers to be the most important questions to ask. A large proportion of the participating carers were surprised to find that the survey questions were focused around them and their quality of life. Often, their previous experience of surveys involved answering questions focusing on the cared for person only. The outcomes questions have been moved closer to the front of the questionnaire (See Appendix A) in recognition of the importance placed on these questions by carers.

Cognitive testing uncovered some evidence that respondents answered in a socially desirable way. For instance, when asked about whether caring has caused financial difficulties some participants selected the neutral or positive category and then made comments such as:

“....other people are worse off”

“I don’t know if you would class it as a difficulty. I mean I don’t go hungry. I’ve always got food in my cupboard. I’ve always got petrol in my car.”

The response categories selected by the participants may accurately reflect their view of their financial circumstances. Alternatively, the presence of the interviewer may have influenced them to respond more positively. This highlights a limitation of cognitive interviews as a method of testing self-completion surveys. The presence of an interviewer creates an artificial situation, which differs from the circumstances in which respondents would usually be completing the questionnaire.

Recommended questions

The tables starting on page 21 shows each of the recommended questions with details about their aims, sources, testing status and notes on the findings from cognitive testing.

Aims

The aims section of each table states the purpose of each question, including:

- Characteristics and demographic information about the carer and cared for person. The collection of this data allows the characteristics of the carers returning questionnaires to CSSRs to be compared with the known characteristics of carers nationally and aids the interpretation of the results (for example, whether the service user group of the person cared for is associated with access to services by the carer).
- Measuring the quality of services, including access to services whether provided by CSSRs, private or voluntary organisations.
- Highlighting which commitments made in the Carers Strategy particular questions are measuring.

Sources

The sources section of each table provides information about the origin of the questions that have been developed. They include:

- The KCC carers' survey questionnaire. This questionnaire provided a basis upon which to develop the Carers' Experience Survey questionnaire. Questions from the KCC carers' survey have been adapted to reflect the broader aims of this survey and were subsequently cognitively tested with carers.
- 'PSSRU' indicates new questions which have been developed to rectify any gaps identified from previous work and to measure new variables relating to the Carers Strategy.
- The Individual Budget pilot evaluation (IBSEN) carer study (Glendinning et al, 2008) which identified variables associated with carers' outcomes.
- Standard surveys, such as the Census and the General Household Survey.
- Previous research on carers.

Testing

The testing section of each table shows which round(s) of cognitive interviews each question was tested in.

Notes

The notes section of each table contains notes on the rationale for the question and the findings from the cognitive testing.

Question 1

How many people aged 18 or over do you care for?

Aim: Carer and cared for person's characteristics

Source: PSSRU

Testing: Untested - added after round 3 testing

Notes: The instructions page asks participants to answer the questions in relation to the main person they care for only. However, round 3 testing identified that some participants tried to answer in relation to more than one person, despite having read the instructions. This question was added in order to acknowledge the multiple caring roles of some participants, before asking them to complete the rest of the questionnaire about one person only.

Question 2

Who is the person that you care for?

Please tick [✓] one box

- Parent
- Parent-in-law
- Spouse/partner
- Child (own/adopted/step)
- Other relative
- Other non-relative/friend/neighbour

Aim: Carer and cared for person's characteristics

Source: Adapted from the General Household Survey (GHS) 2000

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 3

How old is this person? _____ years

Aim: Cared for person's demographics

Source: Adapted from Q2 of KCC carers survey

Testing: Tested in round 3

Notes: The cared for person's exact age is requested instead of using age bands because raw scores are more useful for comparability to the Census and GHS (which ask for respondents' date of birth).

In addition, the item response analysis from the Kent County Council's (KCC) carers' survey found no evidence that carers were reluctant to answer this question.

No evidence was found during cognitive testing, that participants were sensitive about answering this question.

Question 4

Are they male or female?

Please tick [✓] one box

Male

Female

Aim: Cared for person's demographics

Source: Q3 KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 5

Does the person you care for have....?

Please tick [✓] all that apply

Dementia

A physical disability

Sight or hearing loss

A mental health problem

Problems connected to ageing

A learning disability or difficulty

Long-standing illness

Terminal illness

Alcohol or drug dependency

Aim: Cared for person's demographics

Source: Q4 KCC carers survey

Testing: Tested in round 3

Notes: The categories on this list have been based upon the disaggregated primary client types for which CASSRs provide data for the Referrals, Assessments and Packages of Care Project (RAP) with additional categories identified by carers taking part in focus groups for the development of the KCC carers' survey.

It has been highlighted that the categories are not mutually exclusive e.g. dementia could be considered to be a problem connected to ageing. A degree of ambiguity is accepted as it is a 'tick all that apply' question. It allows carer's to define the cared for person's difficulties in a way that is meaningful to them. During cognitive testing, all of the participants were able to select at least one category from this list suggesting that it is comprehensive.

Question 6

Where does the person you care for usually live?

Please tick [✓] one box

With me

Somewhere else

Aim: Carer and cared for person's characteristics

Source: Adapted from General Household Survey 2000

Testing: Untested – Re-written after round 3 testing

Notes: The results from the KCC carers' survey showed that the previous version of this question was problematic. Some respondents misinterpreted the word 'household' as referring to a house only, and did not include in their answers people living in a flat or a bungalow. The aim of the question is to establish whether the carer and the cared for person are co-resident and it has now been simplified to reflect this.

Question 7

Overall, how satisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?

Please tick [✓] one box

..... We haven't received any support or services from Social Services in the last 12 months

I am extremely satisfied

I am very satisfied

I am fairly satisfied

I am neither satisfied nor dissatisfied

I am fairly dissatisfied

I am very dissatisfied

I am extremely dissatisfied

Aim: Measuring the quality of services provided by CASSRs

Source: Adapted from Q15 KCC carers survey

Testing: Tested in rounds 2 & 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 8 – OPTIONAL QUESTION

Has the person you care for used any of the support or services listed below in the last 12 months?

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

	Yes	No	Don't know
Care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal assistant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care/home help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day centre or day activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lunch club	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meals on wheels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Equipment or adaptation to their home (such as a wheelchair, handrails or an alarm system)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supported employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Special College	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Aim: Measuring cared for person's service receipt

Source: Adapted from Q5 KCC carers survey

Testing: Tested in rounds 2 & 3

Notes: The yes/no/don't know format of this question is designed to accommodate those carers who do not live with the cared for person and may not be aware of all the support and services they use.

During testing, not all participants used the 'no' and 'don't know' columns, ticking just for 'yes' answers. They were treating it like a 'tick all that apply' format. A disadvantage of using a 'tick all that apply' format means that an empty box is presumed to be a 'no' when it could be a 'don't know' or may have been accidentally skipped. Therefore the yes/no/don't know format is preferable as it offers the possibility of collecting more definite information from those respondents who use it correctly. In addition, some carers not living with the cared for person may not know which support or services they use.

The categories 'care home' and 'personal assistant' are untested as they were added after round 3 testing.

Originally 'transport' was listed and testing showed that most participants understood it to mean transport services to a day centre. However, a lack of certainty about what other types of transport participants may include when answering meant that 'transport' was omitted from the list.

Response categories in highlighted in yellow are optional. CASSRs can add other services to reflect local service provision.

Question 9 – OPTIONAL QUESTION

Thinking about the support or services the person you care for has received (provided by a voluntary organisation, a private agency or Social Services) in the last 12 months, which of the following statements best describes your present situation?

Please tick [✓] one box

-
- The person I care for has received no support or services in the last 12 months
- The support or services have made things easier for me
- The support or services have made no difference to me
- The support or services have made things harder for me

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations.

Measuring the 2018 carers strategy commitments:

'Carers will have access to integrated and personalized services they need to support them in their caring role'

'Carers will be able to have a life of their own alongside their caring role'

Source: Adapted from Q16 KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 10 – OPTIONAL QUESTION

At the present time, do you and the person you care for have the right amount of support or services, in terms of the hours or days you need?

Please tick [✓] one box

-
- At the present time, we do not receive any support or services
- No, we have more hours or days than we need
- The amount is about right
- No, we need a few more hours or days
- No, we need a lot more hours or days

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations

Source: Adapted from Q26 of KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 11 – OPTIONAL QUESTION

Which of the following types of organisation do you get the most support or services from.....?

Please tick [✓] one box

- Voluntary organisations
- Private agencies
- Social Services
- Don't know

Aim: To increase specificity

Source: PSSRU

Testing: Untested - added after round 3 testing

Notes: Throughout the questionnaire carers are asked to comment on their experiences of information, support or services whether they be provided by voluntary organisations, private agencies or Social Services. This question aims to disentangle which provider the carer generally gets the most help from.

Question 12

Have you used any of the support or services listed below, to help you as a carer over the last 12 months?

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

	Yes	No	Don't know
Information and advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support from carers groups or someone to talk to in confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Training for carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advocacy for carers (Advocates speak on your behalf or assist you to express your views)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency care back-up scheme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with household tasks or gardening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practical help to complete forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Aim: Measuring carers service receipt and the 2008 carers strategy commitment to: 'train carers to strengthen them in their caring role'

Source: Adapted from Q7 of KCC carers survey

Testing: Tested in round 3

Notes: Response categories in highlighted in yellow are optional. CASSRs can add other services to reflect local service provision.

Participants did not identify any difficulties in answering this question during cognitive testing.

Question 13

In the last 12 months, have you used any support or services to help you take a break from caring, lasting more than 24 hours?

Please do not include unpaid help from family and friends.

Please tick [✓] one box

- Yes
- No, because there were no support or services available to me
- No, because the support or services available were not suitable
- No, for other reasons
- Don't know

Aim: Measuring the 2008 carers' strategy commitment to increase the provision of breaks

Source: PSSRU

Testing: Tested in rounds 2 & 3

Notes: During round 3 testing, a few participants queried whether to include help from family and friends. The statement clarifying this has now been added.

Question 14

Overall, how satisfied were you with the support or services that helped you to take a break from caring, lasting more than 24 hours?

Please tick [✓] one box

- I haven't used any support or services to have a break lasting more than 24 hours
- I was extremely satisfied
- I was very satisfied
- I was fairly satisfied
- I was neither satisfied nor dissatisfied
- I was fairly dissatisfied
- I was very dissatisfied
- I was extremely dissatisfied

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations

Source: PSSRU

Testing: Tested in rounds 2 & 3

Notes: Occasionally, participants ticked a box indicating dissatisfaction, instead of using the not applicable option, when they had been unable to access any/enough appropriate support or services enabling them to take a break.

Question 15

In the last 12 months, have you regularly used any support or services to help you have a rest from caring for between 1 hour and 24 hours?

Please do not include unpaid help from family and friends.

Please tick [✓] one box

- Yes
- No, because there were no support or services available to us
- No, because the support or services available were not suitable
- No, for other reasons
- Don't know

Aim: Measuring the 2008 carers' strategy commitment to increase the provision of breaks

Source: PSSRU

Testing: Tested in rounds 2 & 3

Notes: This question aims to measure whether carers have any breaks from caring during a typical day, for example, by using a sitting service.

During testing, it became clear that using the word 'break' encouraged carers to think of going away somewhere for at least one night. This question is asking about shorter breaks within a 24 hour period, so to avoid confusion, the term 'a rest from caring' is now used. The new wording 'a rest from caring' was added after round three and therefore has not been tested.

Question 16

Overall, how satisfied were you with the support or services that regularly helped you to have a rest from caring for between 1 hour and 24 hours?

Please tick [✓] one box

- I haven't used any support or services to have a rest for between 1 and 24 hours
-
- I was extremely satisfied
- I was very satisfied
- I was fairly satisfied
- I was neither satisfied nor dissatisfied
- I was fairly dissatisfied
- I was very dissatisfied
- I was extremely dissatisfied

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations

Source: PSSRU

Testing: Tested in rounds 2 & 3

Notes: Occasionally, participants ticked a box indicating dissatisfaction, instead of using the not applicable option, when they had been unable to access any/enough appropriate support or services enabling them to have a rest from caring.

Question 17

Thinking about the good and the bad things that make up your quality of life, how would you rate the quality of your life as a whole?

Please tick [✓] one box

- So good, it could not be better
- Very good
- Good
- Alright
- Bad
- Very bad
- So bad, it could not be worse

Aim: Measuring 2018 carers strategy commitment that: 'carers will be supported to stay mentally well'

Source: The Individual Budget pilot evaluation (IBSEN) carer study - Glendinning et al (2008)

Testing: Tested in rounds 2 & 3

Notes: During the development of the questionnaire, there was debate about the length of this scale with a suggestion that it be shortened to a 5-point scale. However, several carers selected the bottom category of this 7-point scale during testing and further discussion revealed that 'very bad' would not express in strong enough terms how they felt about their quality of life. This question has been used in other studies and has proved sensitive to identifying differences in outcome.

Question 18

Which of the following statements best describes how you spend your time?

When you are thinking about what you do with your time, please include anything you value or enjoy, including formal employment, voluntary or unpaid work, caring for others and leisure activities

Please tick [✓] one box

- I'm able to spend my time as I want, doing things I value or enjoy
- I do some of the things I value or enjoy with my time but not enough
- I don't do anything I value or enjoy with my time

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be able to have a life of their own alongside their caring role'

Source: Adapted from outcome domains in PSSRU work on Adults Social Care Outcomes Toolkit (ASCOT). Similar question on Carer experience scale (Al-Janabi et al., 2008)

Testing: Previous version tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing; however work carried out for the ASCOT project identified a stronger version of this question (shown above).

Question 19 – OPTIONAL QUESTION

Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your present situation?

Please tick [✓] one box

I have the space and time I need to be myself

I have some of the space or time I need to be myself but not enough

I do not have any space or time to be myself

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be able to have a life of their own alongside their caring role'

Source: New carer-specific domain developed from focus groups carried out prior to KCC carer survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 20

Which of the following statements best describes how much control you have over your daily life?

Please tick [✓] one box

I have as much control over my daily life as I want

I have some control over my daily life but not enough

I have no control over my daily life

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be able to have a life of their own alongside their caring role'

Source: Adapted from outcome domains in PSSRU work on Adults Social Care Outcomes Toolkit (ASCOT)

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 21

Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?

Please tick [✓] one box

- I look after myself
- Sometimes I can't look after myself well enough
- I feel I am neglecting myself

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be supported to stay physically and mentally well'

Source: Adapted from outcome domains in PSSRU work on Adults Social Care Outcomes Toolkit (ASCOT)

Testing: Tested in round 3

Notes: Most participants did not identify any difficulties in answering this question during cognitive testing. One carer felt that the word 'neglecting' was too strong. However, the wording is necessarily strong to reflect the 'high need' category of the outcomes questions and other carers felt it was appropriate.

Question 22

Thinking about your personal safety, which of the statements best describes your present situation?

By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm.

Please tick [✓] one box

- I have no worries about my personal safety
- I have some worries about my personal safety
- I am extremely worried about my personal safety

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be supported to stay physically and mentally well'

Source: Adapted from outcome domains in PSSRU work on Adults Social Care Outcomes Toolkit (ASCOT)

Testing: Tested in round 3

Notes: Most participants interpreted this question to be asking about them about being at risk from the cared for person. It is the intention of this question to capture this as well as other sources of concern. When thinking about their answers, some carers included the worries they had about their own mental health, which ideally would be reported elsewhere (health questions).

Question 23

Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?

Please tick [✓] one box

- I have as much social contact as I want with people I like
- I have some social contact with people but not enough
- I have little social contact with people and feel socially isolated

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be able to have a life of their own alongside their caring role'

Source: Adapted from outcome domains in PSSRU work on Adults Social Care Outcomes Toolkit (ASCOT)

Testing: Previous version tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing; however work carried out for the ASCOT project identified a stronger version of this question (shown above).

Question 24

Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?

Please tick [✓] one box

- I feel I have encouragement and support
- I feel I have some encouragement and support but not enough
- I feel I have no encouragement and support

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be supported to stay mentally well'

Source: New carer-specific domain developed from focus groups carried out prior to KCC carer survey. The Health Survey for England 1998 includes a question on support and encouragement. Similar question on Carer experience scale (Al-Janabi et al, 2008).

Testing: Tested in round 3

Notes: The main sources of support and encouragement cited during testing were family, friends and voluntary organisations.

Some participants who felt they had no encouragement and support were unsure who they would get encouragement and support from.

Question 25

Thinking about the skills needed for caring, which statement best describes your present situation?

Please tick [✓] one box

I do not need any training at present

I would like some training

I need some training

Aim: Measuring the 2008 carers strategy commitment to: 'train carers to strengthen them in their caring role'

Source: Adapted from Q12 KCC carers survey.

Testing: Previous version tested in rounds 2 & 3

Notes: Participants did not identify any difficulties in answering a previous version of this question during cognitive testing which also asked about information. The question was adapted post testing to focus on training only.

Testing explored the types of training that carers were thinking about which were:

Training on:

- lifting and handling,
- nursing skills to change dressings and administer injections
- managing difficult behaviour
- dealing with public bodies
- personnel skills (in order to manage personal assistants)
- counselling skills
- pain therapies

Question 26

Thinking about how easy it is for you to get basic services to meet your needs – such as going to see a GP, visiting a dentist or going to the library – which of the following statements best describes your present situation?

Please tick [✓] one box

I can get the basic services I need

I can't always get the basic services I need

I can't always get the basic services I need, and I think there is a risk to my health

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be supported to stay physically and mentally well' and measuring social exclusion.

Source: New carer-specific domain developed from focus groups carried out prior to KCC carer survey

Testing: Tested in rounds 2 & 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing. Discussions with carers revealed that their answers were related to general poor access to GP services, rather than poor access related to caring.

Question 27

How is your health in general?

Please tick [✓] one box

- Very good
Good
Fair
Bad
Very bad

Aim: Measuring the 2018 carers' strategy commitment that carers will: 'be supported to stay physically and mentally well'. Provides basis for comparison with other surveys.

Source: Euro-REVES 2 project (Robine et al, 2003)

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 28

In the last 12 months, has your health been affected by your caring role in any of the ways listed below?

Please tick [✓] all that apply

- Feeling tired
Feeling depressed
Loss of appetite
Disturbed sleep
General feeling of stress
Physical strain (e.g. back)
Short tempered/irritable
Had to see own GP
Developed my own health condition
Made an existing condition worse
Other
No, none of these

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be supported to stay physically and mentally well'

Source: Adapted from a question due to be used in the Survey of Carers in Households 2009/2010

Testing: Tested in rounds 1 & 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

In order that the results of this survey will be comparable to the planned Survey of Carers in Households 2009/10, the following three categories were added post testing:

'Developed my own health condition'

'Made an existing condition worse'

'No, none of these'

Question 29

In the last 12 months, has caring caused you any financial difficulties?

Please tick [✓] one box

- No, not at all
Yes, to some extent
Yes, a lot

Aim: Measuring the 2018 carers strategy commitment that carers will: 'be supported so they are not forced into financial hardship by their caring role'

Source : PSSRU

Testing: Tested in rounds 1 & 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing. Round 1 of cognitive testing explored whether a greater list of options was needed, however respondents were happy with this format. This question was prone to socially desirable responses in an interview situation as illustrated by one participants' comment "Other people are worse off".

Question 30

Please tick the box which comes closest to describing how quickly Social Services have responded to your queries or questions in the last 12 months.

Please tick [✓] one box

- I have not contacted Social Services with a query or question in the last 12 months

Someone always got back to me
Sometimes they got back to me, but sometimes I had to ask them again
I had to ask them more than twice, but eventually someone got back to me
They didn't get back to me

Aim: Measuring the quality of services provided by CASSRs. Measuring the 2008 carers strategy commitment that every carer should: 'be able to access comprehensive information specific to their locality'

Source: Adapted from Q20 KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 31

In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information from different sources, such as voluntary organisations and private agencies as well as Social Services.

Please tick [✓] one box

- I have not tried to find information or advice in the last 12 months
-
- Very easy to find
- Fairly easy to find
- Fairly difficult to find
- Very difficult to find

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations. Measuring the 2008 carers strategy commitment that every carer should: 'be able to access comprehensive information specific to their locality'

Source: Adapted from Q17 KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 32

In the last 12 months, how helpful has the information and advice you have received been? Please include information and advice from different organisations, such as voluntary organisations and private agencies as well as Social Services.

Please tick [✓] one box

- I have not received any information or advice in the last 12 months
-
- Very helpful
- Quite helpful
- Quite unhelpful
- Very unhelpful

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations. Measuring the 2008 carers' strategy commitment that every carer should: 'be able to access comprehensive information specific to their locality'

Source: Adapted from Q18 KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 33 – OPTIONAL QUESTION

Has it been easy or difficult to get the support or services the person you care for needs in the past 12 months? The services may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

Please tick [✓] one box

- There was no need to get any support or services in the last 12 months
- Very easy
- Quite easy
- Quite difficult
- Very difficult

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations.

Source: Adapted from Q21 of KCC carers survey

Testing: Tested in round 3

Notes: This question may be less relevant for those carers who care for someone who continues to receive support and services that were *arranged* more than 12 months ago.

Question 34

Have you found it easy or difficult to get the support or services you need as a carer in the last 12 months? The services may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

Please tick [✓] one box

- I did not need any support or services in the last 12 months
- Very easy
- Quite easy
- Quite difficult
- Very difficult

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations. Measuring the 2018 carers' strategy commitment that: 'carers will have access to integrated and personalized services they need to support them in their caring role'.

Source: Adapted from Q22 KCC carers survey

Testing: Tested in round 3

Notes: This question may be less relevant for those carers who continue to receive support and services that were *arranged* more than 12 months ago.

Question 35 – OPTIONAL QUESTION

In the last 12 months, have you or the person you care for had to wait to get any support or services?

Please tick [✓] one box

- We haven't asked for any support or services in the last 12 months
- No, we haven't had to wait
- Yes, but the wait was not a problem
- Yes, and the wait should be a bit shorter
- Yes, and the wait should be a lot shorter

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations. Measuring the 2018 carers' strategy commitment that: 'carers will have access to integrated and personalized services they need to support them in their caring role'.

Source: Adapted from Equipment User Experience Survey (Smith & Netten, 2009)

Testing: Tested in round 3

Notes: This question may be less relevant for those carers/persons cared for who receive support and services that were *arranged* more than 12 months ago.

Question 36 – OPTIONAL QUESTION

How do you feel about the level of contact you had with the care manager or social worker that works with the person you care for?

Please tick [✓] one box

- The person I care for does not have a care manager or social worker
- The level of contact should be reduced
- The level of contact is about right
- The level of contact should be increased a little
- The level of contact should be increased a lot

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations. Measuring the 2018 carers' strategy commitment that: 'carers will have access to integrated and personalized services they need to support them in their caring role'.

Source: Adapted from Q23 KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 37

In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

Please tick [✓] one box

- There have been no discussions that I am aware of, in the last 12 months
- I always felt involved or consulted
- I usually felt involved or consulted
- I sometimes felt involved or consulted
- I never felt involved or consulted

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations. To measure the 2008 carers' strategy commitment to: 'empower carers in their dealings with care professionals' and the 2018 commitment to ensure carers are: 'respected as expert care partners'.

Source: Adapted from Q24 for KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing. This question may be less relevant for those carers managing all the care arrangements for the person they care for.

Question 38 – OPTIONAL QUESTION

Does the person you care for get support or services at times of the day or days of the week that suit you?

Please tick [✓] one box

- At the present time, we do not receive any support or services
- Yes
- No, I would like support or services at other times of day
- No, I would like support or services on other days of the week
- No, I would like both different times of the day and days of the week

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations

Source: Adapted from Q28 of KCC carers survey

Testing: Tested in round 3

Notes: This question may be less relevant for:

- those caring for people who are not receiving regular support or services
- carers not living with the cared for person.

Question 39 – OPTIONAL QUESTION

Can the support or services you receive react to changes in your day-to-day needs and those of the person you care for?

For example, can you ask that care workers visit at a different time, the person you care for goes to a day centre on a different day, or that things are done differently?

Please tick [✓] one box

At the present time, we do not receive any support or services

Don't know

Always

Usually

Sometimes

Never

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations

Source: Adapted from Q29 of KCC carers survey

Testing: Tested in round 3

Notes: This question may be less relevant for:

- those caring for people who are not receiving regular support or services
- carers not living with the cared for person.

Question 40 – OPTIONAL QUESTION

Are you kept informed about day-to-day changes to support or services that you or the person you care for receives? (For example, that a care worker will be late or there will be a different care worker)

Please tick [✓] one box

At the present time, we do not receive any support or services

There haven't been any changes

Someone always lets me know about changes

Someone usually lets me know about changes

They hardly ever let me know about changes

They never let me know about changes

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations

Source: Adapted from Q30 of KCC carers survey

Testing: Tested in round 3

Notes: This question may be less relevant for:

- those caring for people who are not receiving regular support or services
- carers not living with the cared for person.

Question 41 – OPTIONAL QUESTION

Do care workers or personal assistants treat you with courtesy and respect?

Please tick [✓] one box

- At the present time, we do not receive any support or services.
- Always
- Usually
- Sometimes
- Never

Aim: Measuring the quality of services provided by CASSRs, private agencies and voluntary organisations. Measuring the 2018 carers strategy commitments that carers will be: "treated with dignity" and 'respected as expert care partners'.

Source: Adapted from Q32 of KCC carers survey

Testing: Tested in round 3

Notes: During testing participants answered this question in relation to different types of care workers according to their experiences. Some included care managers, others key-workers from day centres and some answered in relation to hospital staff.

Question 42

Do you feel you have been treated with respect as a carer, when you have been in contact with health professionals at a NHS hospital about the person you care for, over the last 12 months?

Please tick [✓] one box

- I have not been in contact with health professionals at a NHS hospital about the person I care for in the last 12 months.
-
- Always
- Usually
- Sometimes
- Never

Aim: Measuring 2008 carers strategy commitment to: 'empower carers in their dealings with care professionals' and 2018 commitments that carers will be: "treated with dignity" and 'respected as expert care partners'

Source: PSSRU

Testing: Tested in rounds 1, 2 & 3

Notes: Three different versions of the same question were tested, with the following wordings: 'with respect as an expert carer' – the participants were uncomfortable calling themselves expert carers. The term 'expert carer' was interpreted to mean a professional paid carer.

'With respect for your dignity' – participants associated 'dignity' with getting undressed and intimate personal care and did not think it appropriate wording for a question about themselves.

'With respect' – participants considered 'respect' to be too general, as it only relates to treating someone with respect as an individual rather than in the context of the caring role.

Participants did not identify any difficulties in answering the final version of this question tested during round 3.

Question 43

Do you feel you were involved as much as you wanted to be in discussions about the care and treatment of the person you care for, when you have been in contact with health professionals at a NHS hospital in the last 12 months?

Please tick [✓] one box

I have not been in contact with health professionals at a NHS hospital about the
----- person I care for in the last 12 months

Always

Usually

Sometimes

Never

Aim: Measuring 2008 carers strategy commitment to 'empower carers in their dealings with care professionals' and 2018 commitment that carers will be: 'respected as expert care partners'

Source: PSSRU

Testing: Tested in rounds 1 & 3

Notes: Participants did not identify any difficulties in answering the final version of this question tested during round 3.

Question 44

Do you feel you have been treated with respect as a carer, when you have been in contact with health professionals from a GP surgery/health centre about the person you care for, over the last 12 months?

Please tick [✓] one box

I have not been in contact with health professionals at a GP surgery/health centre
----- about the person I care for in the last 12 months

Always

Usually

Sometimes

Never

Aim: Measuring 2008 carers strategy commitment to 'empower carers in their dealings with care professionals' and 2018 commitments that carers will be: "treated with dignity' and 'respected as expert care partners'

Source: PSSRU

Testing: Tested in rounds 1, 2 & 3

Notes: This question is a repeat of question 42, except the focus is on community health services, rather than hospital services. Discussions with participants during testing highlighted that these two types of health provision are viewed by carers as being different and distinct from one another.

This questionnaire asks questions about community health services and hospital services separately in order to ask carers about their experiences of health professionals, in a way that is meaningful to them.

Participants did not identify any difficulties in answering the final version of this question tested during round 3.

Question 45

Do you feel you were involved as much as you wanted to be in discussions about the care and treatment of the person you care for, when in contact with health professionals from a GP surgery/health centre in the last 12 months?

Please tick [✓] one box

- I have not been in contact with health professionals at a GP surgery/health centre
..... about the person I care for in the last 12 months
- Always
- Usually
- Sometimes
- Never

Aim: Measuring 2008 carers strategy commitment to 'empower carers in their dealings with care professionals' and 2018 commitment that carers will be: "respected as expert care partners"

Source: PSSRU

Testing: Tested in rounds 1 & 3

Notes: Participants did not identify any difficulties in answering the final version of this question tested during round 3.

Question 46

Overall, do you feel GPs support you in your role as a carer?

Please tick [✓] one box

- The GPs I see don't know that I am a carer
- Always
- Usually
- Sometimes
- Never

Aim: Measuring 2008 carers strategy commitment to: 'improve support offered by GPs'

Source: Adapted from the Individual Budget pilot evaluation (IBSEN) carer study (Glendinning et al, 2008)

Testing: Tested in rounds 1, 2 & 3

Notes: Originally, there were two questions, one asking carers whether they felt supported by their own GP and one asking whether carers felt supported by the GP of the person they cared for. This proved problematic as some carers were registered with the same GP as the person they cared for.

Other participants found the wording 'your GP' confusing. Recent changes to the organisation of primary care mean that few people always see the same GP.

Participants did not identify any difficulties in answering the final version of this question tested during round 3.

Question 47 – OPTIONAL QUESTION

In addition to your caring role, please tell us which of the following also applies to you?

Please tick [✓] all that apply

- Retired
- Employed full-time
- Employed part-time (working 30 hours or less)
- Self-employed full-time
- Self-employed part-time
- Not in paid work
- Doing voluntary work
- Other

Aim: Measuring carer characteristics and 2008 carers strategy commitments to: 'enable carers to combine paid employment with caring' and 2018 commitment to ensure that: 'carers will be supported so they are not forced into financial hardship by their caring role'

Source: Adapted from Q49 of KCC carers survey

Testing: Tested in rounds 2 & 3

Notes: The category 'doing voluntary work' was added as a considerable number of participants spent some of their time volunteering.

Participants did not identify any difficulties in answering the final version of this question tested during round 3.

Question 48

Thinking about combining paid work and caring, which of the following statements best describes your current situation?

Please tick [✓] all that apply

- I am in paid work and I feel supported by my employer
- I am in paid work but I don't feel supported by my employer
- I do not need any support from my employer to combine work and caring
- I am not in paid work because of my caring responsibilities
- I am not in paid work for other reasons
- I am self-employed or retired

Aim: Measuring 2008 carers strategy commitments to: 'enable carers to combine paid employment with caring'

Source: PSSRU

Testing: Tested in rounds 2 & 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 49

About how long have you been looking after or helping the person you care for?

Please tick [✓] one box

- Less than 6 months
- Over 6 months but less than a year
- Over 1 year but less than 3 years
- Over 3 years but less than 5 years
- Over 5 years but less than 10 years
- Over 10 years but less than 15 years
- Over 15 years but less than 20 years
- 20 years or more

Aim: Measuring carer characteristics

Source: Adapted from General Household Survey 2000

Testing: Tested in rounds 1, 2 & 3

Notes: This question is based on one from the General Household Survey 2000 which has the following qualifying text after the question.

(That is doing things for him/her over and above what you would normally do for someone living with you/ a child of that age)

The General Household Survey is designed to be administered by an interviewer. Cognitive testing was carried out to establish whether carers were confused or helped by this statement when it was administered in a self completion format.

Carers who were not living with the cared for person or those who were looking after someone who was not their child were confused by the statement above. Two re-written versions of the statement were tested, but also proved problematic for some carers.

In the final round of testing, the full questionnaire was presented to participants with the questions in the correct order. This question was shown without the additional statement and participants interpreted the question as it was intended when it was presented near the end of the questionnaire.

All the carers interviewed were able to select a response but it is important to note that some carers felt that pinpointing the start of caring can be difficult as this carer highlights:

"So my husband has been diagnosed with his illness for two years, but I can say that he's been ill for between five and ten."

Other participants highlighted that caring is sometimes less rigid than this question suggests, with caring occurring 'on and off', depending on the cared for person's changing health status.

Question 50

About how long do you spend each week looking after or helping the person you care for?

Please tick one box

0-9 hours per week

10-19 hours per week

20-34 hours per week

35-49 hours per week

50-99 hours per week

100 or more hours per week

Varies – Under 20 hours per week

Varies – 20 hours or more per week

Other

If other please specify:

Aim: Measuring carer characteristics

Source: Adapted from General Household Survey 2000

Testing: Tested in rounds 2 & 3

Notes: This can be a difficult question for carers to answer as it requires making a numerical calculation. Participants highlighted that this question does not capture the time they spend worrying and being constantly 'on call'.

Analysis of Kent County Council's (KCC) carer survey shows that carers providing care 24/7 tended to choose the 'other' category, rather than the '100 hours or more per week' category. It is advisable that CASSRs brief data entry staff to recode this data prior to entry.

Question 51 – OPTIONAL QUESTION

Over the last 12 months, what kinds of things did you usually do for the person you care for?

Please tick [✓] all that apply

- Personal care?
(Things like dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet)
- Physical help?
(Such as helping with walking, getting up and down stairs, getting into and out of bed)
- Helping with dealing with care services and benefits?
(Things like making appointments and phone calls, filling in forms)
- Helping with paperwork or financial matters?
(Such as writing letters, sending cards, filling in forms, dealing with bills, banking)
- Other practical help?
(Things like preparing meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital)
- Keeping him/her company?
(Things like visiting, sitting with, reading to, talking to, playing cards or games)
- Taking him/her out?
(Such as taking out for a walk or drive, taking to see friends or relatives)
- Giving medicines?
(Things like making sure he/she takes pills, giving injections, changing dressings)
- Keeping an eye on him/her to see he/she is all right?
- Giving emotional support?
- Other help

Aim: Measuring carer characteristics

Source: Adapted from a question due to be used in the Survey of Carers in Households 2009/ 2010

Testing: Tested in rounds 1 & 3

Notes: During round 1, testing explored how carers interpreted some of the response categories if no examples were given in brackets. The results showed that without the examples as guidance, participants tended not to include a broad enough range of activities when thinking about their answers.

During round 3, testing aimed to establish whether participants preferred terms such as 'such as' and 'things like' when examples are listed in brackets compared with 'e.g.'. No evidence was found for any particular preference between these formats.

After round 3 testing two extra response categories have been added. The new Survey of Carers in Households 2009/2010 which will replace the carers module of the GHS has a new category:

'Helping with dealing with care services and benefits'

Several participants spoke about the amount of time they spend making care arrangements and the associated paperwork. In the future, more service users will have an individual budget, meaning that more carers are likely to undertake some, if not all, of the administrative burden as this carer highlights:

"...my parents have been on direct payments for five years. I manage their direct payments. I've become an accountant because I've got to do the NI numbers, tax numbers, audits, I've got to do wage slips. I've got to do the whole caboodle".

During testing, the interviewer asked participants whether the list of response categories for this question is comprehensive. 'Emotional support' was commonly cited as being missing. A large number of participants reported that they were thinking about emotional support when they ticked the 'other' category, suggesting that a new category is required and is particularly relevant to those caring for someone who has mental health problems:

"I think people dealing with people with depression would say that actually a lot of the stuff you do is very much emotional support."

Question 52

Do you have any of the following?

Please tick [✓] all that apply

- A physical impairment or disability
- Sight or hearing loss
- A mental health problem or illness
- A learning disability or difficulty
- A long-standing illness
- Other
- None of the above

Aim: Measuring carer characteristics

Source: Adapted from Q48 of KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 53

How old are you? _____ years

Aim: Measuring carer demographics

Source: Q44 KCC carers survey

Testing: Tested in round 3

Notes: During testing some older females were initially reluctant to state their exact age, however further discussion revealed that this was an artefact of the cognitive interviewing situation. They were less concerned about revealing their exact age in a situation where they would be filling in the questionnaire anonymously and returning it by post. Respondents' willingness to reveal their exact age is further illustrated by the item response analysis from the KCC carers' survey which showed that at least 98% of respondents answered this question. Raw scores are more useful for comparability to the Census and GHS (which ask for respondents' date of birth).

Question 54

Are you male or female?

Please tick [✓] one box

Male

Female

Aim: Measuring carer demographics

Source: Q45 KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 55

To which of these groups do you consider you belong?

Please tick [✓] one box

White
(British, Irish, Traveller of Irish Heritage, Gypsy/Roma, any other White background)

Mixed
(White and Black Caribbean, White and Black African, White and Asian, any other Mixed background)

Asian or Asian British
(Indian, Pakistani, Bangladeshi, any other Asian background)

Black or Black British
(Caribbean, African, any other Black background)

Chinese

Any other ethnic group

Aim: Measuring carer demographics

Source: Adapted from 2001 ONS Census

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 56

Did someone help you to complete this questionnaire?

Please tick [✓] one box

Yes

No

Aim: Measuring authorship and accessibility

Source: PSSRU

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 57 – OPTIONAL QUESTION

If further research were to take place, would you be happy for us to contact you?

Please tick [✓] one box

Yes

No

Aim: Gaining consent for future contact

Source: Q52 of KCC carers survey

Testing: Tested in round 3

Notes: Participants did not identify any difficulties in answering this question during cognitive testing.

Question 58 – OPTIONAL QUESTION

Please use the space provided below to describe any other experiences you would like to tell us about or to write any other comments you would like to make

Aim: Offers respondents the opportunity to add further information

Source: Q53 of KCC carers survey

Testing: Not tested

Notes: Not applicable

5. Conclusion

This report outlines the background and development of a self-completion questionnaire designed to measure the quality and outcome of services affecting carers. It describes the rationale of the design of the carer experience survey questionnaire and illustrates how particular issues and terminology can create difficulties for carers when completing surveys. This document is intended as a resource to be revisited prior to making any changes to the questionnaire in the future.

The results section shows how the survey questions relate to the aims of the strategy for carers (Department of Health, 2008) and aspects of service quality. The survey questionnaire (see Appendix A) is designed to cover a wide range of topic areas, but it is not designed for use with carers under 18. A limitation of this survey is that it is not designed to monitor young carers' achievement of the outcomes outlined in *Every Child Matters: Change for Children* (Department for Education and Skills, 2004). However, the carer experience survey will provide important benchmark information about the impact of support and services on adult carers' lives.

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Appendix A – Recommended questionnaire

The recommended questionnaire starts on the following page. Areas highlighted in yellow indicate where CASSRs can tailor the questionnaire for their locality. Optional questions are marked in blue. CASSRs can also include additional questions if they wish (see Appendix B).

Anytown Council

Adult Social Care
Council Buildings, 100 Town Road

Anytown A27 6BP

Contact	Adult Services Direct Team
Phone	0113 86 47259
Fax	0113 86 47258
Minicom	0113 86 47257
Email	adult.services@anytown.gov.uk
Web	www.anytown.gov.uk
My Ref	
Your Ref	0001

1st November 2009

Caring for Others

Introduction

We would like you to help us by taking around 20 minutes to give us your views about the support and services that you and the person you look after or help receive.

Who do we want to fill in the questionnaire?

We are contacting carers who have been looking after or helping someone aged 18 or over at any time during the last 12 months. By carers, we mean people who look after family, partners or friends in need of support or services because of age, physical or learning disability or illness, including mental illness. If the person you look after or help is in hospital or has moved to a care home or hospice in the last 12 months, we would still like you to fill in this questionnaire.

Why you were selected

Your name was selected randomly from our records from a list of people who have received a carers' assessment or review. We know that some carers may not yet have received an assessment or review, or have chosen not to have one, so you may have been selected if the person you care for has received an assessment or review.

Taking part

Your views are very important and will help us to improve services. The answers you give, or choosing not to respond, won't affect the services you, or the person you care for receive.

If you would like, you can ask a friend or relative to help you complete the questionnaire, but staff from Social Services who may have had involvement in your caring role should not help you.

Confidentiality

Your answers will be treated as confidential: they will not be passed on to your care workers or anyone providing you or the person you care for with services. We will use the code on this form to make sure we do not send you another questionnaire if you have already returned one. You will not be personally identified and we will not respond directly to any of your answers except in the following circumstances:

We will use the code on this form to identify who you are only if you select the option saying that you are **extremely worried** about your personal safety on question **number 22**. In that circumstance, we will use the code to identify you so that someone (but not your care worker) can contact you to talk about it.

Councils may change this if they would contact more than those who say they are extremely worried

If you indicate on this form that you would like to take part in future research on question number 57, we will use the code to identify who you are so that we can contact you.

The above statement should be omitted by councils omitting question 57. Please note that the above question numbers will change, depending on which optional questions are selected by councils and any local questions added.

What will be done with the results of the survey

The results of the survey will be used by the Care Quality Commission, the Department of Health and your local authority to see how happy people are with the support and services they receive, to see whether improvements need to be made to local care services, and for further research or analysis.

If you would like to receive a copy of the results of this survey please tick the last box at the end of the questionnaire.

What to do if you have queries or would like to know how to obtain information on the results

If you, or your friend or relative have questions you would like to ask about the survey, please ring **[insert telephone number]** on Monday to Friday between 10.00 am and 12.00 pm or between 2.00 pm and 4.00 pm.

Any queries you may have about the services you receive should be directed to staff responsible for that service, as the staff supporting this Carers survey may not be specialist advisors.

Reminder Letters

If you do not return this questionnaire then you may be sent reminder letters. If you do not wish to receive reminders then please send back the blank questionnaire in the envelope provided.

Sending back the completed questionnaire

Once you have completed the questionnaire please return it in the envelope provided by **[insert date]**. You don't need to put a stamp on the envelope.

Thank you for helping us by completing this questionnaire.

Councils wishing to provide a channel for carers to get in touch about further information, advice or services could insert contact details here

If you look after a family member, partner or friend in need of support or services because of their age, physical or learning disability or illness, including mental illness, we would like you to complete this questionnaire.

Section 1: About the person you care for

The questions in this section ask about the person you care for, by which we mean the person you look after or help, and your experience of support and services.

1. How many people aged 18 or over do you care for?

If you care for more than one person, please answer **only** in relation to the person you spend the most time helping. If you spend an equal amount of time caring for two or more people, please answer in relation to the person who lives with you. If you live with two or more people that you spend an equal amount of time caring for, please choose **one** person to answer about.

2. Who is the person you care for?

Please tick [✓] one box

Parent

Parent-in-law

Spouse/partner

Child (own/adopted/step)

Other relative

Other non-relative/friend/neighbour

3. How old is this person? _____ years

(If you don't know the exact age please give an approximate one)

4. Are they male or female?

Please tick [✓] one box

Male

Female

5. Does the person you care for have....?

Please tick [✓] all that apply

- Dementia
- A physical disability
- Sight or hearing loss
- A mental health problem
- Problems connected to ageing
- A learning disability or difficulty
- Long-standing illness
- Terminal illness
- Alcohol or drug dependency

6. Where does the person you care for usually live?

Please tick [✓] one box

- With me
- Somewhere else

7. Overall, how satisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?

Please tick [✓] one box

We haven't received any support or services from Social Services in the last 12 months

-
- I am extremely satisfied
 - I am very satisfied
 - I am fairly satisfied
 - I am neither satisfied nor dissatisfied
 - I am fairly dissatisfied
 - I am very dissatisfied
 - I am extremely dissatisfied

8. Has the person you care for used any of the support or services listed below in the last 12 months? OPTIONAL QUESTION

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

	Yes	No	Don't know
Care home	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Personal assistant	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Home care/home help	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Day centre or day activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Lunch club	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Meals on wheels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Equipment or adaptation to their home (such as a wheelchair, handrails or an alarm system)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Supported employment	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Special College	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question answers in red above are optional examples and can be removed if your council does not provide these services. Similarly, additional options can be added if you wish but not returned to the NHS Information Centre on the data return

9. Thinking about the support or services the person you care for has received (provided by a voluntary organisation, a private agency or Social Services) in the last 12 months, which of the following statements best describes your present situation? OPTIONAL QUESTION

Please tick [✓] one box

- The person I care for has received no support or services in the last 12 months
- The support or services have made things easier for me
- The support or services have made no difference to me
- The support or services have made things harder for me

10. At the present time, do you and the person you care for have the right amount of support or services, in terms of the hours or days you need? **OPTIONAL QUESTION**

Please tick [✓] one box

-
- At the present time, we do not receive any support or services
- No, we have more hours or days than we need
- The amount is about right
- No, we need a few more hours or days
- No, we need a lot more hours or days

Section 2: About your needs and experiences of support

The questions in this section ask about the support and services that **you** use as a carer. They may be arranged by you or by Social Services. They may be provided by a voluntary organisation, a private agency or Social Services.

11. Which of the following types of organisation do you get the most support or services from.....? **OPTIONAL QUESTION**

Please tick [✓] one box

- Voluntary organisations
- Private agencies
- Social Services
- Don't know

12. Have you used any of the support or services listed below, to help you as a carer over the last 12 months?

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

	Yes	No	Don't know
Information and advice	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Support from carers groups or someone to talk to in confidence	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Training for carers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Advocacy for carers <small>(Advocates speak on your behalf or assist you to express your views)</small>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Emergency care back-up scheme	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Help with household tasks or gardening	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Practical help to complete forms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Question answers in red above are optional examples and can be removed if your council does not provide these services. Similarly, additional options can be added if you wish but not returned to the NHS Information Centre on the data return

13. In the last 12 months, have you used any support or services to help you take a break from caring, lasting more than 24 hours?

Please do not include unpaid help from family and friends.

Please tick [✓] one box

- Yes
- No, because there were no support or services available to me
- No, because the support or services available were not suitable
- No, for other reasons
- Don't know

14. Overall, how satisfied were you with the support or services that helped you to take a break from caring, lasting more than 24 hours?

Please tick [✓] one box

I haven't used any support or services to have a break lasting more than 24 hours

I was extremely satisfied

I was very satisfied

I was fairly satisfied

I was neither satisfied nor dissatisfied

I was fairly dissatisfied

I was very dissatisfied

I was extremely dissatisfied

15. In the last 12 months, have you regularly used any support or services to help you have a rest from caring for between 1 hour and 24 hours?

Please do not include unpaid help from family and friends.

Please tick [✓] one box

Yes

No, because there were no support or services available to us

No, because the support or services available were not suitable

No, for other reasons

Don't know

16. Overall, how satisfied were you with the support or services that regularly helped you to have a rest from caring for between 1 hour and 24 hours?

Please tick [✓] one box

I haven't used any support or services to have a rest for between 1 and 24 hours

I was extremely satisfied

I was very satisfied

I was fairly satisfied

I was neither satisfied nor dissatisfied

I was fairly dissatisfied

I was very dissatisfied

I was extremely dissatisfied

Section 3: The impact of caring and your quality of life

Some of the questions in this section look at the impact of caring on particular aspects of your life, while others ask about the quality of different parts of your life more generally.

17. Thinking about the good and the bad things that make up your quality of life, how would you rate the quality of your life as a whole?

Please tick [✓] one box

So good, it could not be better

Very good

Good

Alright

Bad

Very bad

So bad, it could not be worse

18. Which of the following statements best describes how you spend your time?

When you are thinking about what you do with your time, please include anything you value or enjoy, including formal employment, voluntary or unpaid work, caring for others and leisure activities.

Please tick [✓] one box

- I'm able to spend my time as I want, doing things I value or enjoy
- I do some of the things I value or enjoy with my time but not enough
- I don't do anything I value or enjoy with my time

19. Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your present situation?

OPTIONAL QUESTION

Please tick [✓] one box

- I have the space and time I need to be myself
- I have some of the space or time I need to be myself but not enough
- I do not have any space or time to be myself

20. Which of the following statements best describes how much control you have over your daily life?

Please tick [✓] one box

- I have as much control over my daily life as I want
- I have some control over my daily life but not enough
- I have no control over my daily life

21. Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?

Please tick [✓] one box

- I look after myself
- Sometimes I can't look after myself well enough
- I feel I am neglecting myself

22. Thinking about your personal safety, which of the statements best describes your present situation?

By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm.

Please tick [✓] one box

- I have no worries about my personal safety
- I have some worries about my personal safety
- I am extremely worried about my personal safety

23. Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?

Please tick [✓] one box

- I have as much social contact as I want with people I like
- I have some social contact with people but not enough
- I have little social contact with people and feel socially isolated

24. Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?

Please tick [✓] one box

- I feel I have encouragement and support
- I feel I have some encouragement and support but not enough
- I feel I have no encouragement and support

25. Thinking about the skills needed for caring, which statement best describes your present situation?

Please tick [✓] one box

- I do not need any training at present
- I would like some training
- I need some training

26. Thinking about how easy it is for you to get basic services to meet your needs – such as going to see a GP, visiting a dentist or going to the library – which of the following statements best describes your present situation?

Please tick [✓] one box

I can get the basic services I need

I can't always get the basic services I need

I can't always get the basic services I need, and I think there is a risk to my health

27. How is your health in general?

Please tick [✓] one box

Very good

Good

Fair

Bad

Very bad

28. In the last 12 months, has your health been affected by your caring role in any of the ways listed below?

Please tick [✓] all that apply

Feeling tired

Feeling depressed

Loss of appetite

Disturbed sleep

General feeling of stress

Physical strain (e.g. back)

Short tempered/irritable

Had to see own GP

Developed my own health condition

Made an existing condition worse

Other

No, none of these

29. In the last 12 months, has caring caused you any financial difficulties?

Please tick [✓] one box

- No, not at all
- Yes, to some extent
- Yes, a lot

Section 4: Information and advice quality

The next questions ask for your views about the quality of information and advice.

30. Please tick the box which comes closest to describing how quickly Social Services have responded to your queries or questions in the last 12 months.

Please tick [✓] one box

- I have not contacted Social Services with a query or question in the last 12 months
-
- Someone always got back to me
- Sometimes they got back to me, but sometimes I had to contact them again
- I had to contact them more than twice, but eventually someone got back to me
- They didn't get back to me

31. In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information and advice from different sources, such as voluntary organisations and private agencies as well as Social Services.

Please tick [✓] one box

- I have not tried to find information or advice in the last 12 months
-
- Very easy to find
- Fairly easy to find
- Fairly difficult to find
- Very difficult to find

32. In the last 12 months, how helpful has the information and advice you have received been? Please include information and advice from different organisations, such as voluntary organisations and private agencies as well as Social Services.

Please tick [✓] one box

- I have not received any information or advice in the last 12 months
-
- Very helpful
- Quite helpful
- Quite unhelpful
- Very unhelpful

Section 5: Arrangement of support and services in the last 12 months

The next questions are about organising the support and services for you and the person you care for.

33. Has it been easy or difficult to get the support or services the person you care for needs in the past 12 months? The services may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services. **OPTIONAL QUESTION**

Please tick [✓] one box

- There was no need to get any support or services in the last 12 months
-
- Very easy
- Quite easy
- Quite difficult
- Very difficult

34. Have you found it easy or difficult to get the support or services you need as a carer in the last 12 months? The services may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

Please tick [✓] one box

- I did not need any support or services in the last 12 months
-
- Very easy
- Quite easy
- Quite difficult
- Very difficult

35. In the last 12 months, have you or the person you care for had to wait to get any support or services? OPTIONAL QUESTION

Please tick [✓] one box

..... We haven't asked for any support or services in the last 12 months

No, we haven't had to wait

Yes, but the wait was not a problem

Yes, and the wait should be a bit shorter

Yes, and the wait should be a lot shorter

36. How do you feel about the level of contact you had with the care manager or social worker that works with the person you care for? OPTIONAL QUESTION

Please tick [✓] one box

..... The person I care for does not have a care manager or social worker

The level of contact should be reduced

The level of contact is about right

The level of contact should be increased a little

The level of contact should be increased a lot

37. In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

Please tick [✓] one box

..... There have been no discussions that I am aware of, in the last 12 months

I always felt involved or consulted

I usually felt involved or consulted

I sometimes felt involved or consulted

I never felt involved or consulted

Section 6: Service quality

The questions in this section ask about how well the support and services you and the person you care for receive suit you and your situation.

38. Does the person you care for get support or services at times of the day or days of the week that suit you? OPTIONAL QUESTION

Please tick [✓] one box

- At the present time, we do not receive any support or services
-
- Yes
- No, I would like support or services at other times of day
- No, I would like support or services on other days of the week
- No, I would like both different times of the day and days of the week

39. Can the support or services you receive react to changes in your day-to-day needs and those of the person you care for? OPTIONAL QUESTION

For example, can you ask that care workers visit at a different time, the person you care for goes to a day centre on a different day, or that things are done differently?

Please tick [✓] one box

- At the present time, we do not receive any support or services
-
- Don't know
- Always
- Usually
- Sometimes
- Never

40. Are you kept informed about day-to-day changes to support or services that you or the person you care for receives? (For example, that a care worker will be late or there will be a different care worker) OPTIONAL QUESTION

Please tick [✓] one box

- At the present time, we do not receive any support or services
-
- There haven't been any changes
- Someone always lets me know about changes
- Someone usually lets me know about changes
- They hardly ever let me know about changes
- They never let me know about changes

41. Do care workers or personal assistants treat you with courtesy and respect?

OPTIONAL QUESTION

Please tick [✓] one box

- At the present time, we do not receive any support or services

Always
Usually
Sometimes
Never

Section 7: Experience of health services as a carer

42. Do you feel you have been treated with respect as a carer, when you have been in contact with health professionals at a NHS hospital about the person you care for, over the last 12 months?

Please tick [✓] one box

- I have not been in contact with health professionals at a NHS hospital about the
person I care for in the last 12 months

Always
Usually
Sometimes
Never

43. Do you feel you were involved as much as you wanted to be in discussions about the care and treatment of the person you care for, when you have been in contact with health professionals at a NHS hospital in the last 12 months?

Please tick [✓] one box

I have not been in contact with health professionals at a NHS hospital about the person I
----- care for in the last 12 months

- Always
- Usually
- Sometimes
- Never

44. Do you feel you have been treated with respect as a carer, when you have been in contact with health professionals from a GP surgery/health centre about the person you care for, over the last 12 months?

Please tick [✓] one box

I have not been in contact with health professionals at a GP surgery/health centre about the
----- person I care for in the last 12 months

- Always
- Usually
- Sometimes
- Never

45. Do you feel you were involved as much as you wanted to be in discussions about the care and treatment of the person you care for, when in contact with health professionals from a GP surgery/health centre in the last 12 months?

Please tick [✓] one box

I have not been in contact with health professionals at a GP surgery/health centre about the
----- person I care for in the last 12 months

- Always
- Usually
- Sometimes
- Never

46. Overall, do you feel GPs support you in your role as a carer?

Please tick [✓] one box

The GPs I see don't know that I am a carer

Always

Usually

Sometimes

Never

Section 8: About yourself

The next group of questions helps us to get a picture of the types of carers who took part in this survey.

47. In addition to your caring role, please tell us which of the following also applies to you? **OPTIONAL QUESTION**

Please tick [✓] all that apply

Retired

Employed full-time

Employed part-time (working 30 hours or less)

Self-employed full-time

Self-employed part-time

Not in paid work

Doing voluntary work

Other

48. Thinking about combining paid work and caring, which of the following statements best describes your current situation?

Please tick [✓] one box

I am in paid employment and I feel supported by my employer

I am in paid employment but I don't feel supported by my employer

I do not need any support from my employer to combine work and caring

I am not in paid employment because of my caring responsibilities

I am not in paid employment for other reasons

I am self-employed or retired

49. About how long have you been looking after or helping the person you care for?

Please tick [✓] one box

- Less than 6 months
- Over 6 months but less than a year
- Over 1 year but less than 3 years
- Over 3 years but less than 5 years
- Over 5 years but less than 10 years
- Over 10 years but less than 15 years
- Over 15 years but less than 20 years
- 20 years or more

50. About how long do you spend each week looking after or helping the person you care for?

Please tick [✓] one box

- 0-9 hours per week
- 10-19 hours per week
- 20-34 hours per week
- 35-49 hours per week
- 50-99 hours per week
- 100 or more hours per week
- Varies – Under 20 hours per week
- Varies – 20 hours or more per week
- Other

If other please specify:

51. Over the last 12 months, what kinds of things did you usually do for the person you care for? OPTIONAL QUESTION

Please tick [✓] all that apply

- Personal care?
(Things like dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet)
- Physical help?
(Such as helping with walking, getting up and down stairs, getting into and out of bed)
- Helping with dealing with care services and benefits?
(Things like making appointments and phone calls, filling in forms)
- Helping with paperwork or financial matters?
(Such as writing letters, sending cards, filling in forms, dealing with bills, banking)
- Other practical help?
(Things like preparing meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital)
- Keeping him/her company?
(Things like visiting, sitting with, reading to, talking to, playing cards or games)
- Taking him/her out?
(Such as taking out for a walk or drive, taking to see friends or relatives)
- Giving medicines?
(Things like making sure he/she takes pills, giving injections, changing dressings)
- Keeping an eye on him/her to see he/she is all right?
- Giving emotional support?
- Other help?

52. Do you have any of the following?

Please tick [✓] all that apply

- A physical impairment or disability
- Sight or hearing loss
- A mental health problem or illness
- A learning disability or difficulty
- A long-standing illness
- Other
- None of the above

53. How old are you? _____ years

Councils may choose to omit the above question if it can be supplied accurately from their current records.

54. Are you male or female?

Please tick [✓] one box

Male

Female

Councils may choose to omit the above question if it can be supplied accurately from their current records.

55. To which of these groups do you consider you belong?

Please tick [✓] one box

White
(British, Irish, Traveller of Irish Heritage, Gypsy/Roma, any other White background)

Mixed
(White and Black Caribbean, White and Black African, White and Asian, any other Mixed background)

Asian or Asian British
(Indian, Pakistani, Bangladeshi, any other Asian background)

Black or Black British
(Caribbean, African, any other Black background)

Chinese

Any other ethnic group

Councils may choose to omit the above question and supply data from their own records if they are confident of the quality and coverage of the information about the carer's assessment of their ethnic origin in their current records. Councils including this question may break down the categories further if they wish to do so.

56. Did someone help you to complete this questionnaire?

Please tick [✓] one box

Yes

No

Councils may seek further information on the category of person who helped here if they wish – but these should only be categories of person (e.g. relative) and not names. Any expanded categories need to be aggregated back to just an overall 'yes' category before entering the results onto the data return.

57. If further research were to take place, would you be happy for us to contact you?

OPTIONAL QUESTION

Please tick [✓] one box

Yes

No

58. Please use the space provided below to describe any other experiences you would like to tell us about or to write any other comments you would like to make?

OPTIONAL QUESTION

Please tick (✓) this box if you would like to receive a copy of the report of this survey

Thank you for helping us by filling in this questionnaire.

Please post it back to us in the envelope provided.

You do not need to put a stamp on the envelope.

For your views to count please return this form by **[insert date]**

Appendix B –Additional questions

Open questions

CASSRs have the option to add the following open questions to the recommended questionnaire if they wish to gather qualitative information about their locality; however this information will not be analysed by the IC.

The question below can be inserted after question 8

Please indicate any other services that would help the person you care for:

The question below can be inserted after question 10

If you or the person you care for need a different amount(s) of support or services, please tell us what is needed:

The question below can be inserted after question 12

Please indicate the support or services you would like to help you as a carer:

The question below can be inserted after question 25

If you would like or need some training on caring, please tell us what you would like:

The question below can be inserted after question 31

If you found it difficult to find helpful information or advice, please tell us about the difficulties you experienced and what might help:

Other additional questions

The following questions are very specific to home/day care services which may not be applicable to all carers. These questions were excluded from the recommended questionnaire in order to improve its overall balance. CASSRs wishing to look at their home/day care provision in depth could re-introduce these questions.

Any or all of the questions below can be inserted after question 41.

Does the person you care for see the same care workers or personal assistants?

Please tick [✓] one box

- The person I care for does not see any care workers or personal assistants
- Don't know
- Always
- Usually
- Sometimes
- Never

Do you feel that the care workers or personal assistants who help the person you care for are trustworthy?

Please tick [✓] one box

- The person I care for does not see any care workers or personal assistants
- Don't know
- Always
- Usually
- Sometimes
- Never

Do you have confidence that care workers or personal assistants are skilled and trained?

Please tick [✓] one box

- The person I care for does not see any care workers or personal assistants
- Don't know
- I feel they are very skilled and well trained
- I feel they are quite skilled and trained
- I feel they are unskilled and urgently need more training

Appendix C – Excluded variables

Variable name	Reason for exclusion
Health services used by carer	After discussion with DH carers' policy team, the focus shifted away from the receipt of particular types of health services, towards more general questions on access to healthcare and the affect of caring on health.
Impact of the environment on caring	Considered a low priority during consultation process carried out in November 2008.
Relationships with social care staff: Carer perception whether cared for person treated with dignity	Excluded to retain focus on the carer.
Impact of equipment on caring activities	Considered a low priority during consultation process carried out in November 2008.
Whether carer disabled	Merged into Q53.
Housing tenure	Originally intended as a proxy for socio-economic status, however testing showed that it was a sensitive question causing concern amongst carers about what the information would be used for.
Receipt of benefits	There was concern about the reliability of self-completion data on this. This variable was suggested to measure the carer's views on the affect of caring on finances which is better captured by Q29.
Impact of personalisation	It was considered that personalisation is too early in its implementation to be measured effectively yet.
Use of hospital services by cared for person	Excluded to retain focus on the carer.
Carer's perception of respect and dignity of cared for person by hospital staff	Excluded to retain focus on the carer.
Use of community healthcare services by cared for person	Excluded to retain focus on the carer.
Carer's perception of respect and dignity of cared for person by community healthcare staff	Excluded to retain focus on the carer.
Timeliness of information and advice	Covered by other questions on information and advice provision.
Carer perceived partnership with services	Covered by Q37.
Whether Social Services consider carer's wishes regarding leisure, study or work	Testing revealed that carers found this question difficult to answer. Some participants had not had any discussions with Social Services. Others did not view this question as relevant because: <ul style="list-style-type: none"> • they felt that the cared for person's wishes should be the priority. • they did not regard it the role of Social Services to ask them about their leisure, employment etc.
Whether religious beliefs taken into account by Social Services	Considered a low priority during consultation process carried out in November 2008.
Reported long standing illness	Covered by Q53.
Positive relationship with person cared for	Considered to be at risk from non-response by those carers with a poor relationship with cared for person. More appropriate for a face to face interviewer administered survey than a self-completion approach.
Satisfaction with support planning	Testing revealed that carers think about various types of meetings and situations with a range of professionals when answering this question. This question was excluded due to the lack of certainty as to what respondents are answering in relation to.
Perception of joint working between health and social care	The SSUSG decided to drop this question in order to reduce the length of the questionnaire.

Appendix D - Cognitive interviewing

Over the last two decades, cognitive interviews have been increasingly adopted to test the validity of survey questions prior to their use in large-scale surveys. Cognitive interviews can be used to determine whether research participants understand and accurately answer survey questions in the ways intended by the research commissioners (Forsyth and Lessler, 1991).

Cognitive interviewing draws heavily upon cognitive psychology and its theoretical traditions. In developing the method, cognitive psychologists applied cognitive theory to the task of answering survey questions. The model proposed by Tourangeau (1984) sets out the task as composed of several mental processes that fall into the four main categories shown below:

- Comprehension
- Retrieval
- Judgement
- Response

These four categories refer to processes or 'components' that respondents must engage in when responding to a question. These components are used by the interviewers as a guide during the interview process to try to uncover differences in the interpretation of questions by respondents.

The two main techniques commonly used when conducting cognitive interviews are think aloud technique⁵ and concurrent probing technique⁶. Each of the techniques has its strengths and drawbacks depending on the main purpose of testing. Think aloud is useful for gathering information on how participants navigate through the questionnaire, whereas concurrent probing technique is more useful for gaining insight into the participants' understanding of the questions (Willis, 2005). The main focus of this project was to test the clarity of question wording and participants' understanding of concepts, therefore the main technique used was concurrent probing.

⁵ In this method, the interviewee leads the interview by filling in the questionnaire and talking about what they are doing as they are filling it in. The interviewer observes the person as they fill it in. Usually any difficulties are followed up by the interviewer at the end with retrospective probing.

⁶ In this method, the interviewer reads the question and asks the interviewee to respond. Following the response, the interviewer then asks further questions or "probes" to determine what the interviewee understood by the question and how they came to this understanding.