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Personal Social Services Survey of Adult Carers in England - 2009-10

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Summary

This is the first national user experience survey of carers known to Councils with Adult Social Services Responsibilities (CASSRs). Carers' thoughts, opinions and feelings are sought on a number of topics that are thought to be integral to helping them achieve a balanced life alongside their caring role. The survey was aimed at carers identified by local authorities aged 18 and over who are caring for someone aged 18 and over.

On 10 June 2008¹, the then Government published a Carers' Strategy which set out an aim that by 2018:

- carers will be respected as expert care partners and will have access to the integrated and personalised 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;
- carers will be supported so that they are not forced into financial hardship by their caring role;
- carers will be supported to stay mentally and physically well and treated with dignity

This survey along with other survey work acts as a benchmark for the strategy and a number of the questions analysed throughout the report address these aims.

Headline findings 2009/10

The Carer

- Nearly half (49%) of carers who responded to the survey were aged 65 or over, 44 per cent were aged 45-64 and the remaining 7 per cent were aged 18-44.
- Almost two-thirds (66%) of carers who responded to the survey were female.
- 91 per cent of respondents where ethnicity was known came from the White ethnic background.
- 57% of carers spent 35 hours or more per week looking after or helping the person they were caring for, 49% spent 50 hours or more caring and 37% of carers spent 100 hours or more per week caring.
- Almost three quarters (73%) of carers said that the person they were caring for lived with them.
- 29 per cent were looking after a parent, 47 per cent were looking after a spouse or partner, 14 per cent were looking after their child, 2 per cent were looking after their parent-in-law, 5 per cent were looking after another relative and the remaining 2 per cent were looking after a non-relative, friend or neighbour.

Experience of Support and Services

- 54 per cent of carers reported that they were either extremely or very satisfied with the support or services they and the person they cared for had received in the last 12 months from Social Services, a further 29 per cent said they were fairly satisfied, 9

¹ "Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own" available from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085345

per cent were neither satisfied or dissatisfied and the remaining 8 per cent were either extremely, very or fairly dissatisfied.

- 29 per cent of carers were using support or services to enable them to take a break lasting longer than 24 hours and 35 per cent took shorter breaks lasting less than 24 hours.
- For longer breaks, 16 per cent were not using them because they were not available, a further 6 per cent were not doing so because they did not feel the services available were suitable and the remaining 48 per cent were not doing so for other reasons.
- For shorter breaks 15 per cent were not using them because they were not available, a further 5 per cent were not doing so because they did not feel the services available were suitable and the remaining 46 per cent were not doing so for other reasons.
- 61 per cent of users who were accessing longer breaks lasting more than 24 hours were either very or extremely satisfied with the breaks. This compared to 65 per cent of carers accessing short breaks lasting up to 24 hours.
- Of respondents who had indicated they had used carer support and services, 72 per cent stated that they found the support or services either quite easy or very easy to access, 21 per cent found it quite difficult and the remaining 7 per cent found it very difficult.
- Half (50%) of carers felt they were always involved or consulted as much as they wanted to be in discussions about the support or services the person they were caring for was receiving. A further 28 per cent said this was usually the case, 15 per cent were sometimes involved but 6 per cent said they were never involved to a level they would have liked.

Quality of Life

- 36 per cent of carers who responded to the survey said the overall quality of their lives was either good, very good or could not be better, a further 47 per cent said their quality of life was alright and the remaining 17 per cent said it was either bad, very bad or so bad it could not be worse.
- 23 per cent of carers reported they were able to spend their time as they wanted doing the things they valued or enjoyed. 64 per cent felt they did some things they valued or enjoyed but not enough and the remaining 13 per cent said they don't do anything they value or enjoy with their time.

Health

- Almost half (49%) of respondents reported that their health in general was either good or very good, 42 per cent said it was fair and the remaining 9 per cent said it was either bad or very bad.
- 82 per cent of carers stated that they were either always or usually involved in discussions with health professionals about the treatment of the person they care for at NHS hospitals compared to 88 per cent at GP surgeries or health centres
- 85 per cent of carers either always or usually felt they were treated with respect as a carer by health professionals at NHS hospitals compared to 90 per cent at GP surgeries or health centres.

Employment and Finance

- Nearly half (47%) of carers were either retired or self employed. 12 per cent were in employment and felt supported by their employer but 4 per cent were in employment and did not feel supported. A further 17 per cent were not working because of their caring responsibilities, 6 per cent did not need support from their employer to combine work and caring, and the remaining 14 per cent were not in employment for other reasons.
- 8 per cent of carers said they had suffered a lot of financial difficulty because of their caring role, 33 per cent had suffered to some extent but 60 per cent said they had suffered no financial difficulties at all.

Information and Advice

- A quarter (25%) of respondents reported that they found it very easy to find the information and advice they needed about support, services and benefits from either voluntary organisations, private agencies or Social Services. Almost half (48%) stated they found it fairly easy to get this information, but 19 per cent found it fairly difficult and 7 per cent found it very difficult.
- The majority of carers who had received information and advice felt it had been helpful to them. 92 per cent said that they had found it either quite or very helpful but the remaining 8 per cent said they had found it either quite or very unhelpful.

Introduction

Background

There are 5 million carers in England and Wales², but only a subset of these are known to CASSRs. Around 440,000 carers were offered an assessment in 2008/09 by their council and 208,000 of these went on to receive a carers specific service and a further 148,000 received information only³.

This is the first national user experience survey to focus on carers that have been identified by local authorities. CASSRs had the option of deciding whether to take part in this survey as it was voluntary and 90 out of the 152 councils (59%) decided to take part.

Councils were asked to survey a sample of carers (aged 18+) who had been assessed or reviewed, (either separately or jointly with the cared for person), by social services during the past 12 months when the sample was chosen, and also carers who were named on the file of carers who had been assessed or reviewed in the last 12 months when the sample was chosen. This latter group of carers were referred to as “carers known by association”.

However, a pilot survey conducted in February 2009 had shown that not all councils held enough detailed information to identify carers known by association, so not all councils were able to include this further group of carers. In total, 41 of the 90 councils (46%) were able to include this group and they are included in the following analyses within this report.

Prior to the survey, a successful pilot was run in early 2009 with 25 councils taking part. Following the pilot, some questions were either revised or excluded with some new questions also added.

The questionnaire contained a total of 58 questions with 39 being mandatory and 19 being optional and councils could exclude some or all of these if they wished. The fieldwork for the full survey was carried out in November 2009.

Data Quality

A sample of 88,000 carers out of an eligible population of 176,000 was selected and sent questionnaires. 35,000 of these carers responded to the survey giving a response rate of 40 per cent.

Despite not all local authorities taking part in the survey, it is felt that the results can be taken to be representative of England as a whole. Analysis to support this assumption can be found in the Coverage section of the report (section 5).

Any differences discussed between categories or questions in the commentary within the report have been tested for significance.

² From “Survey of Carers in Households - 2009/10 England - Provisional Results”
www.ic.nhs.uk/pubs/carersurvey0910

³ From “Community Care Statistics 2008-09: Social Services Activity Report, England” published on 28 April 2010 and available from <http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information/community-care-statistics-2008-09-social-services-activity-report-england>

1. The carer

Introduction

This section begins with some demographic profiles of carers known to councils before moving on to look at some of the factors that are likely to affect the everyday lives of carers, and how these measure up against the overall quality of life of the carer. This chapter therefore provides information which is useful for assessing all the aims of the carers' strategy,

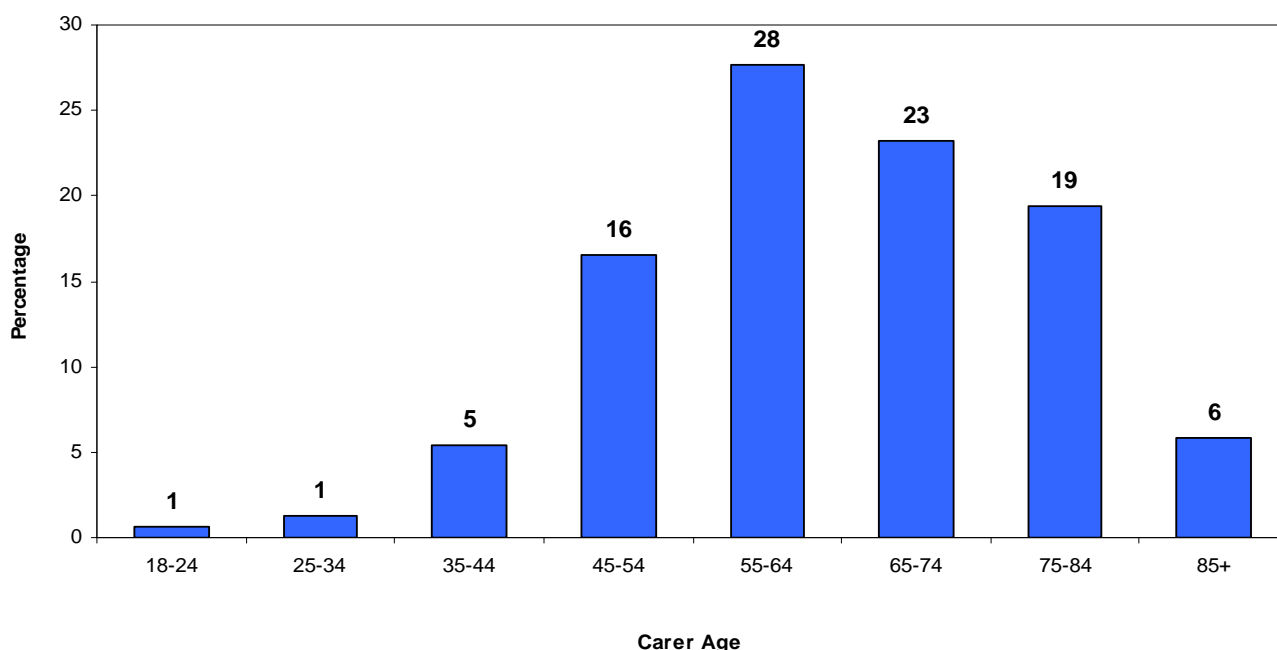
Demographic Profile of Carers Known to Councils

This section is restricted to carers who actually responded as there was concern that some of the carers known by association who were sampled may have been next of kin rather than actual carers and may therefore not have responded to the survey. Therefore, including them in this analysis may have distorted the results. More discussion on this is given later in the report.

Questions on age, gender and ethnicity were provided from council records although councils could instead add questions to the survey if they were not confident of the accuracy of this information from their own records.

Figure 1.1 shows that nearly half (49%) of carers who responded to the survey were aged 65 or over, 44 per cent were aged 45-64 and the remaining 7 per cent were aged 18-44.

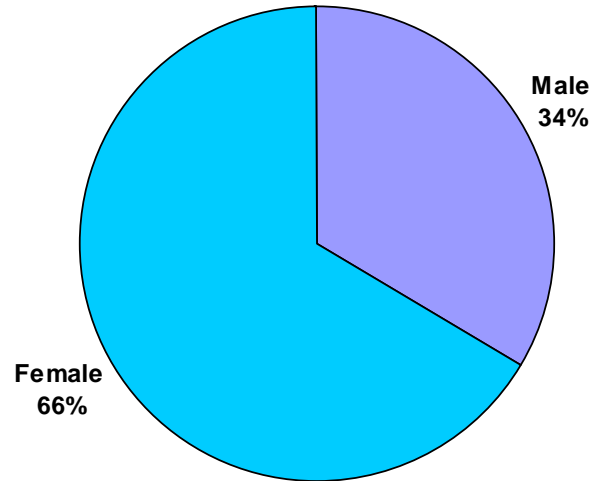
Figure 1.1 Age of Carers who Responded to Survey



1. Figures may not add up to 100 per cent due to rounding
2. Based on 33,800 responses where age was known. Excludes 1,300 carers where age was unknown

The carers strategy document outlines in several places that the vast majority of caring is carried out by women and this is supported by the findings of this survey. Nearly two-thirds (66%) of carers responding to the survey were females and the remaining one-third (34%) were male as shown in **figure 1.2**.

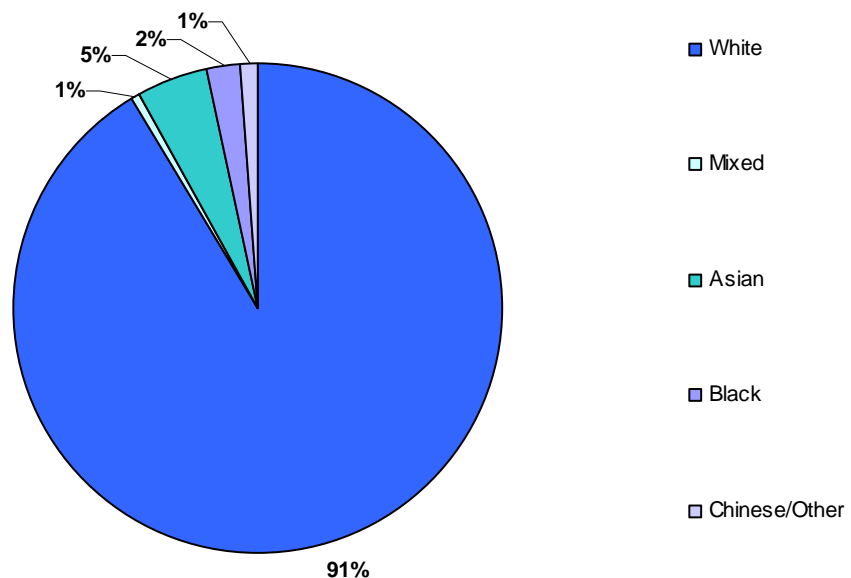
Figure 1.2 Gender of Carers who Responded to the Survey



1. Figures may not add up to 100 per cent due to rounding
2. Based on 34,800 responses where gender was known. Excludes 400 carers where gender was unknown

Figure 1.3 shows that 91 per cent of respondents where ethnicity was known came from a White ethnic background. The next largest group was the Asian ethnic group at 5 per cent.

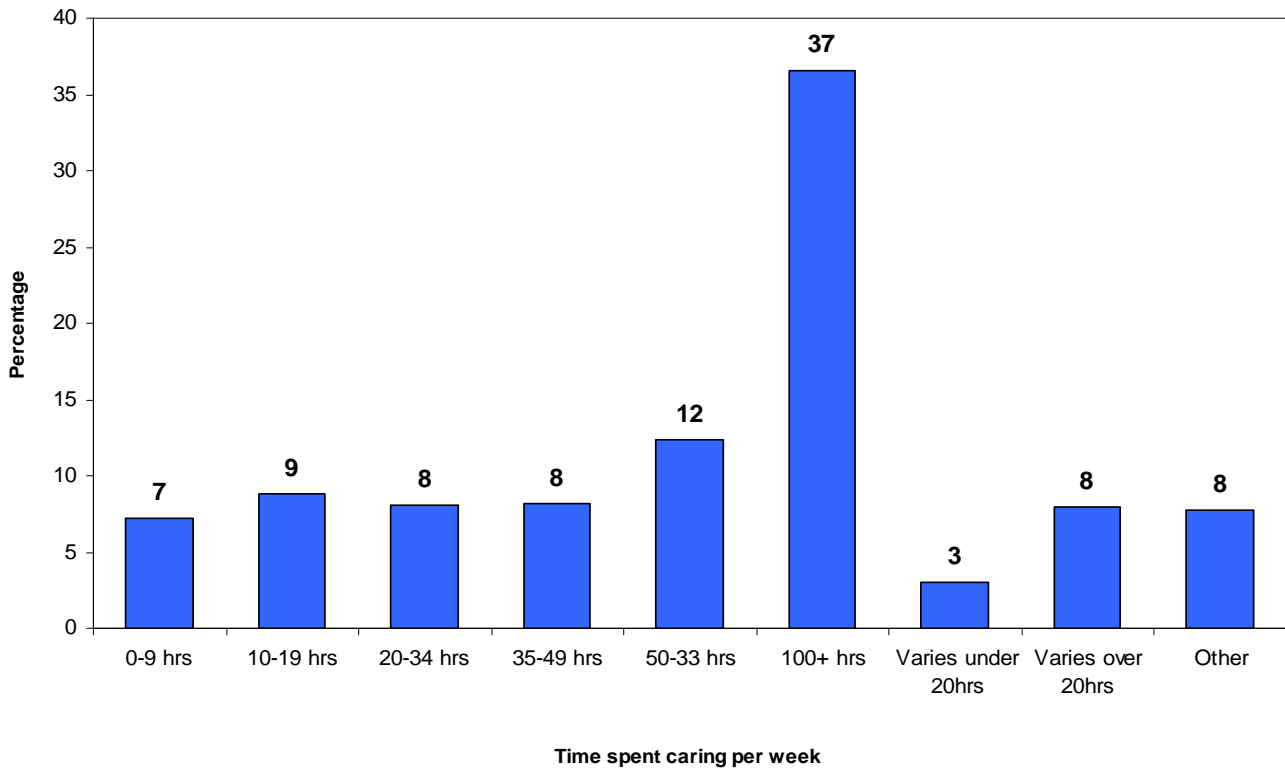
Figure 1.3 Carers ethnic background who responded to the Survey



1. Figures may not add up to 100 per cent due to rounding
2. Based on 31,900 responses where ethnicity was known. Excludes 3,200 responses where ethnicity was unknown

Figure 1.4 shows how long respondents stated they spent caring per week. 57% of carers spent 35 hours or more per week looking after or helping the person they were caring for, 49% spent 50 hours or more caring and 37% of carers spent 100 hours or more per week caring. A further 8 per cent gave an answer of “other” and were asked to specify how many hours they did spend caring. This information was not collected centrally but councils were instructed to recode answers such as “all the time” or “24/7” to “100 or more hours”.

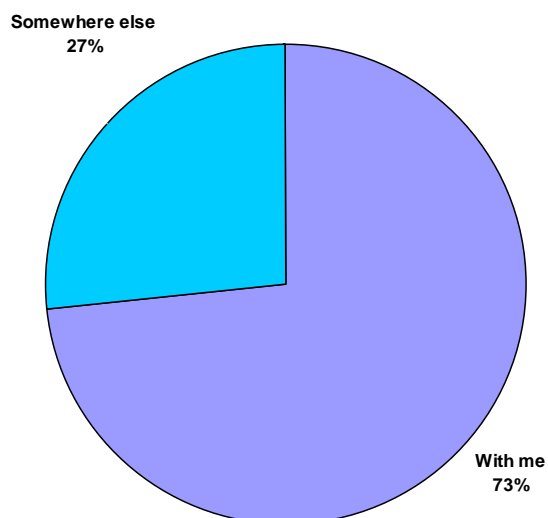
Figure 1.4 About how long each week do you spend looking after or helping the person you care for? (Q50)



1. Figures may not add up to 100 per cent due to rounding
2. Based on 32,600 responses

Figure 1.5 shows where the person being cared for usually lives. Almost three quarters (73%) of respondents reported that this was with them with the remainder stating that the cared for person lived elsewhere.

Figure 1.5 Where does the person you care for usually live? (Q6)

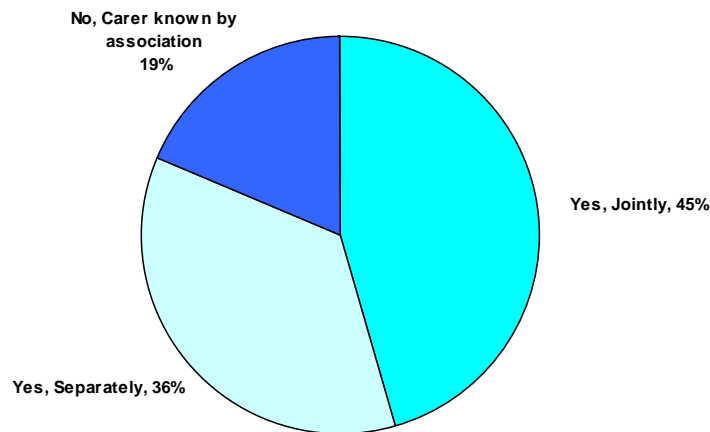


1. Figures may not add up to 100 per cent due to rounding
2. Based on 33,900 responses

Figure 1.6 shows how and whether the carer has been assessed in the last 12 months. It should be noted that of the 90 councils who took part, only 41 were able to include carers “known by association” within their samples. Reasons for not including this group of carers included not being able to record such information on their current IT systems and having this information but being unsure of its accuracy.

Despite the omission of carers known by association by many councils, this group still formed 19 per cent of the total of respondents. 45 per cent of the carers who responded to the survey had had a joint assessment with the person they were caring for and the remaining 36 per cent had been assessed separately.

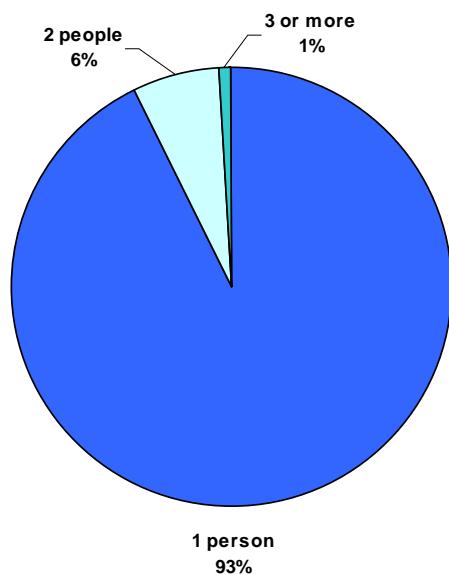
Figure 1.6 Carer assessed or reviewed in last 12 months or 'Carer known by association'?



1. Figures may not add up to 100 per cent due to rounding
2. Based on 32,300 responses where it was known how and whether the carer had been assessed. Excludes 2,800 responses where it was not known.

Carers were asked how many people aged over 18 they cared for. **Figure 1.7** shows that for the majority of respondents (93%), this is one person. A further 6 per cent reported they cared for 2 people and the remaining 1 per cent cared for 3 or more people.

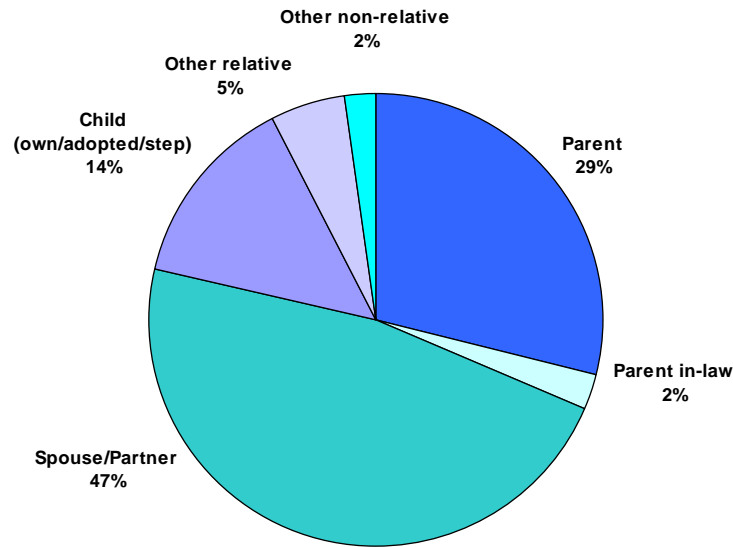
Figure 1.7 How many people aged 18 or over do you care for? (Q1)



1. Based on 33,300 responses
2. Figures may not add up to 100% due to rounding

Although carers were asked the number of people they cared for they were asked to fill in the survey in relation to just one person. **Figure 1.8** shows who carers reported to be the main person that they cared for. 47 per cent of respondents said that this was their spouse/partner, 29 per cent said it was their parent and 14 per cent said it was their child. The remaining 10 per cent is split between other relative, other non-relative and parent in-law.

Figure 1.8 Who is the person you care for? (Q2)

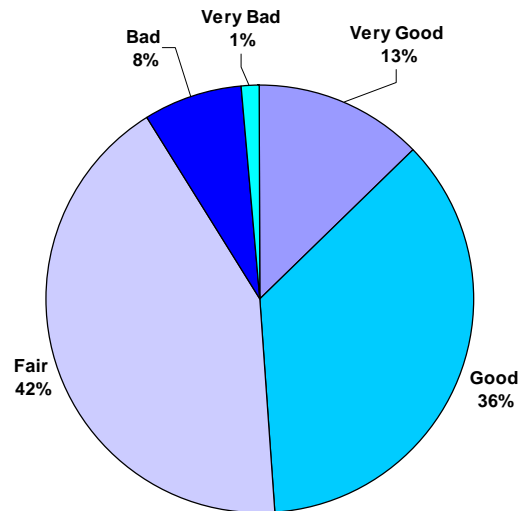


1. Based on 34,600 responses
2. Figures may not add up to 100% due to rounding

Health of the Carer

Figure 1.9 shows how carers felt about their health in general. Almost half (49%) of respondents reported that their health was either good or very good, 42 per cent said it was fair but 9 per cent reported that it was either bad or very bad.

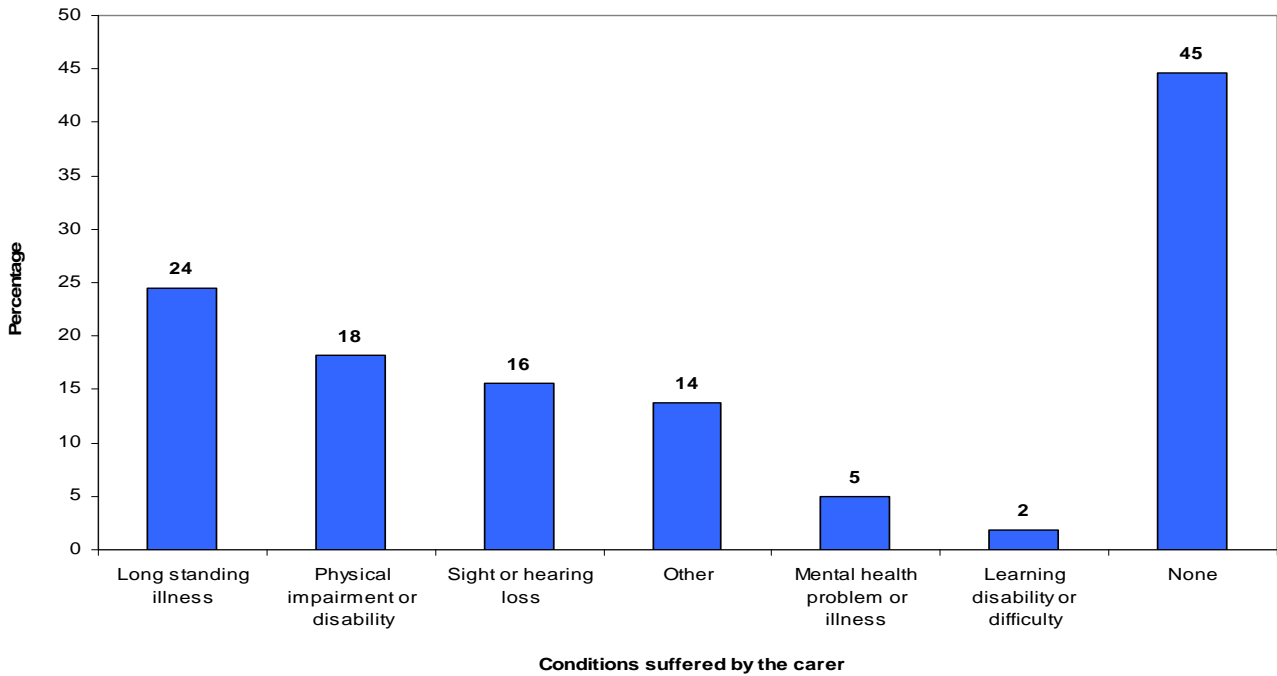
Figure 1.9 How is your health in general? (Q27)



1. Figures may not add up to 100 per cent due to rounding
2. Based on 33,700 responses

Figure 1.10 shows whether carers suffered from various long-term health conditions although 45 per cent said they did not. 24 per cent reported suffering from a long standing illness, and 18 per cent suffered from a physical impairment or disability. Respondents could select more than one option.

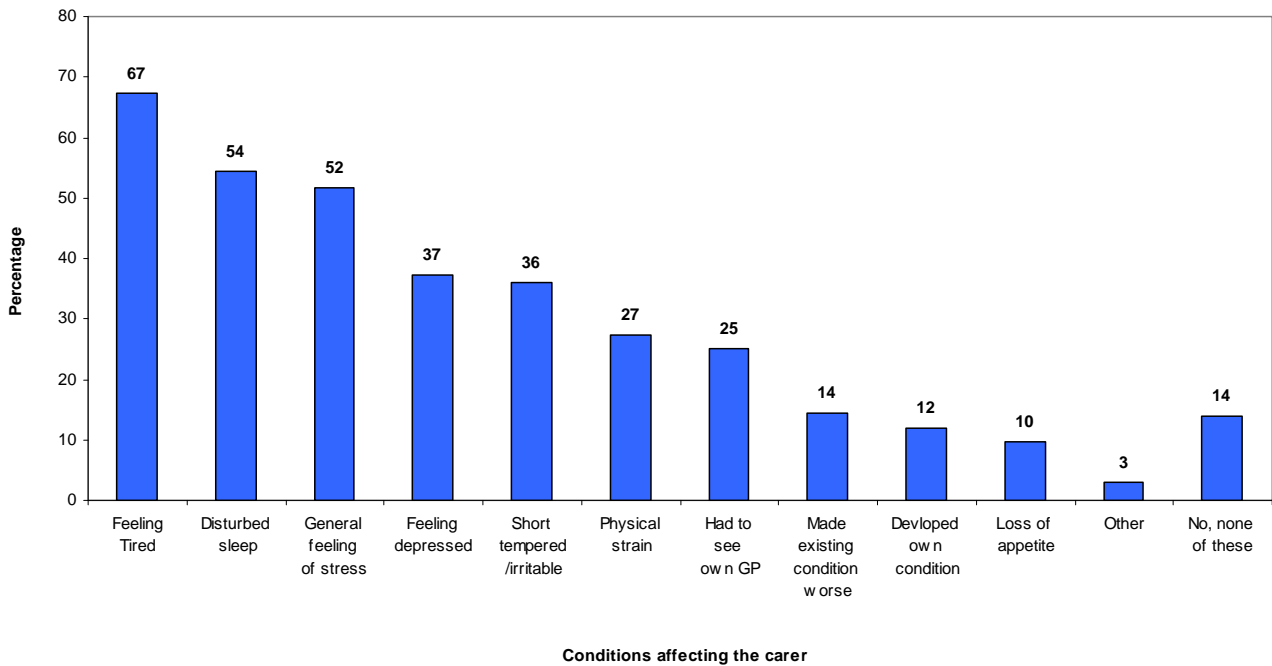
Figure 1.10 Do you have any of the following conditions? (Q52)



1. Figures do not add up to 100 per cent as respondents could select more than one option
2. Based on 31,000 responses

Carers were also asked whether their health had been affected by their caring role. **Figure 1.11** shows that two-thirds (67%) of carers reported feeling tired in the last 12 months, 54 per cent had suffered from disturbed sleep, 52 per cent had experienced a general feeling of stress and 37 per cent had felt depressed. Conversely, 14 per cent said their health had not been affected by any of these conditions in the last 12 months. Again, respondents could select more than one option.

Figure 1.11 In the past 12 months, has your health been affected by your caring role in any of the ways listed? (Q28)



1. Figures do not add up to 100 per cent as respondents could select more than one option
2. Based on 33,900 responses

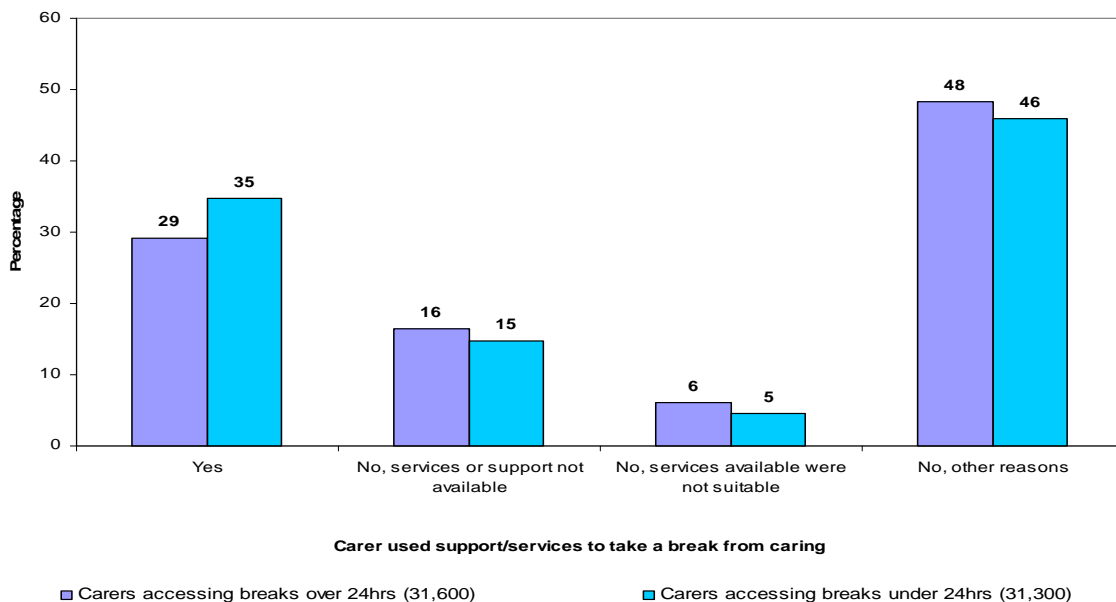
Services Accessed by Carers

Figure 1.12 shows that 29 per cent of carers were using support or services to enable them to take a break lasting longer than 24 hours compared to 35 per cent of carers accessing shorter breaks of less than 24 hours.

For longer breaks lasting more than 24 hours, 16 per cent were not using them because they were not available, a further 6 per cent were not doing so because they did not feel the services available were suitable and the remaining 48 per cent were not doing so for other reasons.

For shorter breaks 15 per cent were not using them because they were not available, a further 5 per cent were not doing so because they did not feel the services available were suitable and the remaining 46 per cent were not doing so for other reasons.

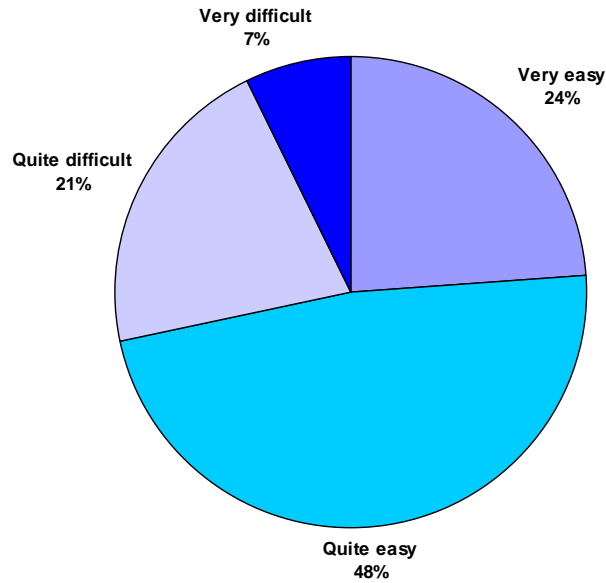
Figure 1.12 In the last 12 months, have you used any support or services allowing you to take a break from caring lasting more than 24 hours (Q13) or less than 24 hours (Q15)



1. Figures may not add up to 100 per cent due to rounding
2. Excludes 1,200 responses where carer did not know if they were using breaks of more than 24 hours.
3. Excludes 1,000 responses where carer did not know if they were using breaks less than 24 hours

Figure 1.13 shows how easy or difficult carers found it to get the support or services they as carers need. Almost three quarters (72%) reported they found it either very or quite easy to get the support/services they needed, 21 per cent found it quite difficult but 7 per cent found it very difficult.

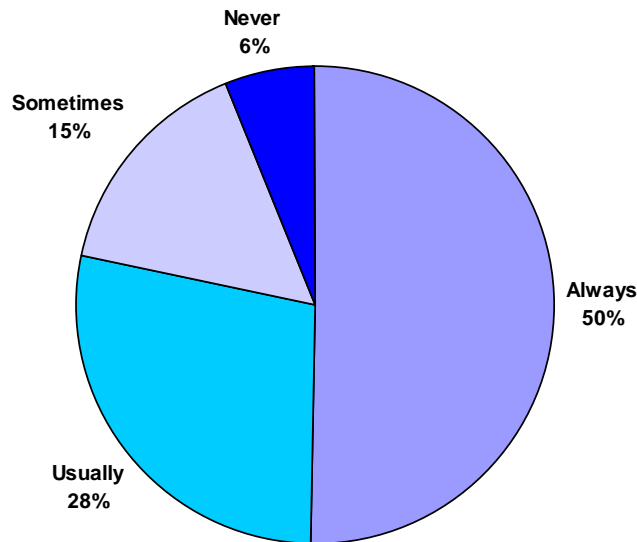
Figure 1.13 Have you found it easy or difficult to get the support or services you need as a carer in the last 12 months (Q34)



1. Figures may not add up to 100 per cent due to rounding
2. Based on 22,300 responses
3. 10,300 respondents who stated 'They did not need any support or services in the last 12 months' are excluded from the above chart

Figure 1.14 shows whether carers felt involved or consulted as much as they wanted to be in discussions about support or services provided to the person they were caring for. Half the respondents (50 %) said they were always involved as much as they wanted to be with a further 28 per cent stating this was usually the case. 15 per cent were sometimes involved but 6 per cent said they were never involved as much as they would have liked.

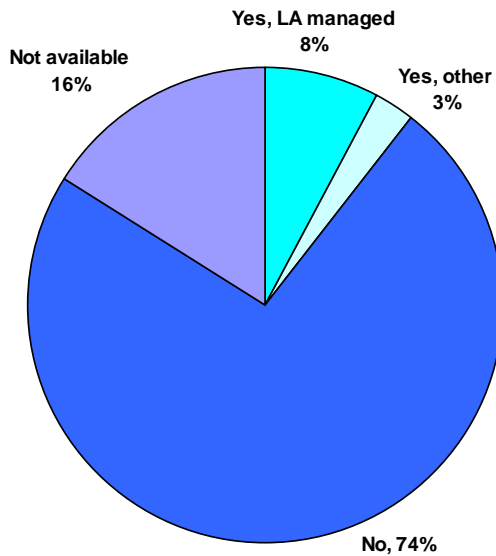
Figure 1.14 In the last 12 months, do you feel involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for? (Q37)



1. Figures may not add up to 100 per cent due to rounding
2. Based on 24,500 responses
3. 8,900 carers who said 'There have been no discussions that I am aware of in the last 12 months' are excluded from the above chart

Councils were asked to provide information on whether the carer was in receipt of a direct payment or personal budget. **Figure 1.15** shows that 8 per cent of carers who responded to the survey were in receipt of Personal Budgets/Direct Payments where this was managed by the LA, and a further 3 per cent had a personal budget/direct payment managed either by the carer themselves or by another organisation. However, almost three quarters of respondents (74%) reported they were not receiving direct payments or personal budgets, and for 16 per cent of carers it was not known whether they were in receipt of direct payments or personal budgets.

Figure 1.15 Carer in Receipt of Direct Payments or Personal Budgets of those who Responded to the Survey



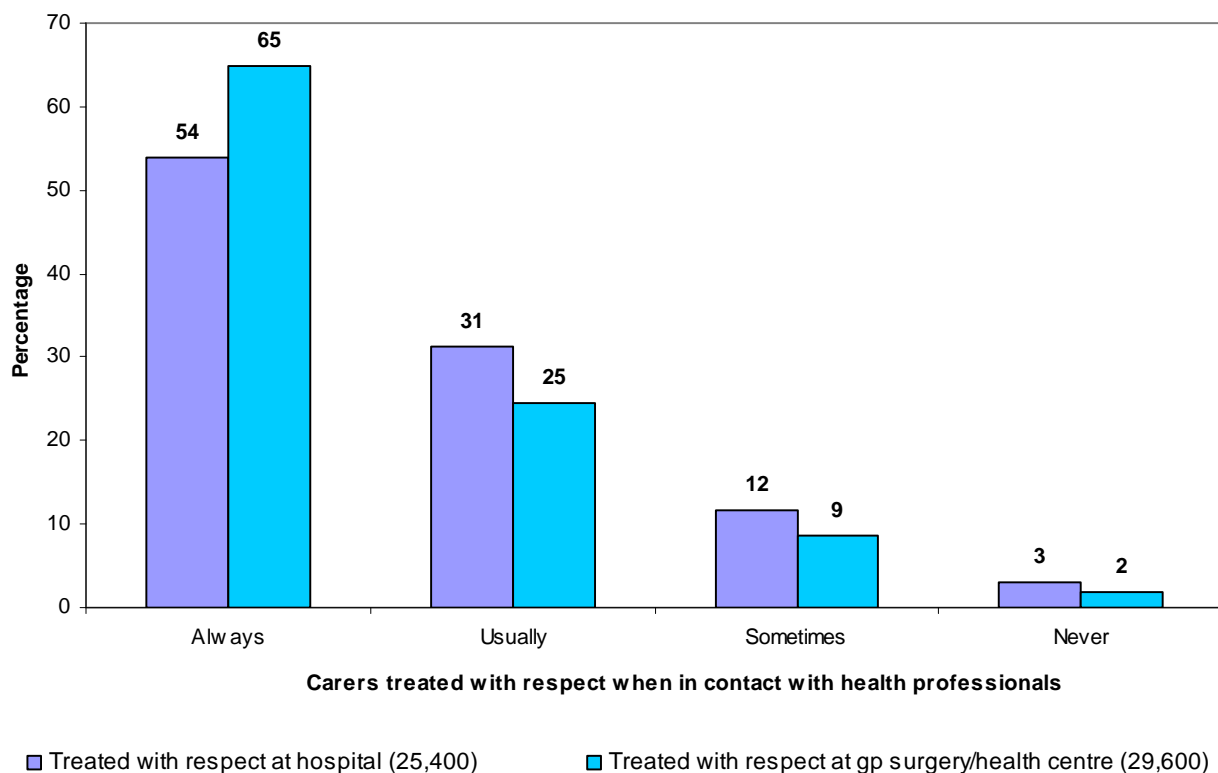
1. Figures may not add up to 100 per cent due to rounding
2. Based on 35,200 responses

Interaction with NHS

Figure 1.16 shows that 85 per cent of carers either always or usually felt they were treated with respect as a carer when they had been in contact with health professionals at NHS hospitals about the person they were caring for. 12 per cent said they were sometimes treated with respect but 3 per cent said they were never treated with respect.

In GP surgeries or health centres, the proportion of carers being always or usually treated with respect by NHS professionals was higher at 90 per cent. 9 per cent were sometimes treated with respect but 2 per cent said they were never treated with respect as a carer.

Figure 1.16 Do you feel you have been treated with respect as a carer when you have been in contact with professionals at a NHS hospital (Q42) or at a GP surgery/health centre (Q44) about the person you care for over the last 12 months

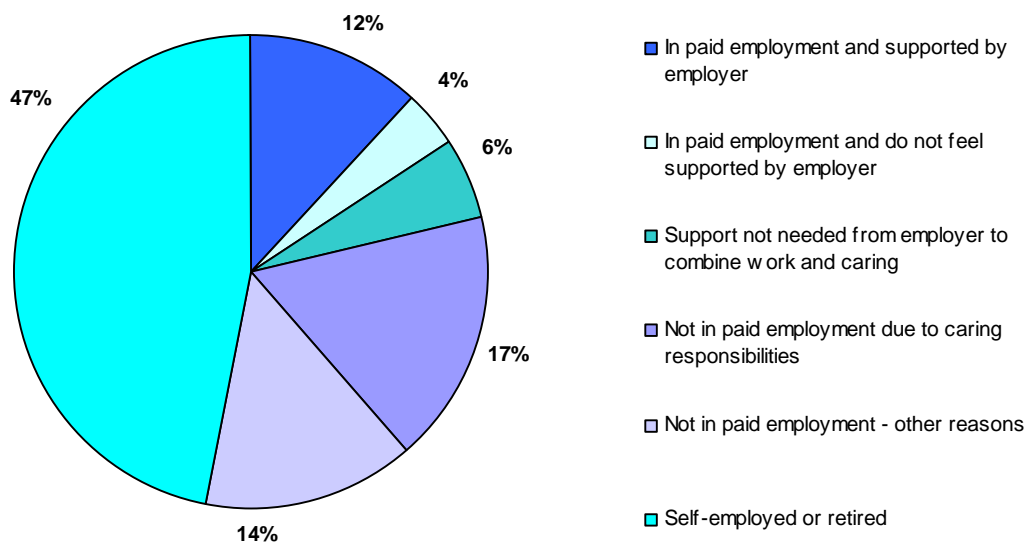


1. Figures may not add up to 100 per cent due to rounding
2. 8,300 respondents stating 'They had not been in contact with professional at a NHS hospital in the last 12 months' are excluded from the above chart
3. 4,100 respondents stating 'They had not been in contact with professional at a GP surgery/health centre in the last 12 months' are excluded from the above chart

Employment

Figure 1.17 shows that nearly half (47%) of carers were either self-employed or retired. 12 per cent of carers were in employment and felt supported by their employer but 4 per cent did not, and a further 17 per cent were not working because of their caring responsibilities.

Figure 1.17 Thinking about combining paid work and caring, which of the following statements best describes your current situation (Q48)

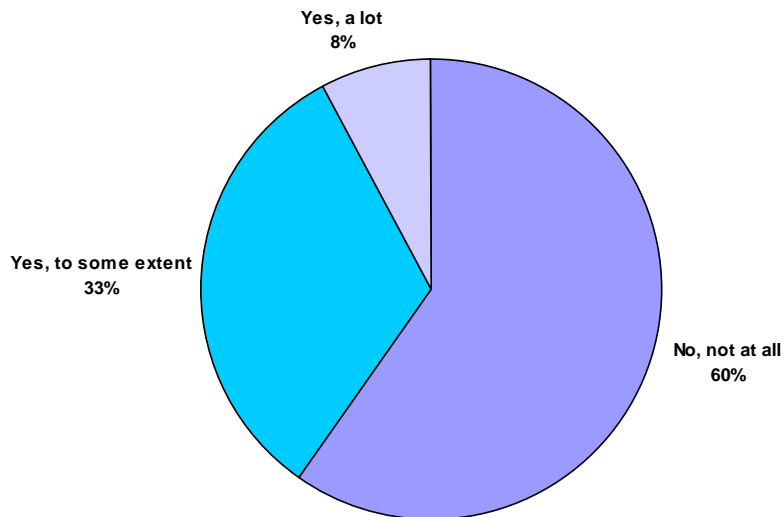


1. Figures may not add up to 100 per cent due to rounding
2. Based on 31,600 responses

Impact of Caring Duties on Finances

Figure 1.18 shows that 8 per cent of carers said they had suffered a lot of financial difficulty because of their caring role, 33 per cent had suffered to some extent but 60 per cent said they had suffered no financial difficulties at all.

Figure 1.18 In the last 12 months, has caring caused you any financial difficulties? (Q29)



1. Figures may not add up to 100 per cent due to rounding
2. Based on 33,500 responses

2. Experience of support and services

Introduction

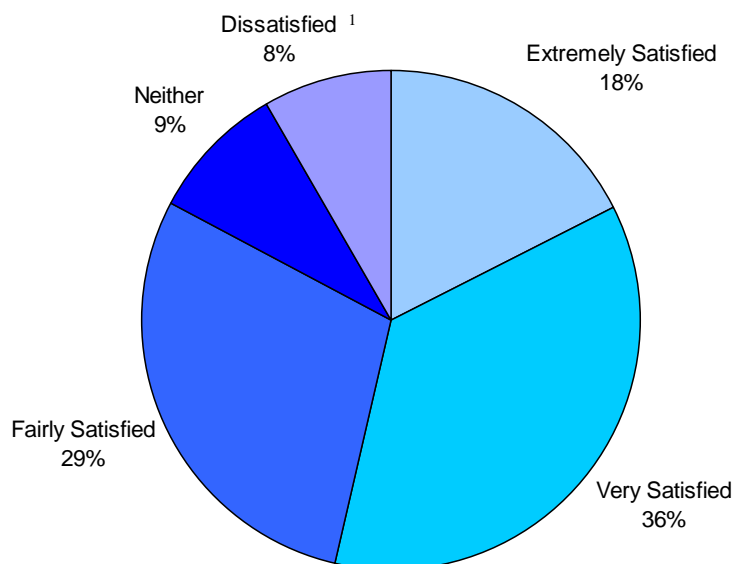
The questions in this section are concerned with the support and services both the carer and cared for person receive from social services. The happiness of the carer often depends on the availability and quality of the services the cared for person is receiving so it is important to look at the services for both of them together.

This has relevance to the carers' strategy particularly the outcomes which state; "carers will have access to the integrated and personalised services they need to support them in their caring role" and "carers will be able to have a life of their own alongside their caring role".

Satisfaction with the help the carer and cared for person receives

Figure 2.1 shows that 54 per cent of carers reported that they were either extremely or very satisfied with the support or services both they and the person they cared for have received from Social Services in the last 12 months, and a further 29 per cent reported they were fairly satisfied. 9 per cent of respondents said they were neither satisfied or dissatisfied and the remaining 8 per cent said they were dissatisfied with the support or services they had received.

Figure 2.1: 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 (Q7)?



1. Includes Fairly Dissatisfied, Very Dissatisfied and Extremely Dissatisfied

2. Based on 29,900 respondents

3. 4,000 respondents stated they received no support or services and are not included in the above chart

Relationship between satisfaction and other questions

Table 2.1 shows that carers who cared for someone who had dementia (54%), a physical disability (54%), sight or hearing problems (53%), problems connected to ageing (55%), a long standing illness (52%) or a terminal illness (54%) all reported relatively high levels of being extremely or very satisfied. In contrast, carers were less likely to be extremely or very satisfied if they were caring for someone with an alcohol or drugs problems (38%), mental health problems (45%) or a learning disability (43%).

Levels of dissatisfaction were also higher for carers caring for someone who had an alcohol or drugs problem (15%), a mental health problem (13%) or a learning disability (14%).

Table 2.1 Satisfaction with support and services received (Q7) by condition of the cared for person (Q5)¹

England 2009-10		Percentages ² and Rounded Figures				
Does the person you care for have....?	Degree of Satisfaction					Total Respondents
	Extremely Satisfied	Very Satisfied	Fairly Satisfied	Neither	Dissatisfied ³	
Dementia	18	36	30	8	8	8,200
A physical disability	18	36	29	9	8	15,700
Sight or hearing loss	17	37	30	9	8	8,300
A mental health problem	15	30	31	11	13	4,700
Problems connected to ageing	16	39	29	9	7	11,500
A learning disability or difficulty	12	31	32	12	14	4,500
Long standing illness	18	34	29	10	9	10,100
Terminal illness	21	34	27	8	10	1,400
Alcohol/Drugs	13	25	36	12	15	300

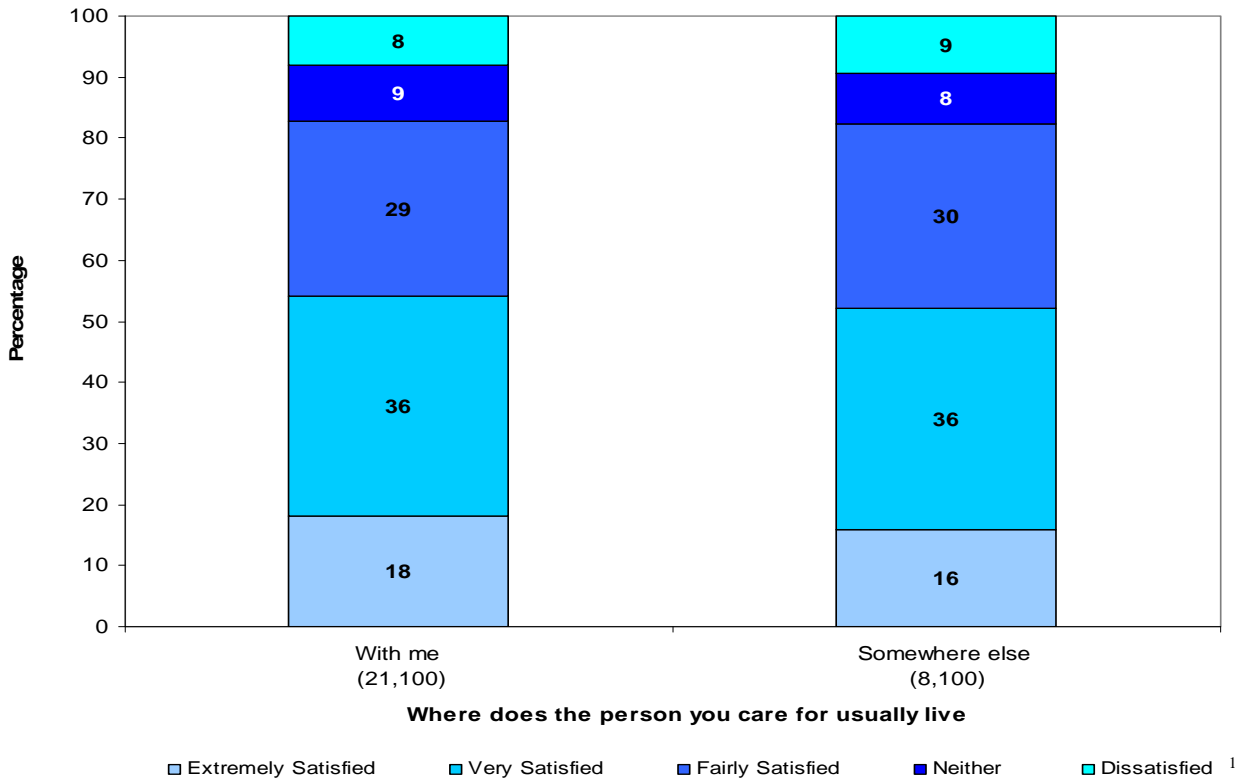
1. Respondents could select more than one option

2. Figures may not add up to 100 per cent due to rounding

3. Includes fairly, very and extremely dissatisfied

Figure 2.2 shows there to be a very small difference in overall satisfaction levels reached in relation to where the cared for person lives. 18 per cent of respondents where the cared for person lived with them stated they were extremely satisfied with support or services they had received compared with 16 per cent where the cared for person lived somewhere else.

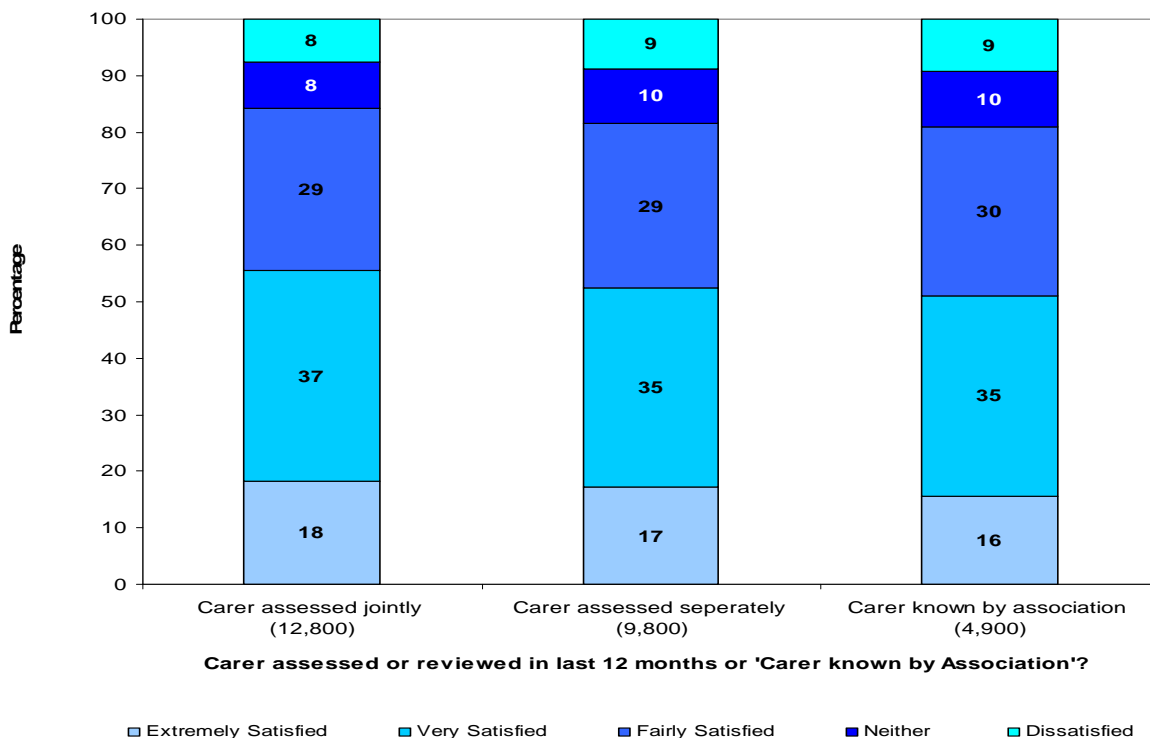
Figure 2.2 Where does the person you care for usually live (Q6) by degree of overall satisfaction (Q7)



1. Includes Fairly dissatisfied, Very Dissatisfied and Extremely Satisfied
2. Figures may not add up to 100% due to rounding

Figure 2.3 shows there to only be a small relationship between satisfaction and how the carer was assessed. 56 per cent of all carers who were assessed jointly with the cared for person were extremely or very satisfied compared to 52 per cent where the carer was assessed separately and 51 per cent where the carer was known by association. Dissatisfaction also showed only a very small difference.

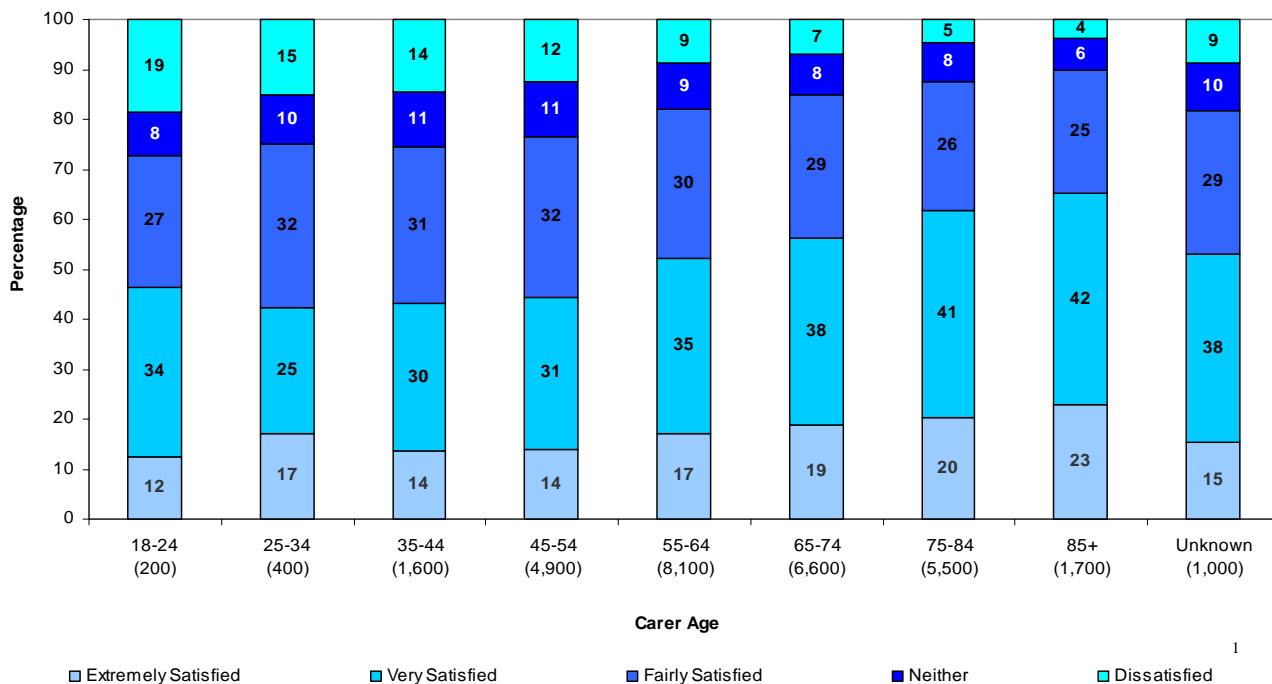
Figure 2.3 Satisfaction with support or services (Q7) by whether the carer was assessed separately or jointly with the person they care for or whether they were known by association



1. Includes Fairly dissatisfied, Very Dissatisfied and Extremely Satisfied
2. Figures may not add up to 100% due to rounding

Figure 2.4 demonstrates a relationship between the overall levels of satisfaction and the age of the carer. Levels of satisfaction are generally higher amongst older carers with 65 per cent of the over 85 age group reporting they were either very or extremely satisfied compared to 42 per cent of 25-34 year olds. Younger carers were more likely to say they were dissatisfied with nearly one-fifth (19%) of 18-24 year old carers doing so compared to 4 per cent of carers aged 85 or over.

Figure 2.4 Overall, how satisfied are you with the support or services you and the person you care for have received in the last 12 months (Q7) by carers age



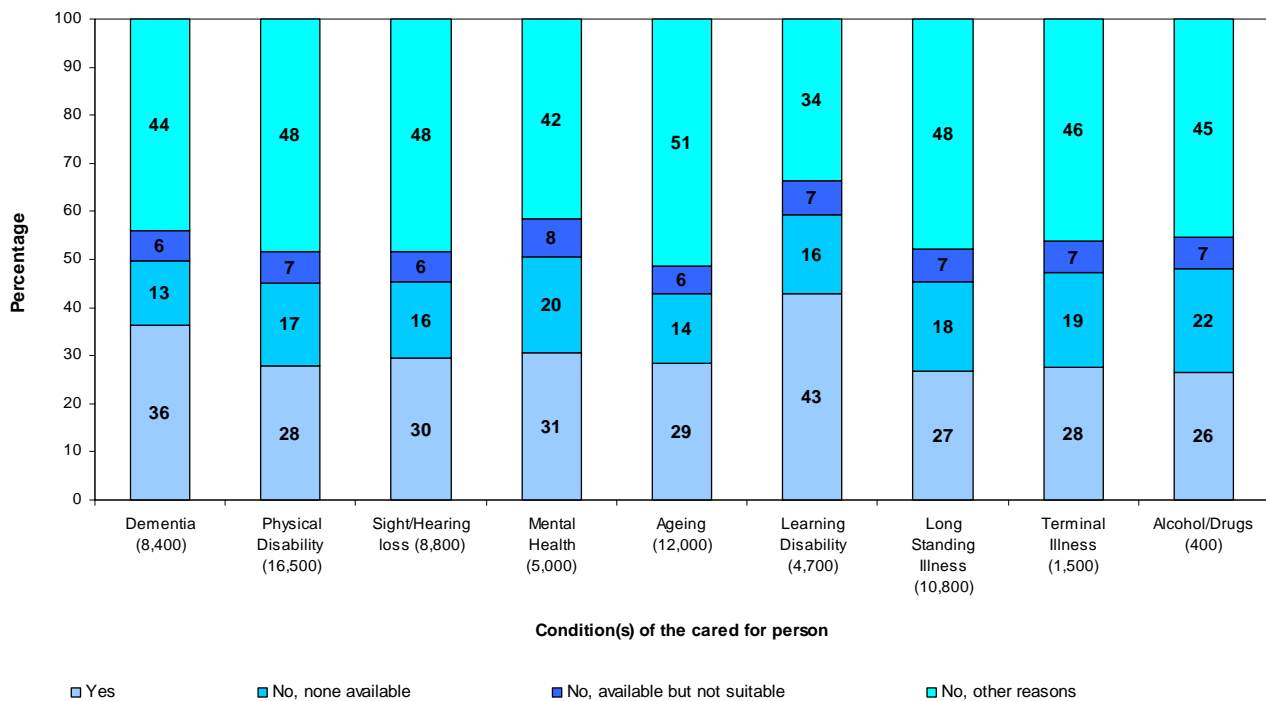
1. Includes Fairly dissatisfied, Very Dissatisfied and Extremely Satisfied
2. Figures may not add up to 100% due to rounding

Condition of cared for person and access to breaks

Figure 2.5 shows there is a larger percentage of carers accessing breaks over 24 hours where the cared for person has a learning disability (43%) compared to any other condition. This figure is notably higher than for instances where the cared for person has a long-standing illness (27%) or issues relating to alcohol or drug misuse (26%).

The highest percentage of carers who said they were not accessing longer breaks because there were none available cared for someone with mental health problems (20%) or alcohol or drug problems (22%).

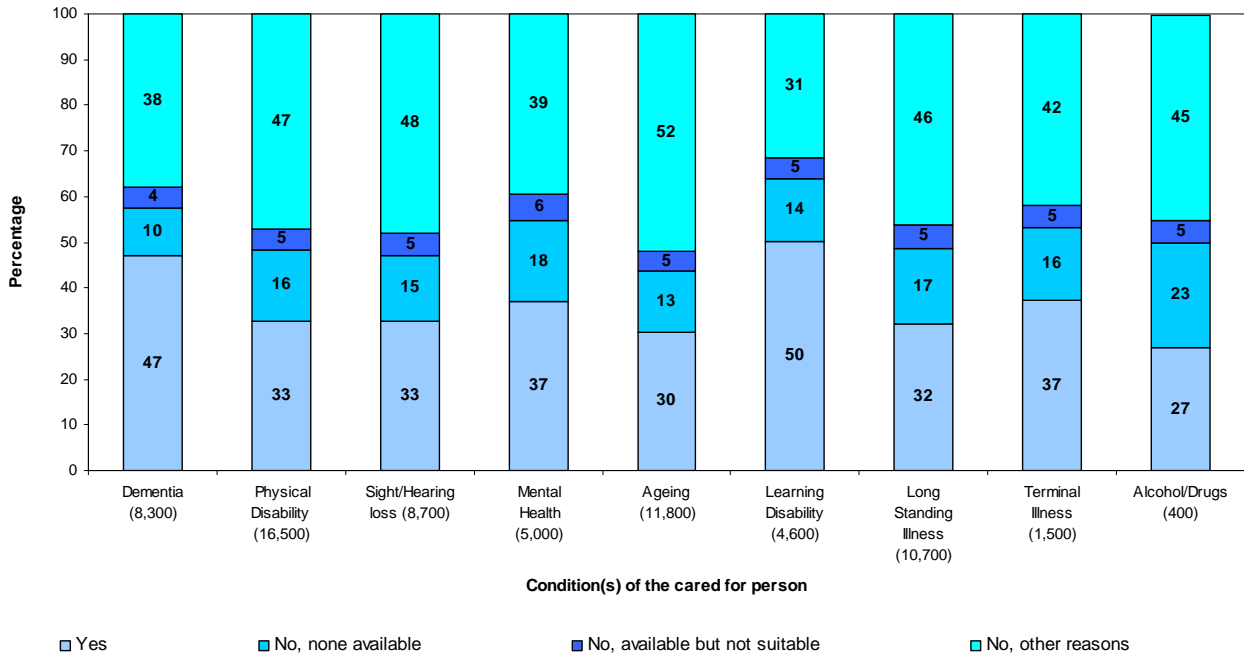
Figure 2.5 Condition of cared for person (Q5) by whether carer accessed breaks lasting more than 24 hours in the last 12 months (Q13)



1. Figures may not add up to 100 per cent due to rounding
2. 1,200 respondents who stated Don't know for q13 are excluded from this chart

Figure 2.6 looks at the relationship between the condition for the cared for person and whether the carer accessed breaks lasting less than 24 hours and shows similar patterns. There is a larger proportion of carers accessing breaks lasting less than 24 hours where the cared for person has a learning disability (50%) or dementia (47%). It also shows that over two-thirds of carers (70%) where the person they cared for had problems connected to ageing were not accessing any short breaks, and nor were 73 per cent of carers caring for someone with an alcohol or drugs problem.

Figure 2.6 Condition of cared for person (Q5) by whether carers accessed breaks lasting less than 24 hours in the last 12 months (Q15)



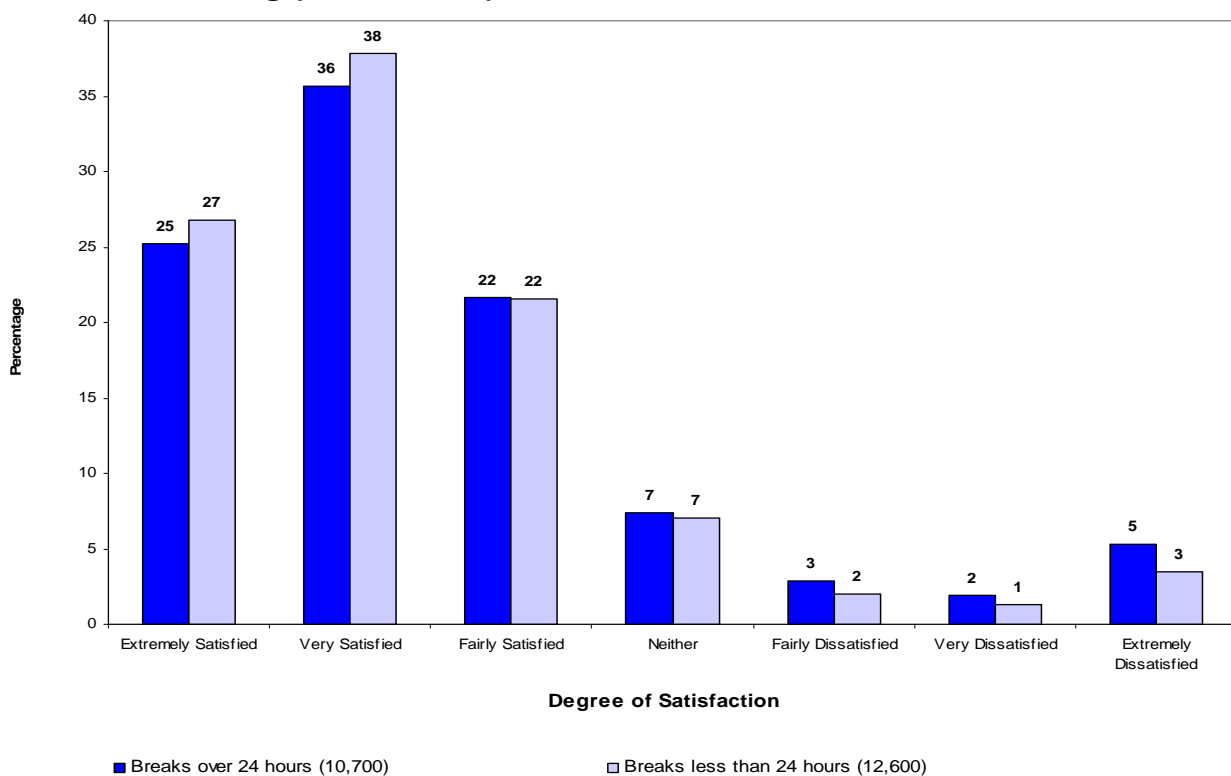
1. Figures may not add up to 100 per cent due to rounding
2. 1,000 respondents who stated Don't know for q15 are excluded from this chart

Carers using breaks and satisfaction with those breaks

Figure 2.7 shows that the majority of carers were satisfied with breaks although they were slightly more satisfied with shorter breaks than with those lasting more than 24 hours. 61 per cent of carers who used support or services to allow them to take a break from caring for more than 24 hours reported they were either extremely or very satisfied with the service they received compared to 65 per cent for breaks lasting less than 24 hours.

Dissatisfaction also tended to be slightly higher with longer breaks (10%) compared to shorter breaks of 1-24 hours (7%).

Figure 2.7 Satisfaction with support or services enabling carers to take a break from caring (Qns 14 & 16)

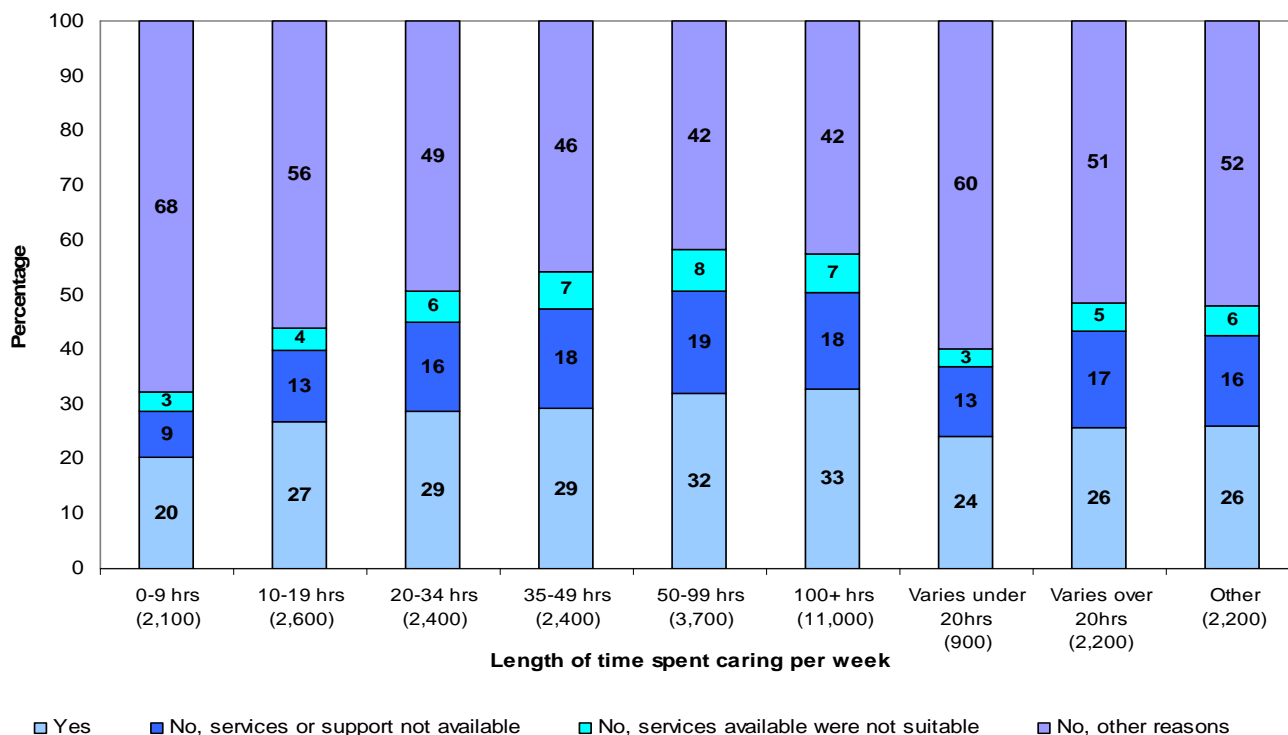


1. Figures may not add up to 100 per cent due to rounding

Carers accessing breaks and length of time spent caring

Figure 2.8 shows that carers are less likely to access breaks over 24 hours when they spend less time per week caring. One fifth (20%) of those carers who spent 0 to 9 hours caring per week reported they accessed breaks over 24 hours. This figure then rises slowly as the amount of time spent caring rises with one third (33%) of respondents who care for 100 or more hours per week accessing longer breaks. However, two thirds (67%) of carers with such intensive caring responsibilities did not access breaks.

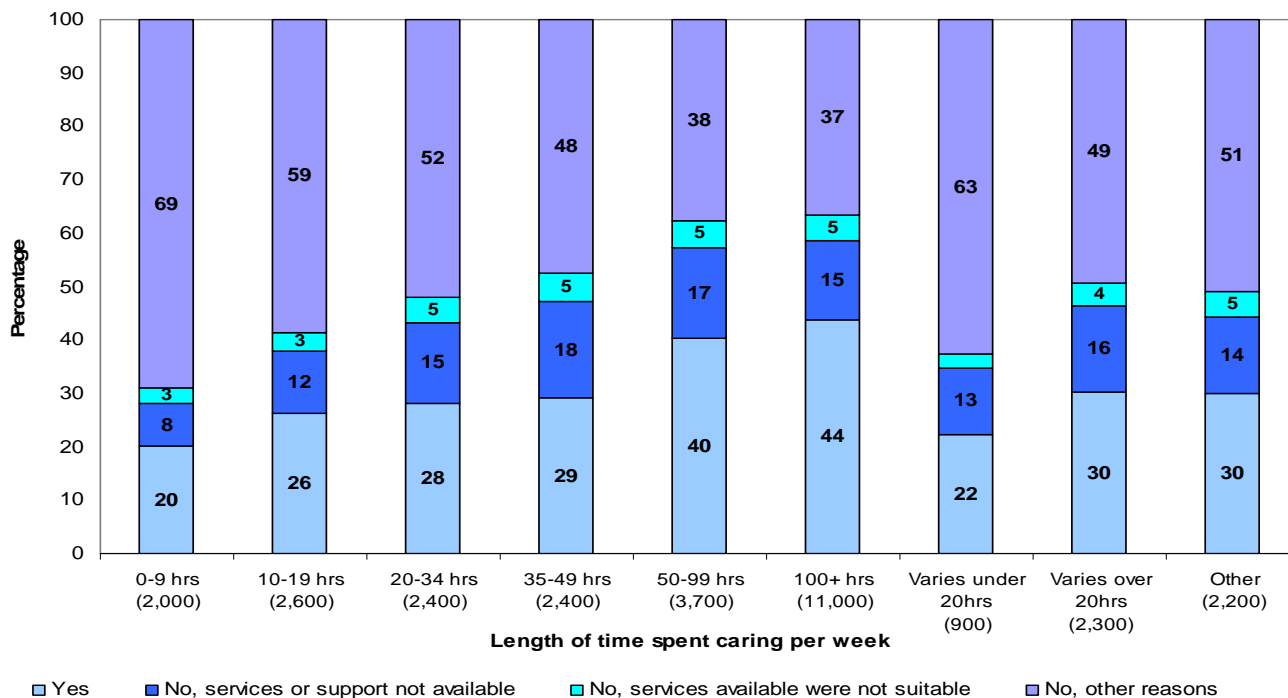
Figure 2.8 Carers accessing breaks over 24 hours (Q13) by length of time spent caring per week (Q50)



1. Figures may not add up to 100 per cent due to rounding

Figure 2.9 shows that the pattern for shorter breaks of up to 24 hours is even more marked with one fifth (20%) of carers who spent 0 to 9 hours caring reporting they accessed breaks less than 24 hours compared to 44 per cent of those caring for 100 hours or more per week.

Figure 2.9 Carers accessing breaks less than 24 hours (Q15) by length of time spent caring per week (Q50)

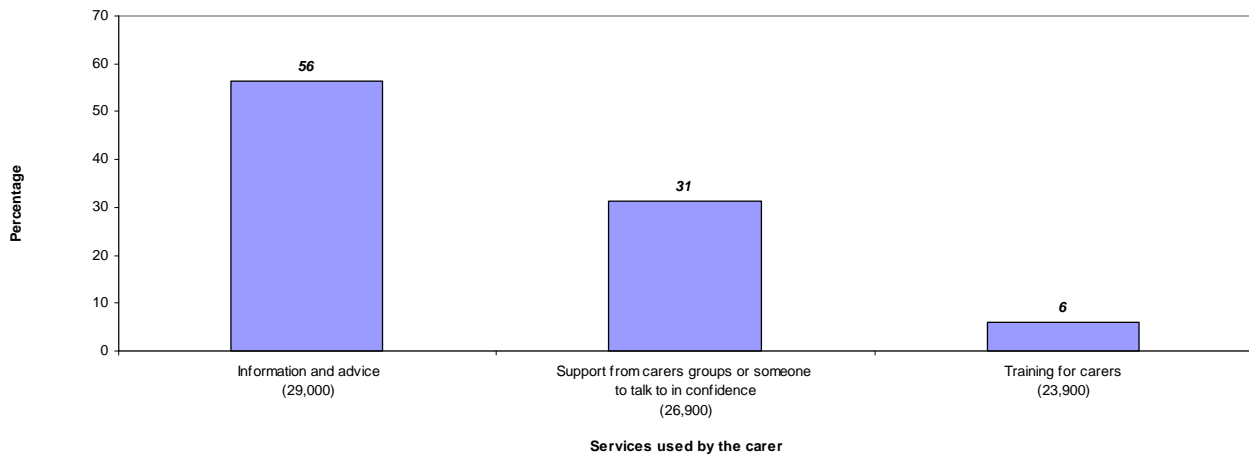


1. Figures may not add up to 100 per cent due to rounding

Information and Advice

Carers were asked whether they'd used specific support or services in the last 12 months from voluntary organisations, private agencies or Social Services. **Figure 2.10** shows that the most common type of support or service used by carers was receiving information and advice, with 56 per cent of respondents stating this was the case. 31 percent of respondents said they get support from carers groups or spoke to someone in confidence, but only 6 per cent of carers had received training for their caring role.

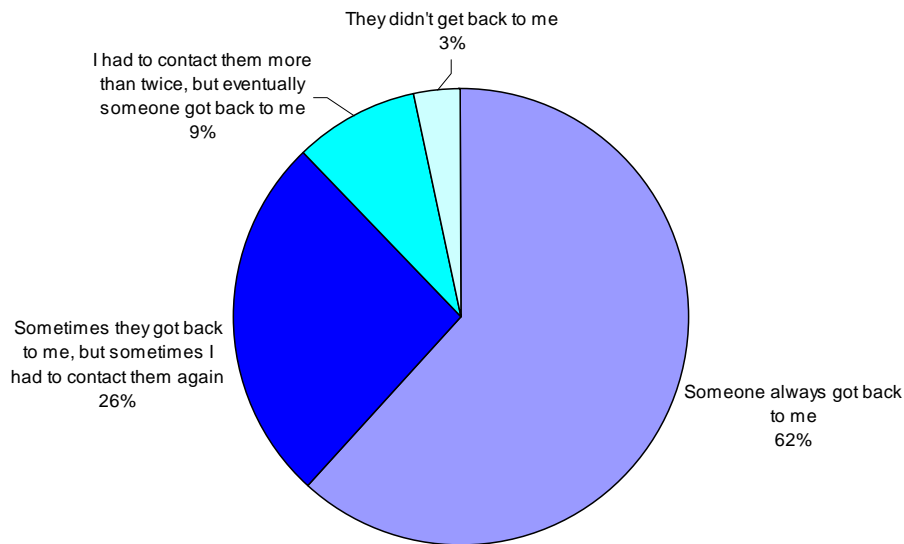
Figure 2.10 Which support or services have you used to help you as a carer in the last 12 months (Q12)



1. Figures do not add up to 100 per cent as respondents could select more than one option

62 per cent of carers reported that when they contacted social services someone always got back to them, as shown in **figure 2.11**. Over a quarter (26%) stated that sometimes they had to contact Social services again before they got back to them, 9 per cent had to contact them more than twice, but 3 per cent of carers said that no-one responded to their questions or queries.

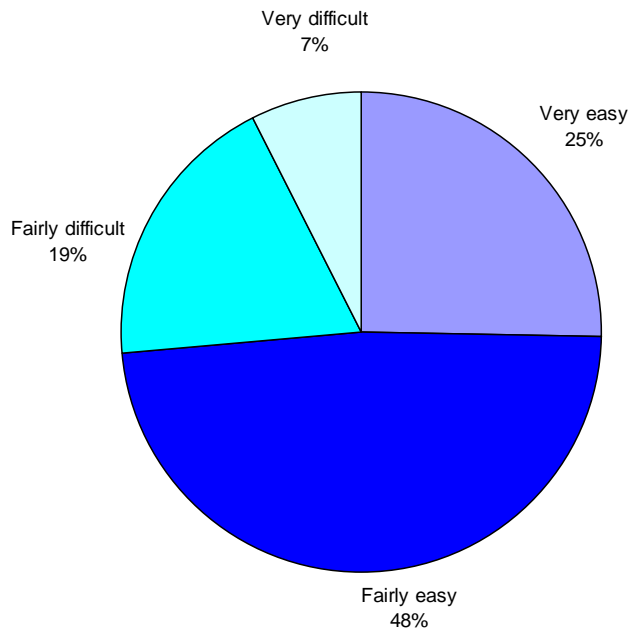
Figure 2.11 Please describe how quickly Social Services have responded to your queries or questions in the last 12 months (Q30)



1. Figures may not add up to 100 per cent due to rounding
2. Based on 22,900 responses
3. 10,400 respondents who stated 'I have not contacted social services with a query or question in the last 12 months' are excluded from this analysis

A quarter (25%) of respondents reported they found it very easy to find the information and advice they needed about support, services and benefits from either voluntary organisations, private agencies or Social Services as shown in **figure 2.12**. Almost half (48%) stated they found it fairly easy to get this information, but 19 per cent found it fairly difficult and 7 per cent found it very difficult.

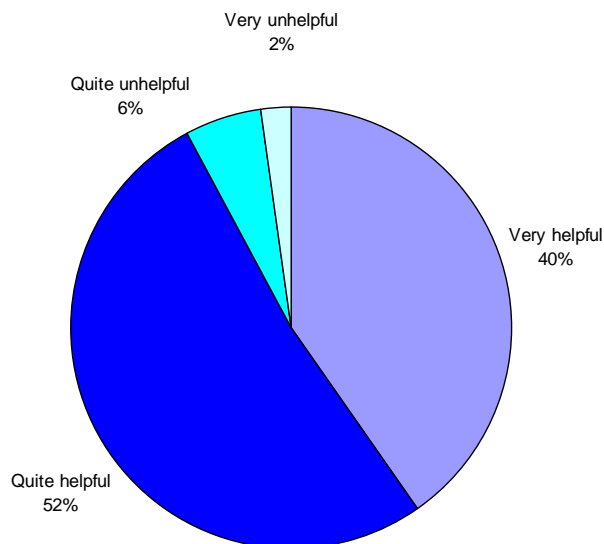
Figure 2.12 In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? (Q31)



1. Figures may not add up to 100 per cent due to rounding
2. Based on 23,100 responses
3. 10,700 respondents who stated 'I have not tried to find information or advice in the last 12 months' are excluded from this analysis

Figure 2.13 shows that the majority of carers who had received information and advice felt it had been helpful to them. 92 per cent said that they had found it either quite or very helpful but the remaining 8 per cent said they had found it either quite or very unhelpful.

Figure 2.13 In the last 12 months, how helpful has the information and advice you have received been? (Q32)



1. Figures may not add up to 100 per cent due to rounding
2. Based on 23,700 responses
3. 9,600 respondents who stated 'I have not received any information or advice in the last 12 months' are excluded from this analysis

3. The impact of caring upon quality of life

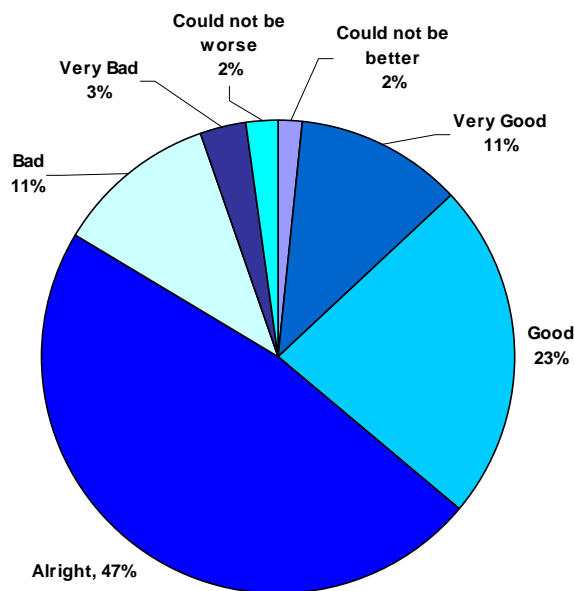
Introduction

This section moves away from looking at the services carers and the cared for person receives and looks more broadly at the overall quality of life of the carer and examines a number of everyday factors that are affected by the caring role. One of the primary aims of the Carers Strategy is to ensure that “Carers will be able to have a life of their own alongside their caring role”.

Overall Quality of life

Figure 3.1 shows that 2 per cent of carers said their life was so good it could not be better and a further 34 per cent stated it was either very good or good. Conversely, 17 per cent of respondents said that their lives were either bad, very bad or could not be worse.

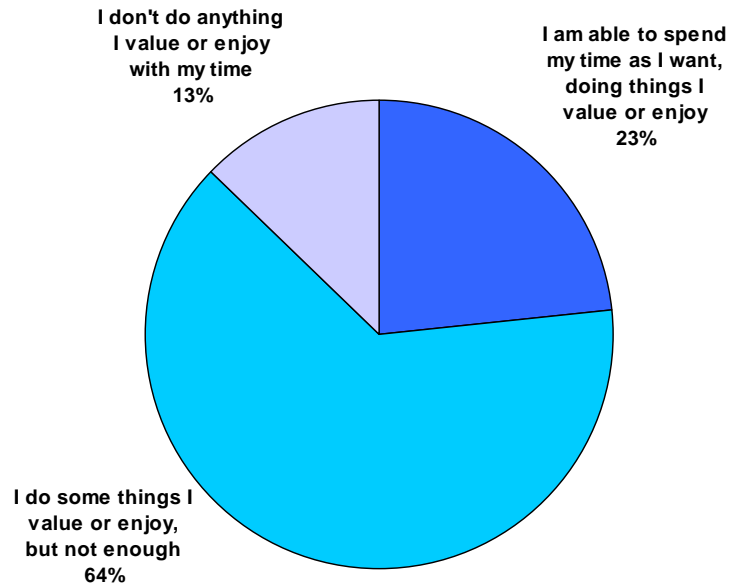
Figure 3.1 Overall quality of life of the carer (Q17)



- 1. Figures may not add up to 100 per cent due to rounding
- 2. Based on 33,500 respondents

Figure 3.2 shows how carers spent their time in relation to being able to do the things they valued or enjoy. Just under a quarter (23%) stated that they were able to spend their time as they wanted doing the things they valued or enjoyed, 64 per cent were able to do some of the things they valued and enjoyed but not enough, but 13 per cent reported that they did not have the time to do anything they valued or enjoyed.

Figure 3.2 Which statement best describes how you spend your time? (Q18)



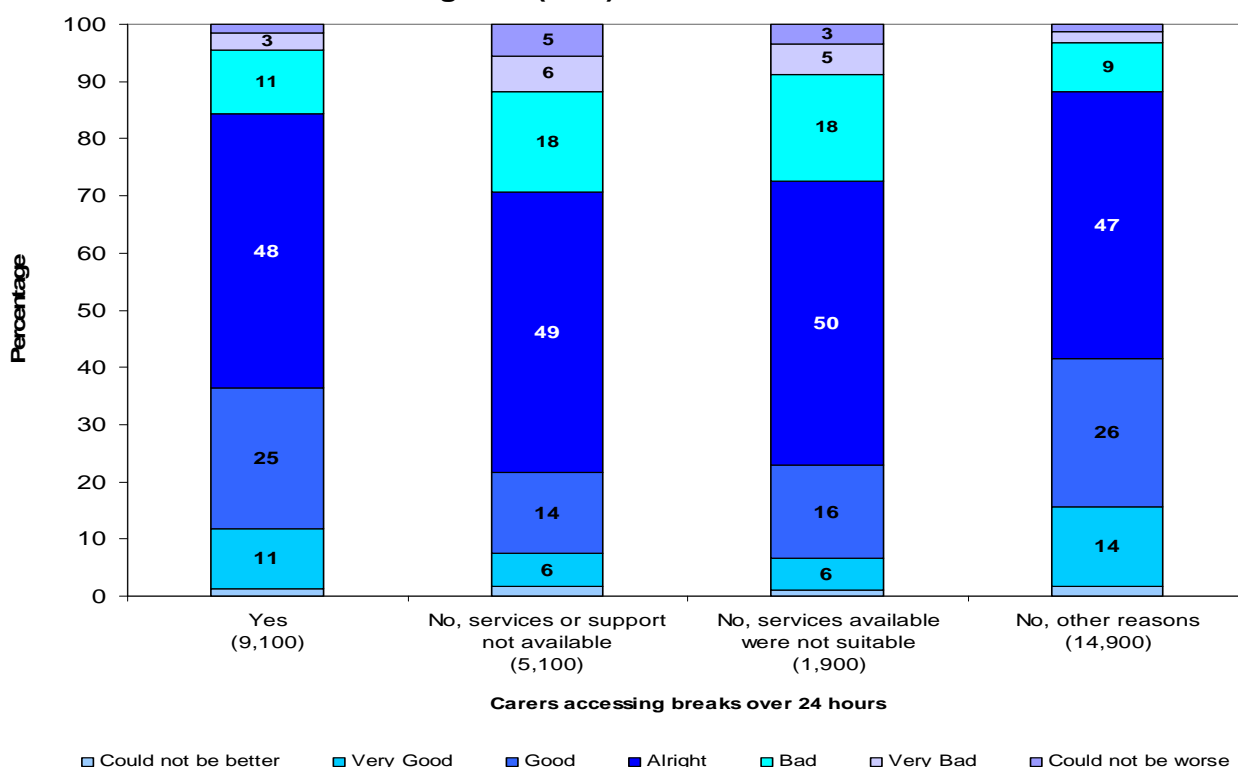
1. Figures may not add up to 100 per cent due to rounding
2. Based on 33,300 responses

Relationship between Overall Quality of life and other questions

Figure 3.3 shows respondents who stated they were not accessing breaks over 24 hours for 'other reasons' to have the highest levels of overall quality of life with 42 per cent stating that their lives were either good, very good or could not be better. This can be linked to findings in the previous chapter which suggested that on average, carers were less likely to access breaks if they spent less time caring so therefore some may feel that they do not need a break (see figures 2.8 and 2.9).

29 per cent of respondents who stated that they were not accessing breaks because there were none available said that the quality of their lives was either bad, very bad or could not be worse. This is in marked contrast to respondents who stated they were receiving these breaks with only 16 per cent stating their lives were equally bad.

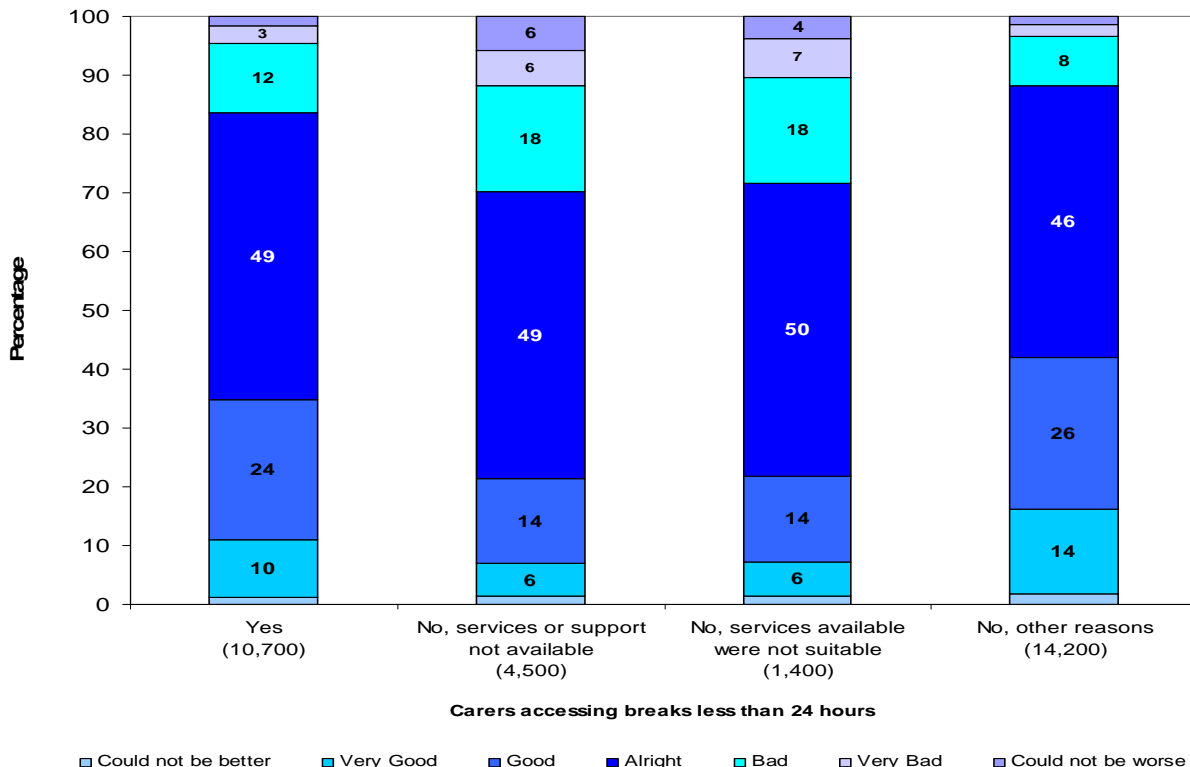
Figure 3.3 Overall quality of life (Q17) by carer receiving breaks lasting more than 24 hours from caring role (Q13)



1. Figures may not add up to 100 per cent due to rounding

Figure 3.4 looks at breaks lasting less than 24 hours and shows a similar pattern. Those not accessing these breaks for 'other reasons' reported a higher overall quality of life with 42 per cent of this group stating that their lives were either good, very good or could not be better. The lowest levels of quality of life were experienced among those who were not accessing breaks due to absence of availability with 30 per cent of respondents stating their lives were either bad, very bad or could not be worse. In contrast, only 16 per cent of those who were accessing breaks said their lives were either bad, very bad or could not be worse.

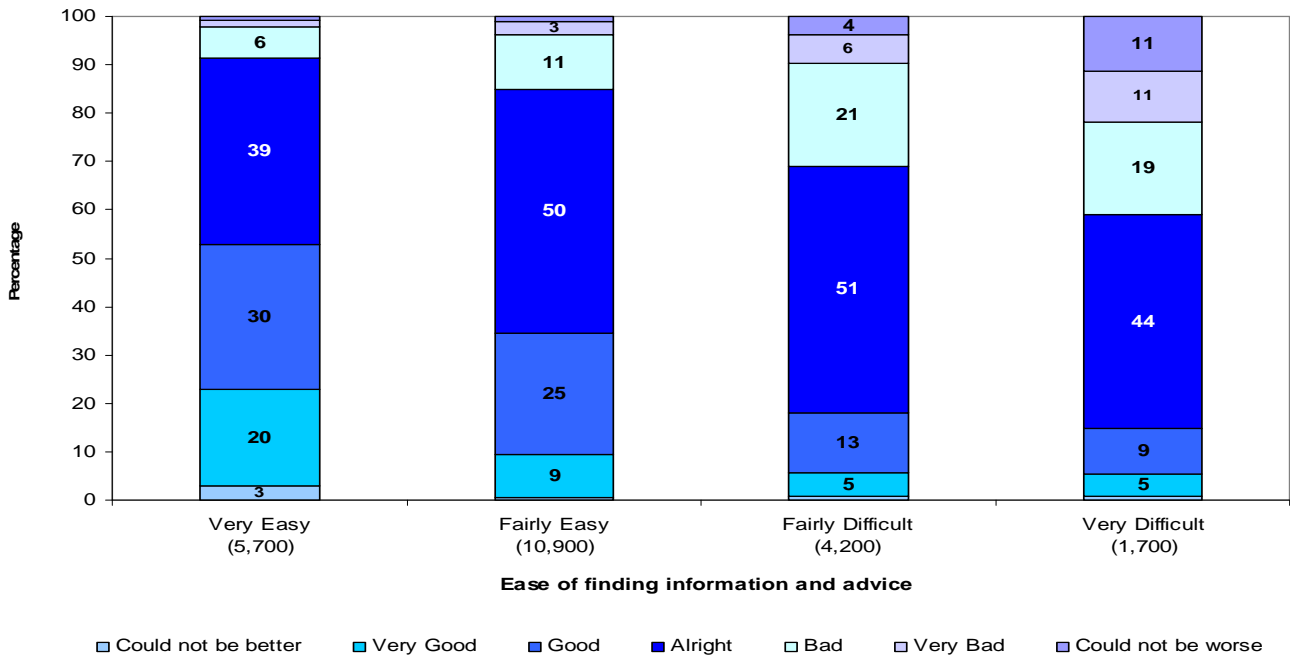
Figure 3.4 How would you rate your quality of life as a whole (q17) by carer receiving breaks lasting less than 24 hours from caring role (Q15)



1. Figures may not add up to 100 per cent due to rounding

Figure 3.5 shows there to be a link between the carers overall quality of life and how easy or difficult they found it to access information and advice about support, services or benefits. Of those who found it very difficult to access such information, 41 per cent said their lives were either bad, very bad or could not be worse compared to only 9 per cent of carers who found it very easy to access information and advice. In contrast, over half (53%) of these carers reported that their quality of life was either good, very good or could not be better compared to only 15 per cent of those who had found it very difficult.

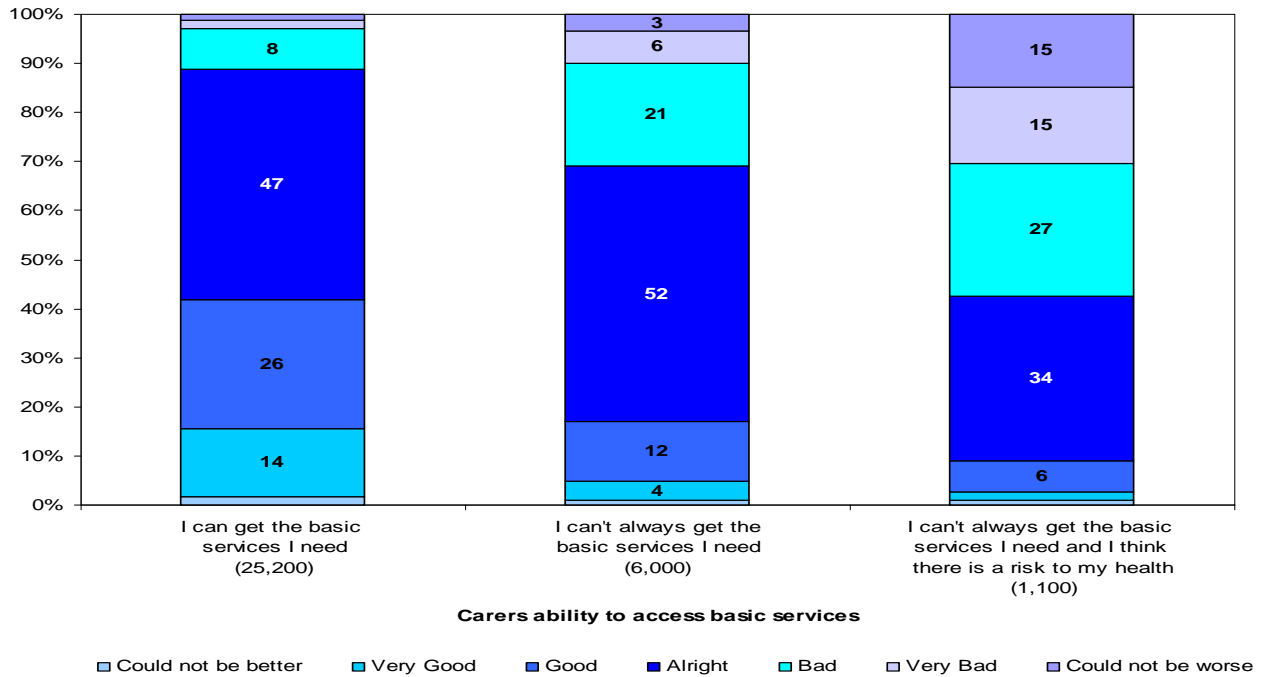
Figure 3.5 How would you rate your quality of life as a whole (Q17) by how easy or difficult have you found it to find information and advice about support, services or benefits (Q31)



1. Figures may not add up to 100 per cent due to rounding

Figure 3.6 shows there to be a link between overall quality of life and the carers ability to access basic services, such as seeing a GP or visiting a dentist. Of those unable to access basic services and subsequently feeling their health may be at risk, over half (57%) said that their lives were either bad, very bad or could not be worse. Of those able to access the services they need, 11 per cent reported their lives to be equally bad. In contrast, 42 per cent of those able to access these services reported their lives to be either good, very good or could not be better compared to only 9 per cent of the group who stated they could not access basic services and felt their health to be at risk.

Figure 3.6 Overall quality of life of the carer (Q17) by Access to basic services (Q26)

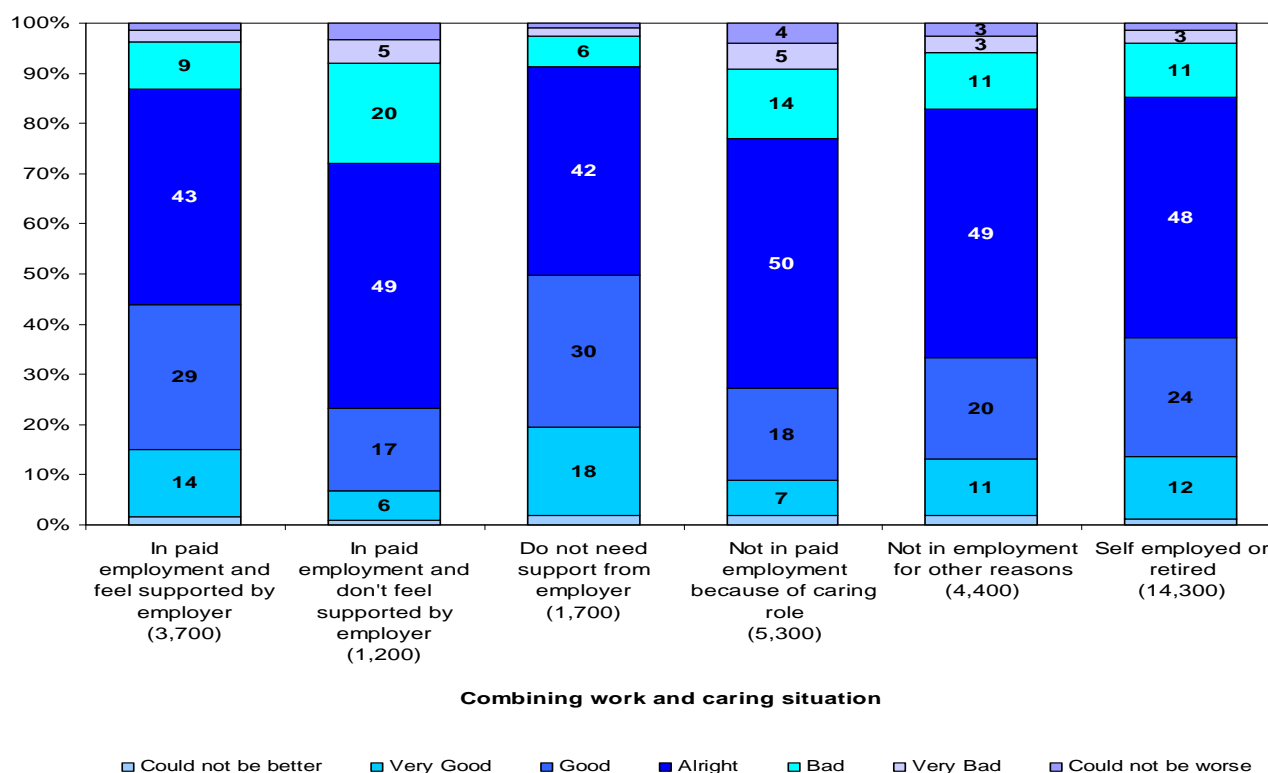


1. Figures may not add up to 100 per cent due to rounding

Figure 3.7 shows that those who are in employment as well as carrying out their caring roles have the lowest levels of overall quality of life when they do not feel supported by their employer. 28 per cent of this group stated they their lives were either bad, very bad or could not be worse with 23 per cent stating it was either good, very good or could not be better. This is in contrast to respondents who stated that they did feel supported by their employer or did not need support from their employer with 44 per cent and 50 per cent respectively stating their lives were either good, very good or could not be better.

The largest number of respondents to this question stated that they were self-employed or retired and of this group 37 per cent thought their lives were either good, very good or could not be better with 15 per cent stating their lives were either bad, very bad or could not be worse.

Figure 3.7 Overall quality of life of the carer (Q17) by combining paid work and caring (Q48)

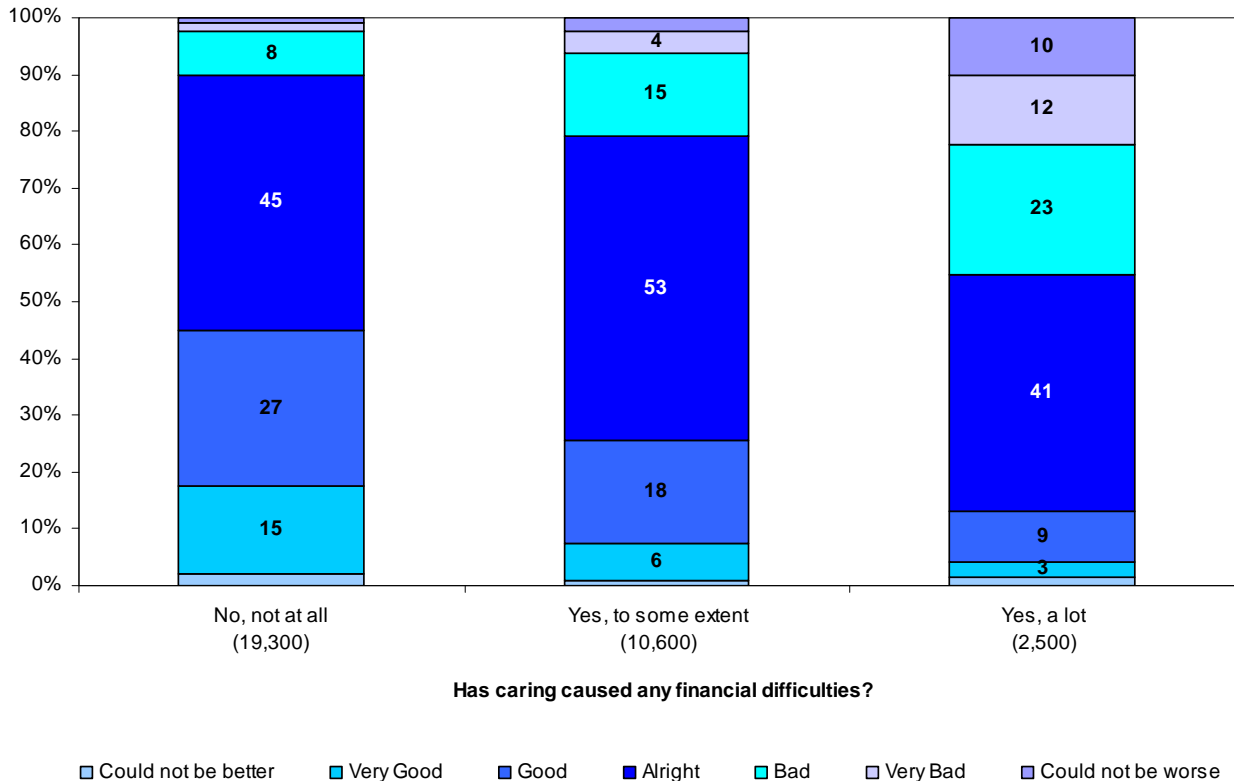


1. Figures may not add up to 100 per cent due to rounding

Figure 3.8 shows there to be a clear link between overall quality of life and whether the caring role has caused financial difficulties. For those that reported they had not experienced any difficulties 45 per cent stated that their lives were either good, very good or could not be better. This figure then declines with those who had experienced some difficulties to 26 per cent and to 13 per cent for those who had experienced a lot of financial difficulties.

Correspondingly, of the group who had experienced a lot of financial difficulties, 45 per cent said their lives were either bad, very bad or could not be worse. Of the group who had experienced no financial difficulties at all 10 per cent said their lives were equally bad.

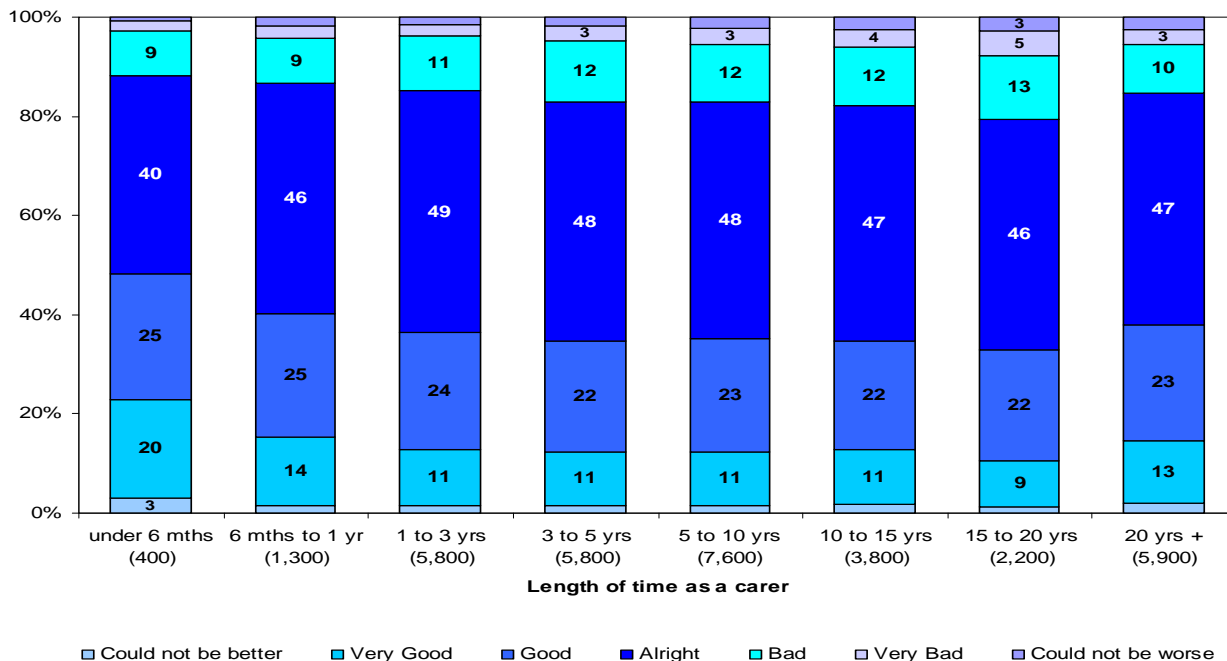
Figure 3.8 Overall quality of life of the carer (Q17) by caring causing financial difficulties (Q29)



1. Figures may not add up to 100 per cent due to rounding

Figure 3.9 shows there does appear to be some links between the length of time respondents said they had been caring and their overall quality of life. Quality of life appears to be slightly higher among carers who have been caring for shorter periods of time and decreases as the length of time spent caring increases although there is an improvement for those who have been caring for over 20 years who reported similar levels of quality of life (both good and bad) to those who have been caring for shorter periods.

Figure 3.9 Overall quality of life of the carer (Q17) by length of time in caring role (Q49)

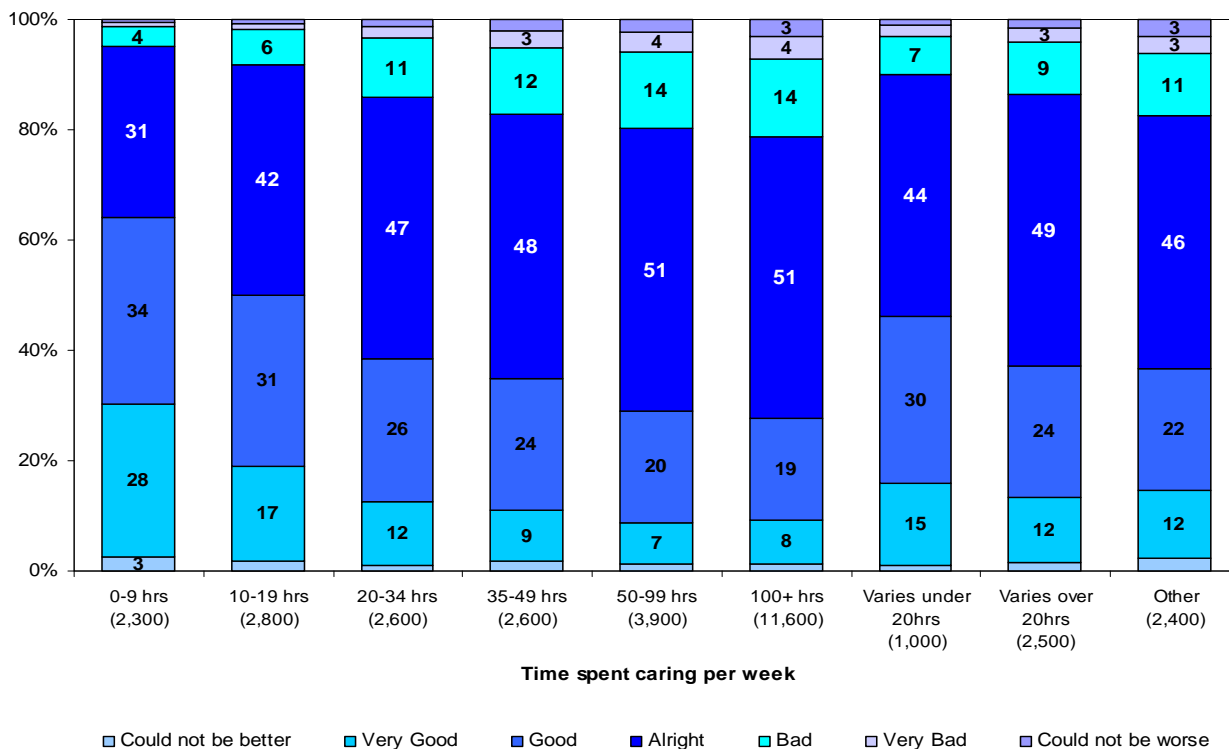


1. Figures may not add up to 100 per cent due to rounding

Figure 3.10 demonstrates that quality of life was higher for those who spend less time caring per week. For those caring between 0-9 hours per week almost two-thirds (64%) stated their lives were either good, very good or could not be better. This level of quality of life then declines as the length of time per week spent caring increases with just over a quarter (28%) of those who care for 100 hours or more per week stating the same level of quality of life.

In addition, lower levels of quality of life can be seen to increase as the time per week spent caring increases with 21 per cent of those caring for 100 hours or more stating their lives were either bad, very bad or could not be worse.

Figure 3.10 Overall quality of life of the carer (Q17) by time spent in caring role per week (Q50)



1. Figures may not add up to 100 per cent due to rounding

Table 3.1 shows that respondents to the survey from a white ethnic background had the highest quality of life with 36 per cent stating the overall quality of their life as either good, very good or could not be better with 16 per cent stating it was bad, very bad or could not be worse. In contrast, 21 per cent of respondents from the Black ethnic group had equally low levels of quality of life. The high proportion of people in the Mixed ethnic group who said their lives were bad, very bad or could not be worse was not statistically significantly different to the other groups.

Table 3.1 Overall quality of life of the carer (Q17) by Ethnicity

England 2009-10		Percentages and Rounded Figures						
Carer Ethnicity	Overall Quality of life							Total Respondents
	Could not be better	Very Good	Good	Alright	Bad	Very Bad	Could not be worse	
White	2	12	23	48	11	3	2	27,900
Asian	3	8	23	46	13	4	4	1,500
Black	3	10	19	47	12	4	5	700
Mixed	1	11	17	50	12	5	4	200
Chinese/Other	3	9	18	47	15	6	3	400
Unknown/Not stated	1	13	24	46	11	3	2	2,900

1. Figures may not add up to 100 per cent due to rounding

Table 3.2 shows that overall quality of life is rated as better amongst people caring for someone with age related problems or with a learning disability or difficulty with 37 per cent and 38 per cent respectively reported that their lives were either good, very good or could not be better. Those caring for someone with a mental health problem (28%), terminal illness (25%) or with an alcohol or drugs problem (26%) had the lowest proportion of respondents reporting similar levels.

Lower levels of quality of life (the percentage who said it was either bad, very bad or could not be worse) were reported by carers who care for someone with a mental health problem (25%), a terminal illness (25%) or have an alcohol or drugs problem (31%).

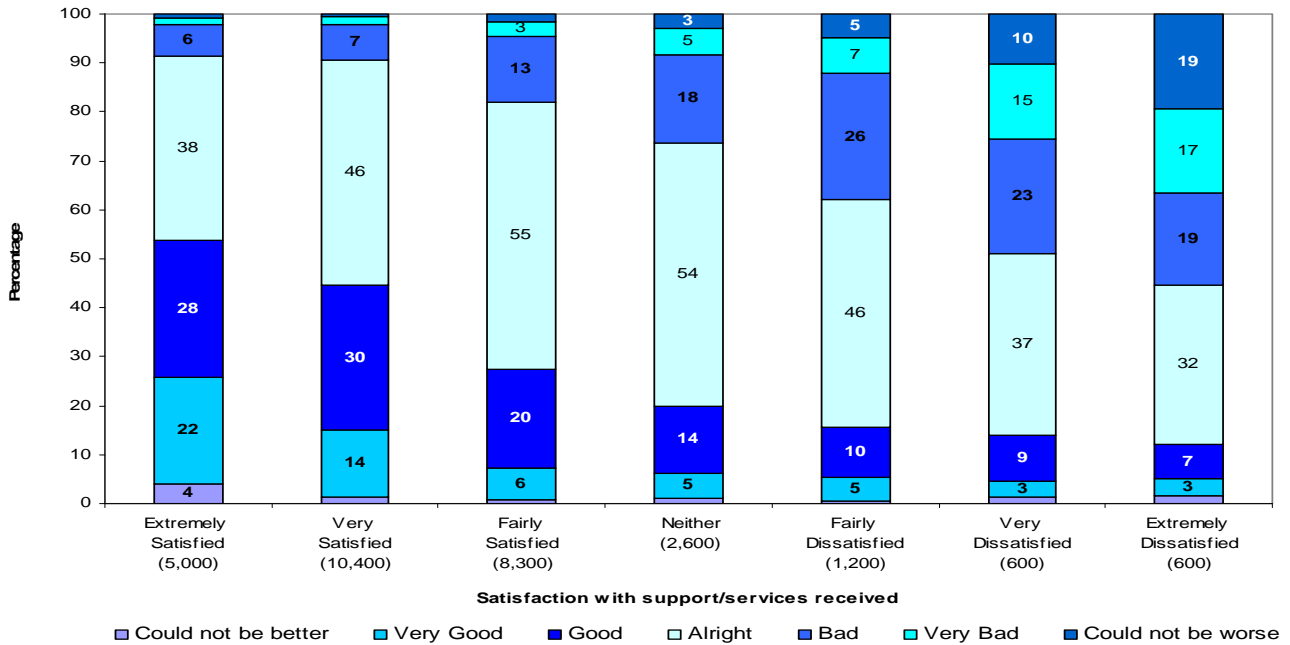
Table 3.2 Overall Quality of life (Q17) by condition of cared for person (Q5)

England 2009-10		Percentages and Rounded Figures						
Condition of cared for person	Overall Quality of life							Total Respondents
	Could not be better	Very Good	Good	Alright	Bad	Very Bad	Could not be worse	
Dementia	1	9	20	48	15	4	2	8,800
Physical disability	1	11	23	48	12	3	2	17,500
Sight/Hearing	1	11	23	48	12	3	2	9,200
Mental Health problem	1	8	19	47	15	6	4	5,300
Problems connected with ageing	1	12	24	47	12	3	2	12,600
Learning disability	2	12	24	46	9	3	3	4,900
Long term illness	1	9	20	50	13	4	3	11,400
Terminal illness	2	7	16	50	15	6	4	1,600
Alcohol or Drugs	1	7	17	43	17	6	7	400

1. Figures may not add up to 100 per cent due to rounding

Figure 3.11 demonstrates the link between satisfaction with support or services received and overall quality of life. 54 per cent of respondents who reported they were extremely satisfied with the support or services they received also said the quality of their lives was either good, very good or could not be better. Only 12 per cent of respondents who said they were extremely dissatisfied reported that their lives were this good and 19 per cent said their lives so bad they could not be worse.

Figure 3.11 Satisfaction with support/services received by the carer and cared for person (Q7) by overall quality of life (Q17)

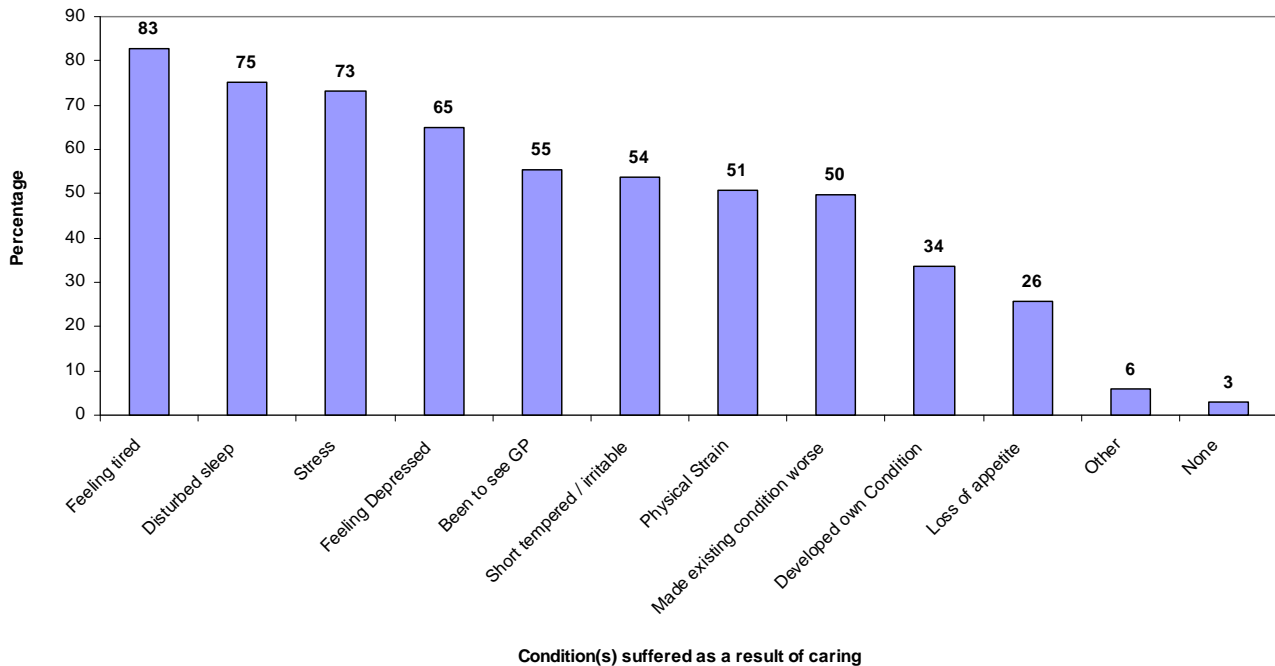


1. Figures may not add up to 100% due to rounding

Investigations into Specific Aspects of Quality of Life

Figure 3.12 shows the most common conditions of carers who had stated that their health in general was either bad or very bad (Q27). The most common condition was feeling tired which affected 83 per cent of carers followed by disturbed sleep at 75 per cent and stress at 73 per cent. The least reported condition was loss of appetite although this was still recorded by over a quarter of respondents (26%). 6 per cent of respondents reported suffering from another condition which was not listed in the questionnaire and 3 per cent reported no health conditions.

Figure 3.12 Carers who had stated their health was either bad or very bad (Q27) by types of conditions affecting those carers (Q28)

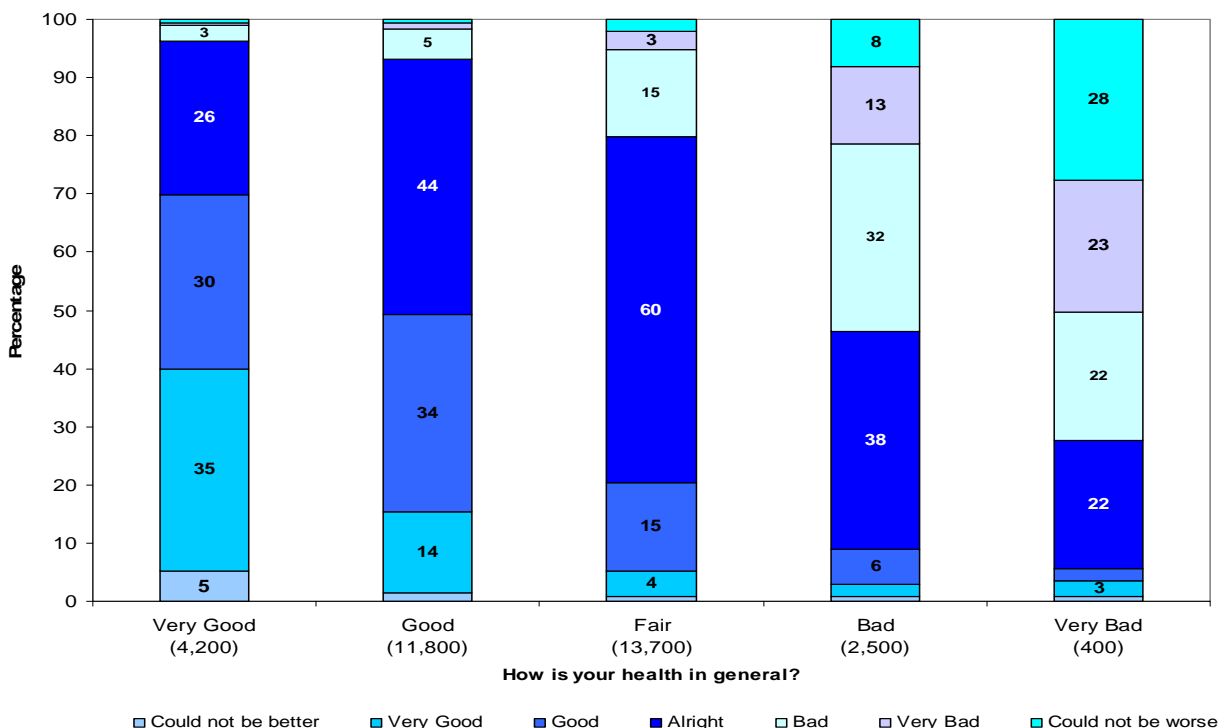


1. Based on 3,000 responses to both questions
2. Figures do not add up to 100 per cent as respondents could select more than one answer for Q28

Figure 3.13 shows there to be a strong link between the health in general of carers and their overall quality of life. Of respondents who stated that their health was very good, almost three-quarters (70%) reported that their lives were either good, very good or could not be better. This figure then declines gradually as the respondent indicates their health is good, fair, bad or very bad with only 6 per cent of those with very bad health stating their quality of life was either good, very good or so good it could not be better, and almost three quarters (72%) stating their life was either bad, very bad or could not be worse.

As with the previous chart, responses to these questions will be of interest in terms of the carers' strategy and its aims to ensure carers stay mentally and physically well.

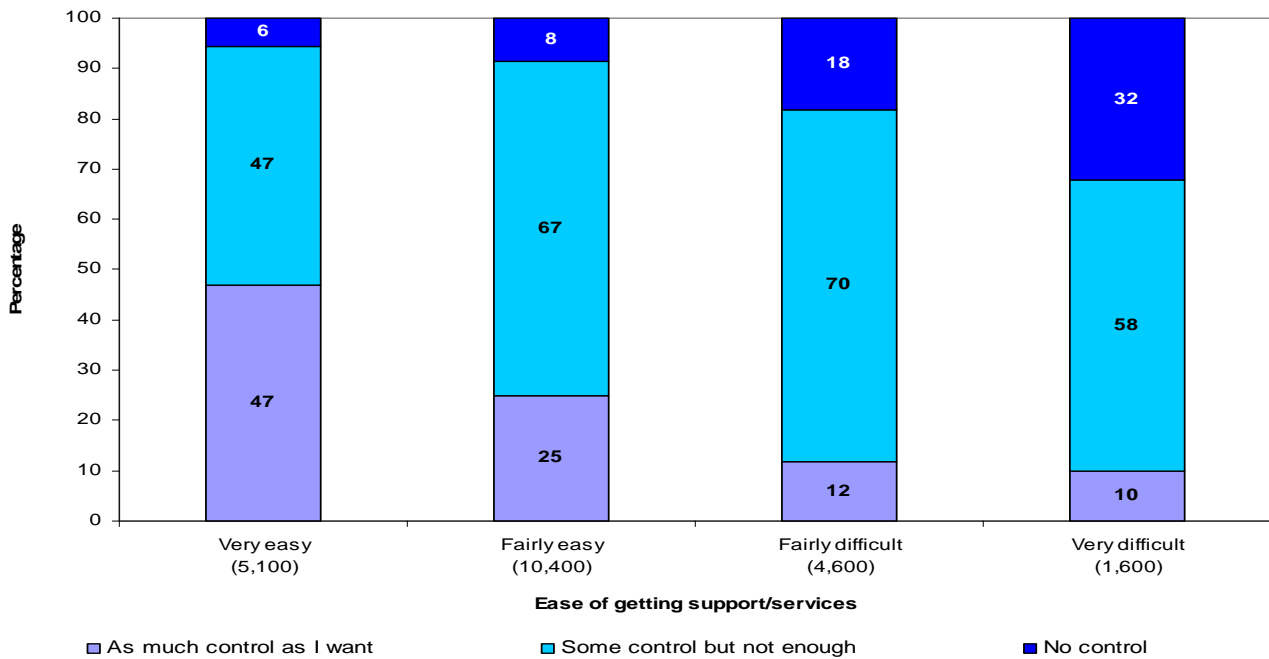
Figure 3.13 Overall Quality of life of the carer (Q17) by how is your health in general (Q27)



1. Figures may not add up to 100 per cent due to rounding

Figure 3.14 shows how much control carers have over their daily lives can be linked to how easy or difficult they found it to get the support or services they need. Nearly half (47%) of carers who stated they found it very easy to get the support/services they needed also reported that they had as much control over their daily lives as they wanted. In contrast, of those who found it very difficult to get support/services only 10 per cent reported they had as much control as they wanted.

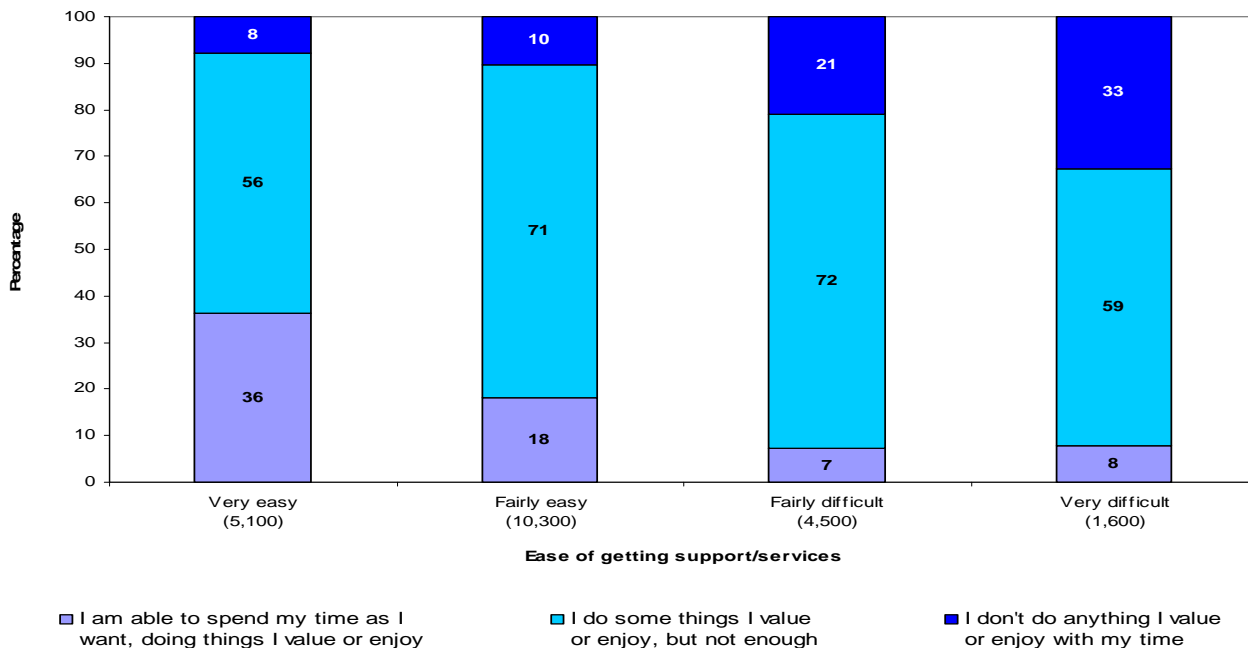
Figure 3.14 Have you found it easy or difficult to get the support or services you need as a carer (Q34) by how much control do you have over your daily life (Q20)



1. Figures may not add up to 100% due to rounding

Figure 3.15 shows that over a third (36%) of respondents who said they found it very easy to get the support/services they needed were able to spend their time as they want, whereas only 8 per cent of respondents who found it very difficult to get support/services they needed reported they could spend their time as they wanted. A third (33%) of the same group also reported that they didn't do anything they valued or enjoyed with their time compared to 8 per cent of those who found it very easy to get support or services.

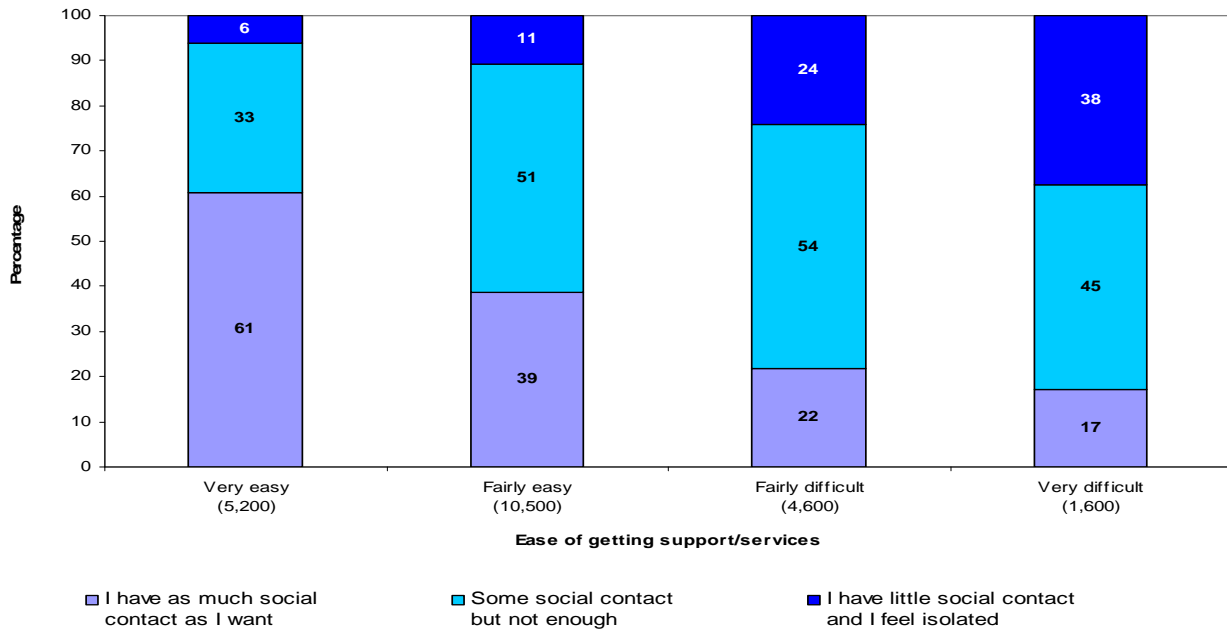
Figure 3.15 Have you found it easy or difficult to get the support or services you need as a carer (Q34) by, the statement which best describes how you spend your time (Q18)



1. Figures may not add up to 100% due to rounding

Figure 3.16 shows a relationship exists between respondents who stated they found it easy to get the support/services they needed and their social situation. For example, 61 per cent of carers who said they found it easy to get the support/services they needed also said they had as much social contact as they needed. Of those who found it very difficult, only 17 per cent reported they were able to do this. 38 per cent of this group also reported that they had little social contact and felt isolated.

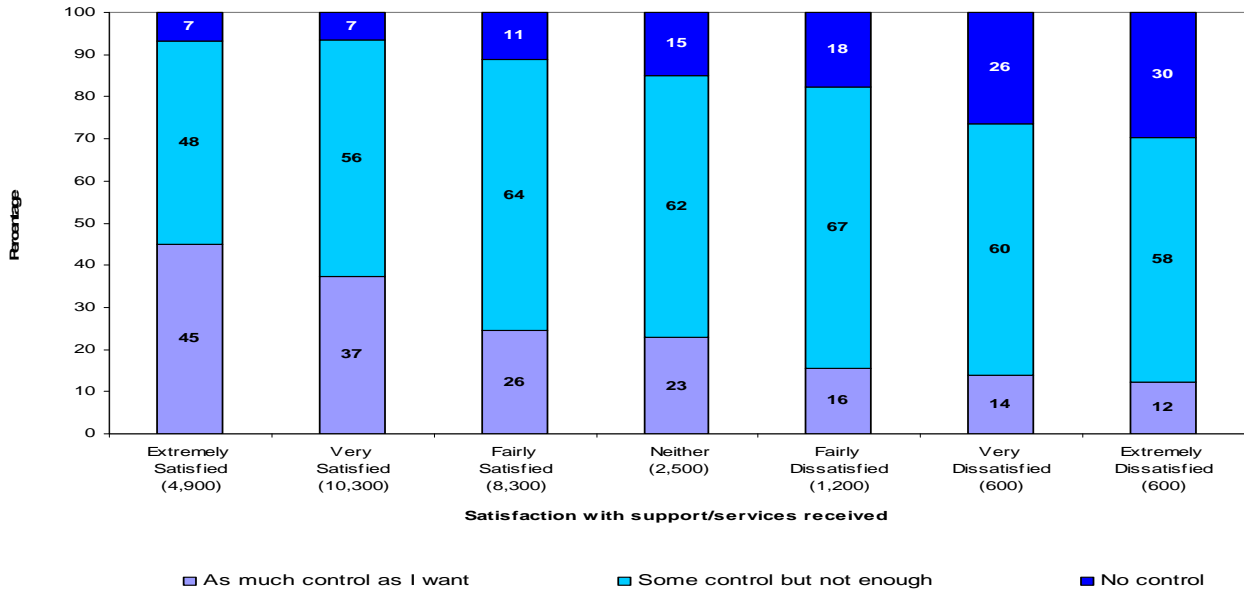
Figure 3.16 Have you found it easy or difficult to get the support or services you need as a carer (Q34) by thinking about social contact you've had with people you like which statement best describes your present social situation (Q23)



1. Figures may not add up to 100% due to rounding

Figure 3.17 shows a link exists between the satisfaction reported with support or services received and how much control the carer has over their daily lives. Of those carers who said they were extremely satisfied with the support or services they had received, 45% said they had as much control over their daily lives as they wanted. Of respondents who were extremely dissatisfied, only 12 per cent said they had as much control as they would like and 30 per cent said they had no control over their daily lives.

Figure 3.17 Satisfaction with support/services received by the carer and cared for person (Q7) by how much control the carer has over their daily lives (Q20)



1. Figures may not add up to 100% due to rounding

Combining Quality of Life Questions

It's interesting to combine the answers to some of the quality of life outcome questions to see how respondents measure. The questions in **table 3.3** all followed a well established format which has been used in previous surveys of social care users' outcomes. The possible answers to the questions are equated with having either no needs in a specific life area or domain, having low level needs or high level needs.

Table 3.3: Questions and their link to domains

No:	Question (See appendix C for the full question including answers)	Domain
18	Which of the following statements best describes how you spend your time?	Occupied in valued activities
19	Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your current situation? (<i>optional question</i>)	Sufficient space and time
20	Which of the following statements best describes how much control you have over your daily life?	Control over daily life
21	Thinking about how much time you have to look after yourself – in terms of getting enough to eat and sleep – which statement best describes your current situation?	Looking after themselves
22	Thinking about your personal safety which of the statements best describes your present situation?	Feeling safe
23	Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?	Social participation
24	Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?	Support and encouragement
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?	Access to basic services

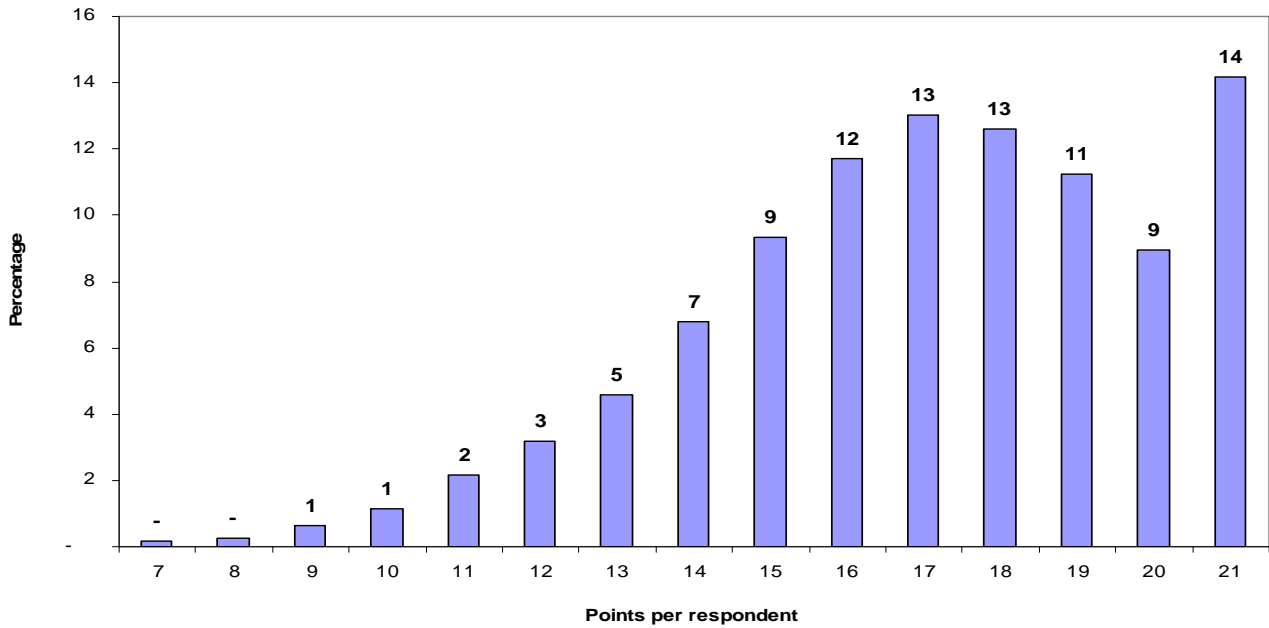
Restricting the analysis to respondents who answered all of these questions (and excluding Q19 as it was optional for councils to include, it is possible to construct a measure of social care related quality of life. Scores were given for each of the different levels of need as follows:

- High needs = 1
- Low level needs = 2
- No needs = 3

Therefore a score of 7 for a respondent would indicate high level needs on all questions and a maximum score of 21 would indicate no needs. This combined social care related quality of life measure can then be examined to see how it differs for different types of carers.

Figure 3.19 shows a peak in the distribution at a score of 17 points. It then begins to tail off before reaching a group of carers (14% of respondents) who said they had no needs across all of the domains and therefore had a maximum score of 21 points. In contrast, less than 0.5% of carers reported high level needs in all domains.

Figure 3.19 Percentage distribution of social care related quality of life scores



1. Figures may not add up to 100% due to rounding
 2. Based on 31,000 responses
- Less than 0.5 per cent

Table 3.4 shows that carers from the White ethnic group reported better outcomes (aside from the unknown category), with the lowest outcomes being reported by respondents from the Chinese/Other ethnic group.

Table 3.4 Social care related quality of life average scores by ethnicity

England 2009-10		
Ethnicity	Average Score	Total respondents
White	17.1	25,800
Mixed	16.3	200
Asian	16.0	1,400
Black	16.4	600
Chinese/Other	15.9	400
Unknown/Not stated	17.3	2,700

Table 3.5 shows that, older carers tended to report better outcomes than younger carers although the youngest carers (those aged 18 to 24) scored slightly higher than those aged 25 to 54 although the difference was not quite statistically significant. The highest score was 17.5 for those aged 85 or over and the lowest score was 16.4 for those aged 35 to 44.

Table 3.5 Social care related quality of life average scores by age

England 2009-10		
Age group	Average Score	Total respondents
18-24	17.0	200
25-34	16.5	400
35-44	16.4	1,600
45-54	16.6	5,100
55-64	17.1	8,500
65-74	17.2	6,900
75-84	17.2	5,600
85+	17.5	1,600
Unknown	17.5	1,000

Table 3.6 shows a relationship between the combined social care related quality of life score and the amount of time spent caring each week. Carers who spent between 0-9 hours per week caring reported the highest average score at 19.2 compared to a score of 16.3 for those who reported they cared for 100 or more hours per week.

Table 3.6 Social care related quality of life average scores by hours spent caring per week (Q50)

England 2009-10

Time spent caring per week	Average Score	Total respondents
0-9 hrs	19.2	2,100
10-19 hrs	18.2	2,600
20-34 hrs	17.4	2,400
35-49 hrs	16.9	2,500
50-99 hrs	16.5	3,600
100+ hrs	16.3	10,700
Varies under 20hrs	18.0	900
Varies over 20hrs	17.3	2,300
Other	17.1	2,200

Table 3.7 shows that respondents who reported the person they cared for had problems connected to ageing had the highest average combined score with 17.1. Carers who helped someone who had an alcohol or drugs problem reported the lowest average score of 15.9.

Table 3.7 Social care related quality of life average scores by conditions of cared for person (Q5)

England 2009-10

Condition of cared for person	Average Score	Total respondents
Dementia	16.7	8,200
A physical disability	16.9	16,200
Sight or hearing loss	16.9	8,500
A mental health problem	16.2	4,900
Problems connected to ageing	17.1	11,800
A learning disability or difficulty	16.8	4,600
Long standing illness	16.5	10,600
Terminal illness	16.2	1,400
Alcohol/Drugs	15.9	400

4. Experience of health services as a carer

Introduction

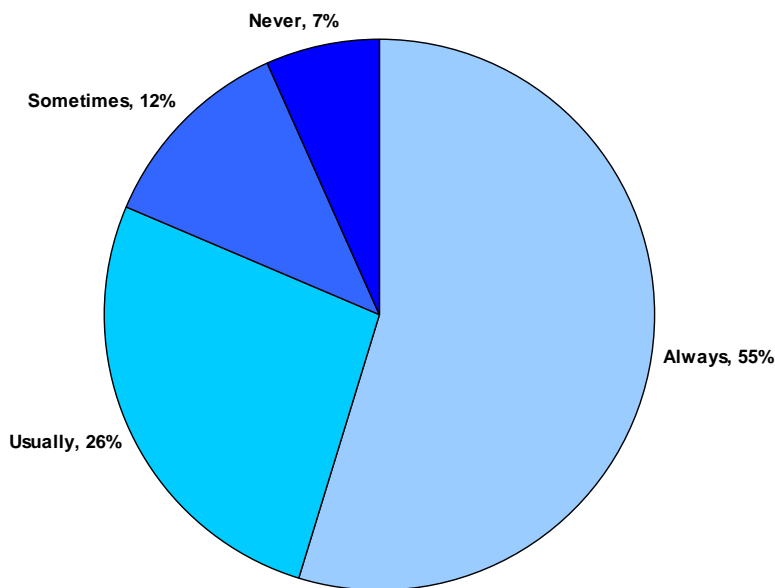
This section looks at the questions which asked the carer about their experiences of using health services particularly whether they had been treated with respect, whether they felt they had been involved in discussions about the treatment of the person they were caring for, and whether they felt supported by their GP in their caring role.

These questions are relevant to the aim of the carers' strategy that carers will be treated as expert care partners and are also treated with dignity. This is particularly pertinent as the carers' strategy is a vision for carers which is intended to be shared among central and local government as well as the NHS and other sectors.

Support from GPs for Carers

Figure 4.1 shows the extent to which carers feel they are supported by their GP in their caring role. Over half (55%) of respondents to the question stated they always felt supported by their GP with a further 26 per cent saying this was usually the case. 12 per cent said they were sometimes supported but 7 per cent said they never felt supported by their GP.

Figure 4.1 Overall, do carers feel supported by GPs in their caring role (Q46)

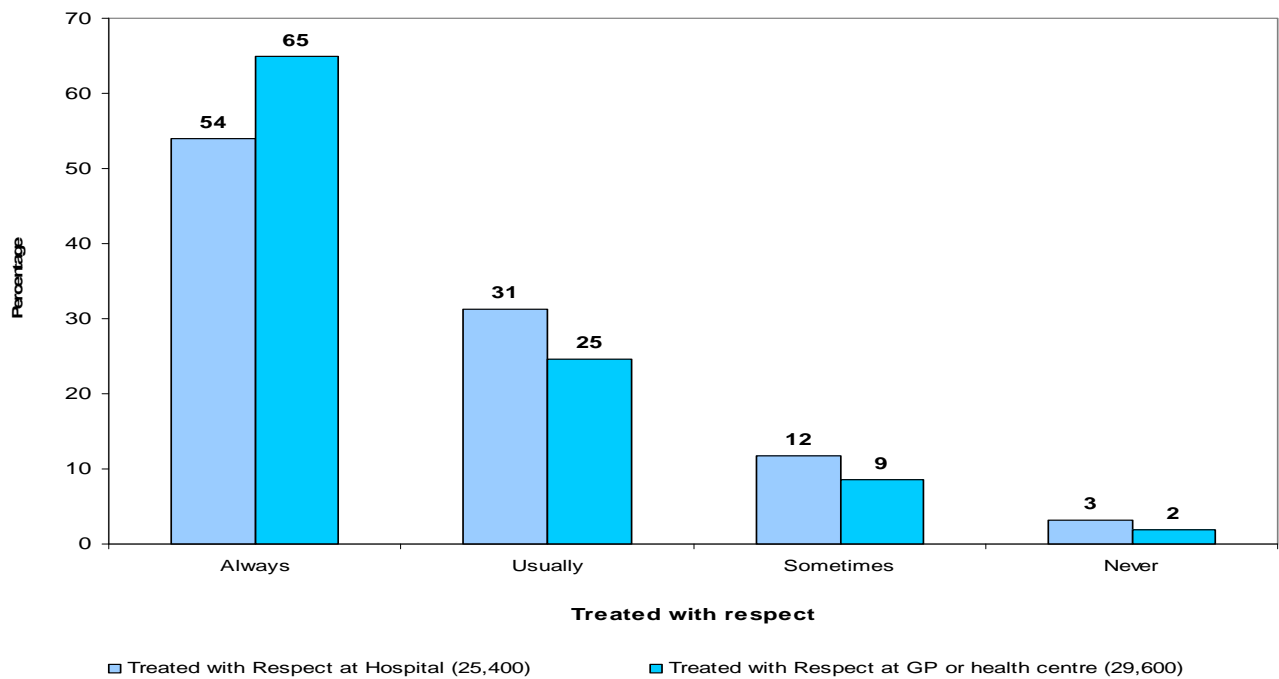


1. Figures may not add up to 100 per cent due to rounding
2. Based on 28,100 respondents
3. Excludes 5,500 respondents who said their GP did not know they were a carer

Are carers treated with respect and involved in discussions about the cared for person when in contact with NHS services

Figure 4.2 shows that the majority of carers using NHS services felt that they were always or usually treated with respect at both NHS hospitals (85%) and at a GP surgery or health centre (90%). 3 per cent of respondents stated that they were never treated with respect at NHS hospitals and the corresponding figure for those visiting a GP surgery or health centre was 2 per cent.

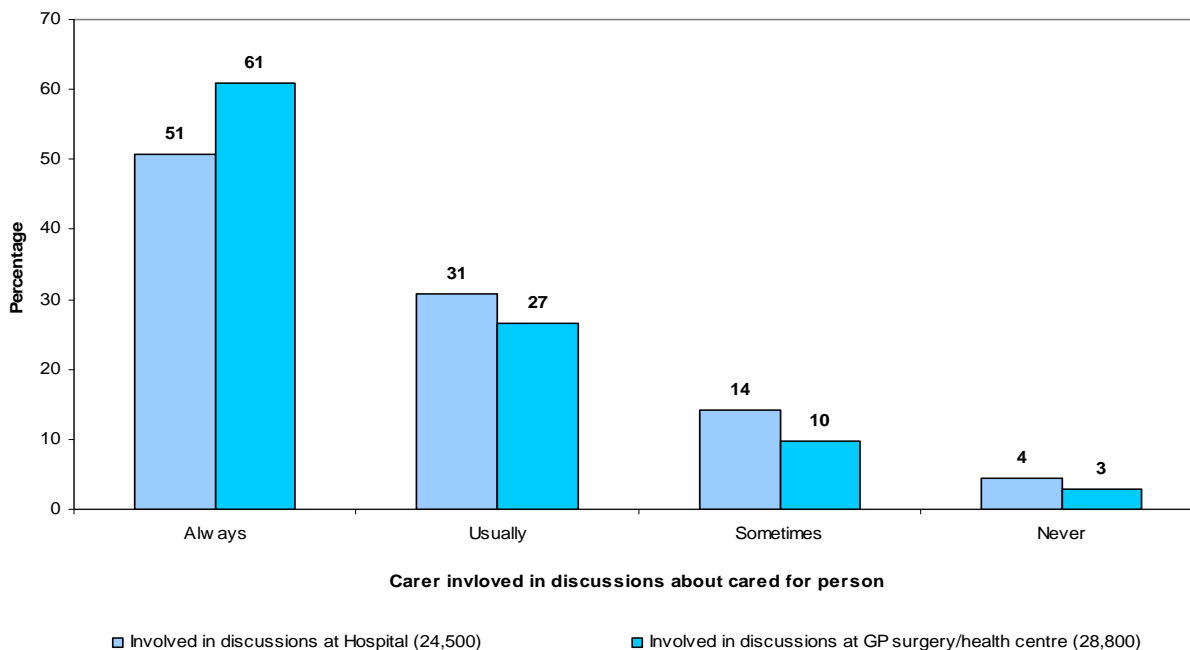
Figure 4.2 Carers treated with respect as a carer by professionals at NHS hospitals (Q42) and treated with respect as a carer by professionals at a GP surgery/health centre (Q44)



1. Figures may not add up to 100 per cent due to rounding

Figure 4.3 shows to what extent carers feel they are involved as much as they would like to be in discussions about the treatment of the person they are caring for when in contact with NHS professionals. 82 per cent of respondents reported that they were either always or usually involved in discussions as much as they wanted to be about the person they cared for at an NHS hospital, whereas 88 per cent of respondents stated they were always or usually involved in discussions at a GP surgery/health centre. Those never involved in discussions as much as they wanted to at an NHS hospital or GP surgery/health centre was reported as 4 per cent and 3 per cent respectively.

Figure 4.3 Are carers involved in discussions about treatment of the cared for person as much as they want to be when in contact with professionals at a NHS hospital (Q43) or GP surgery/health centre (Q45)

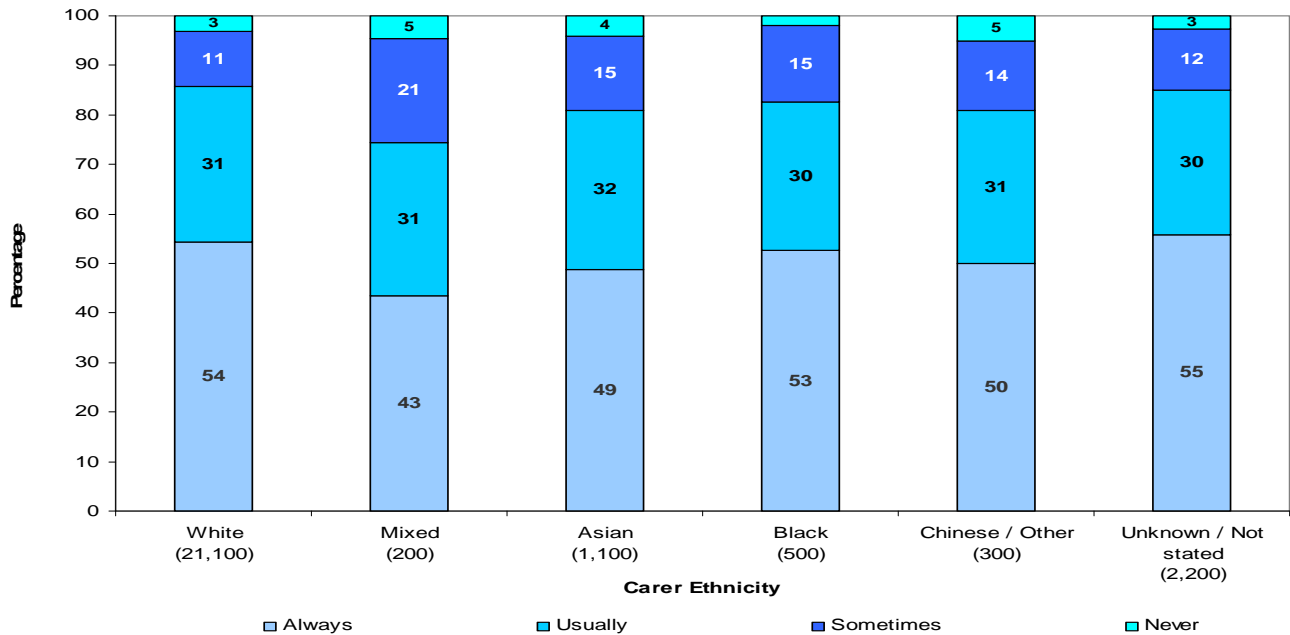


1. Figures may not add up to 100 per cent due to rounding

Carers treated with respect when in contact with NHS services by demographic factors

Figure 4.4 shows that carers from the White ethnic group were most likely to always or usually be treated with respect at a hospital (86%) compared to only 74 per cent of those from the Mixed ethnic group. This group also reported the highest level of never being treated with respect (5%) along with those from the Chinese or other ethnicity group.

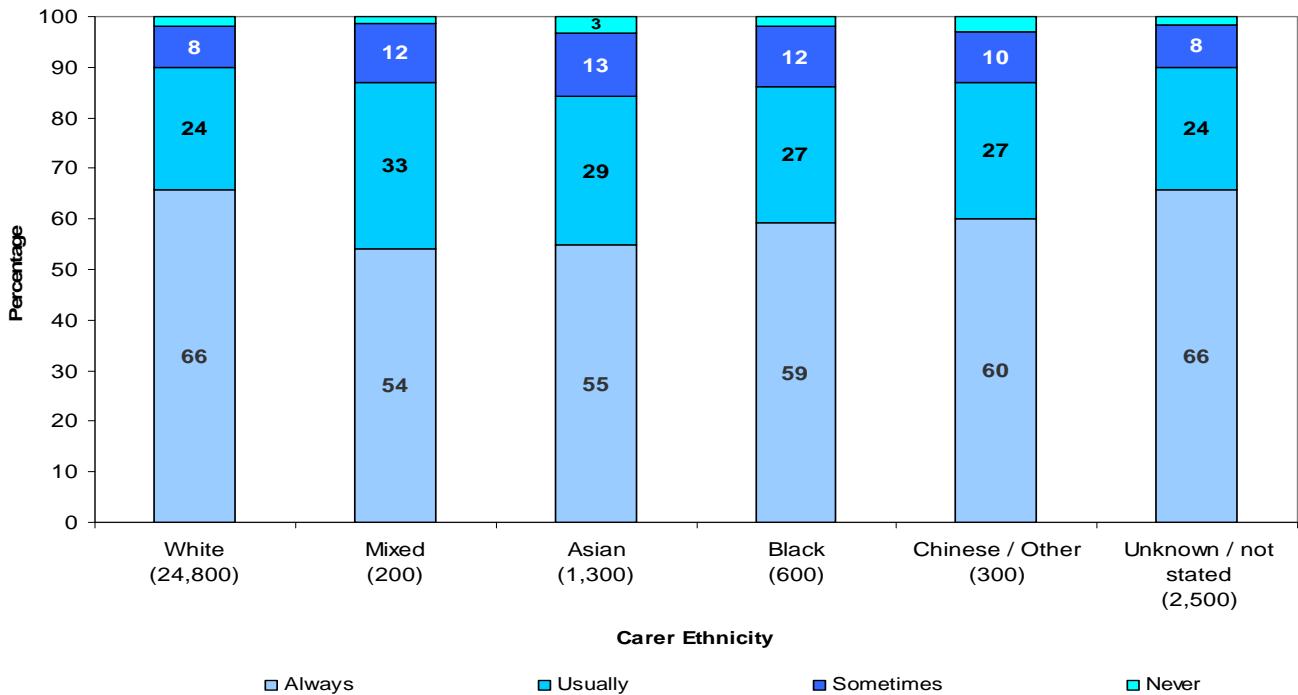
Figure 4.4 Carers treated with respect when in contact with professionals at an NHS hospital (Q42) by ethnicity



1. Figures may not add up to 100 per cent due to rounding

Figure 4.5, similarly to figure 4.4, shows that excluding the ethnicity not stated or unknown group, carers from the White ethnic group were most likely to be always or usually treated with respect (90%) when in contact with health professionals at GP surgery compared to only 84 per cent of carers from the Asian ethnic group.

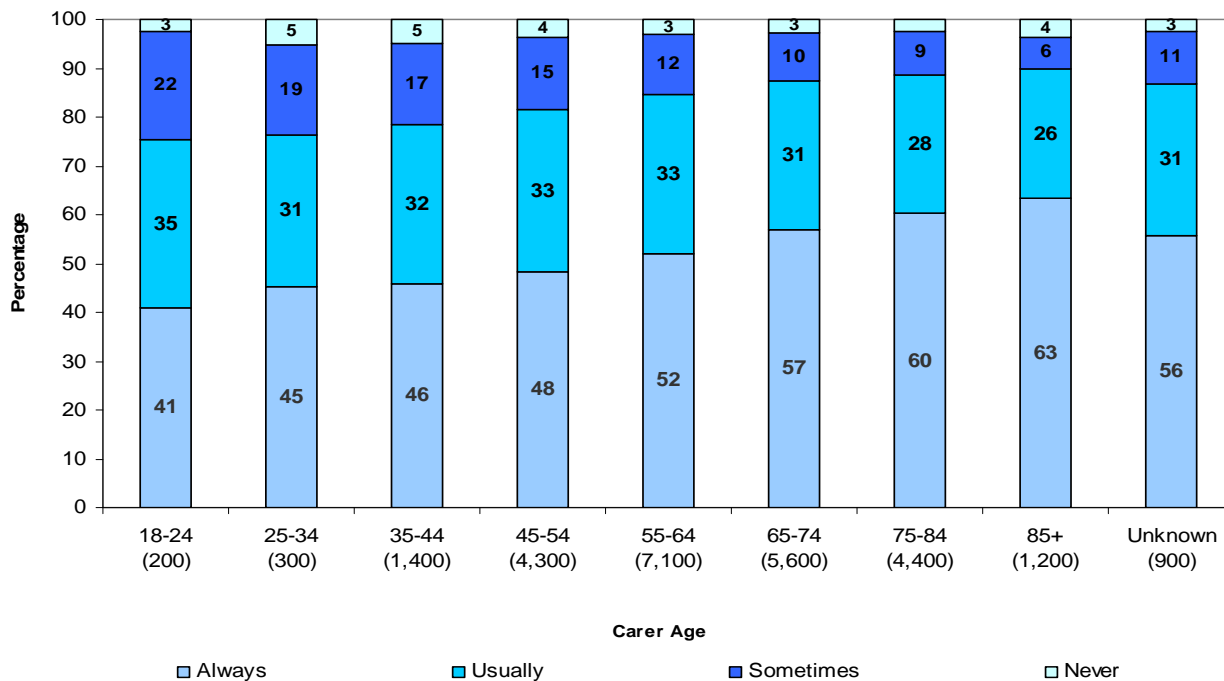
Figure 4.5 Carers treated with respect when in contact with professionals at GP surgery or health centre (Q44) by ethnicity



1. Figures may not add up to 100 per cent due to rounding

Figure 4.6 shows there is a link between the age of the carer and whether they were treated with respect by professionals at an NHS hospital. Younger carers tended to be less likely to be always treated with respect (41 per cent of carers aged 18-24) compared to older carers (63 per cent of carers aged 85+).

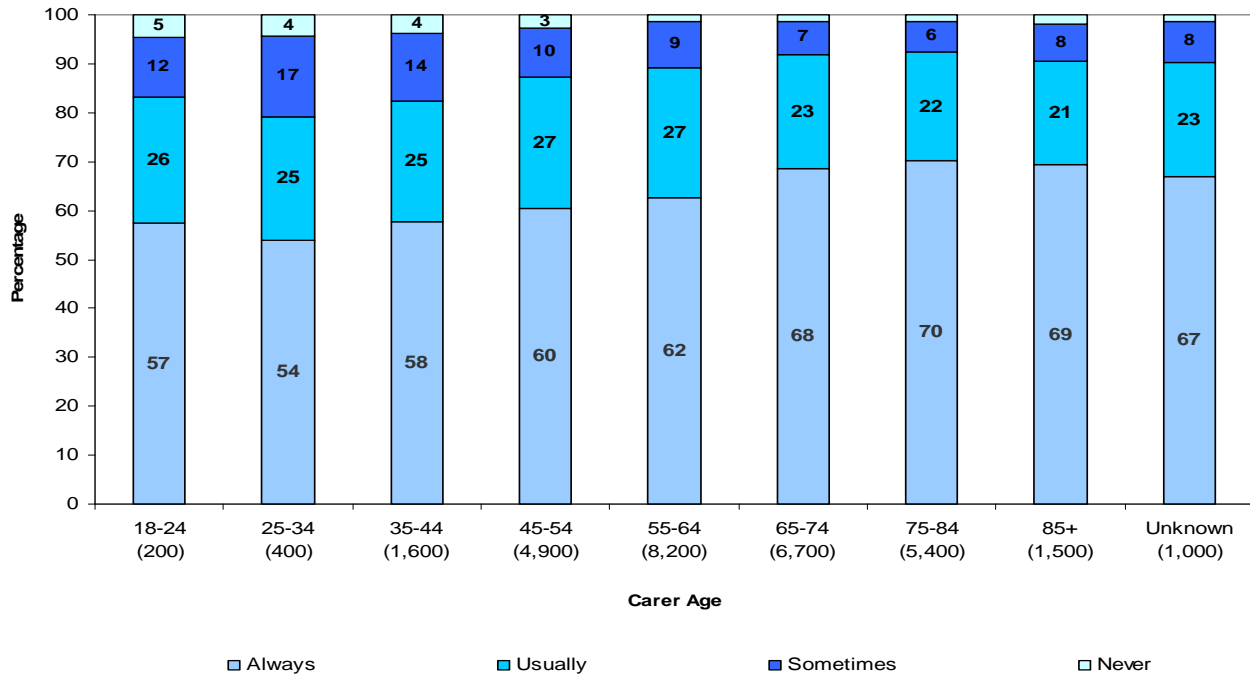
Figure 4.6 Carers treated with respect when in contact with professionals at an NHS hospital (Q42) by age



1. Figures may not add up to 100 per cent due to rounding

Figure 4.7 looks at whether the carer was treated with respect by NHS professionals at a GP surgery or health centre. Again, it shows that older carers were more likely to always be treated with respect with 70 per cent of 75-84 year olds reporting this. Younger carers were less likely to be treated with respect, 54 per cent of 25-34 year olds stating that this was always the case.

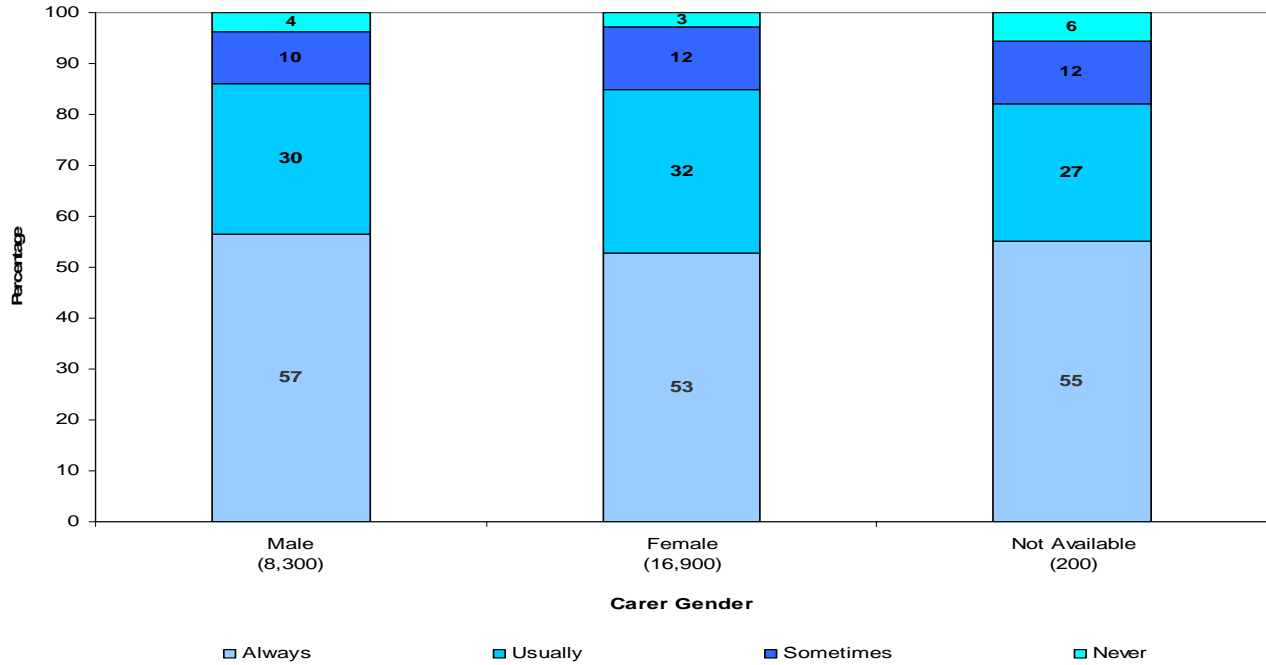
Figure 4.7 Carers treated with respect when in contact with professionals at GP surgery or health centre (Q44) by age



1. Figures may not add up to 100 per cent due to rounding

Figure 4.8 shows there was only a very small relationship between the gender of the carer and whether they were treated with respect by professionals at an NHS hospital. The majority of both male and female carers reported that they were either always or usually treated with respect, 86 per cent and 85 per cent respectively.

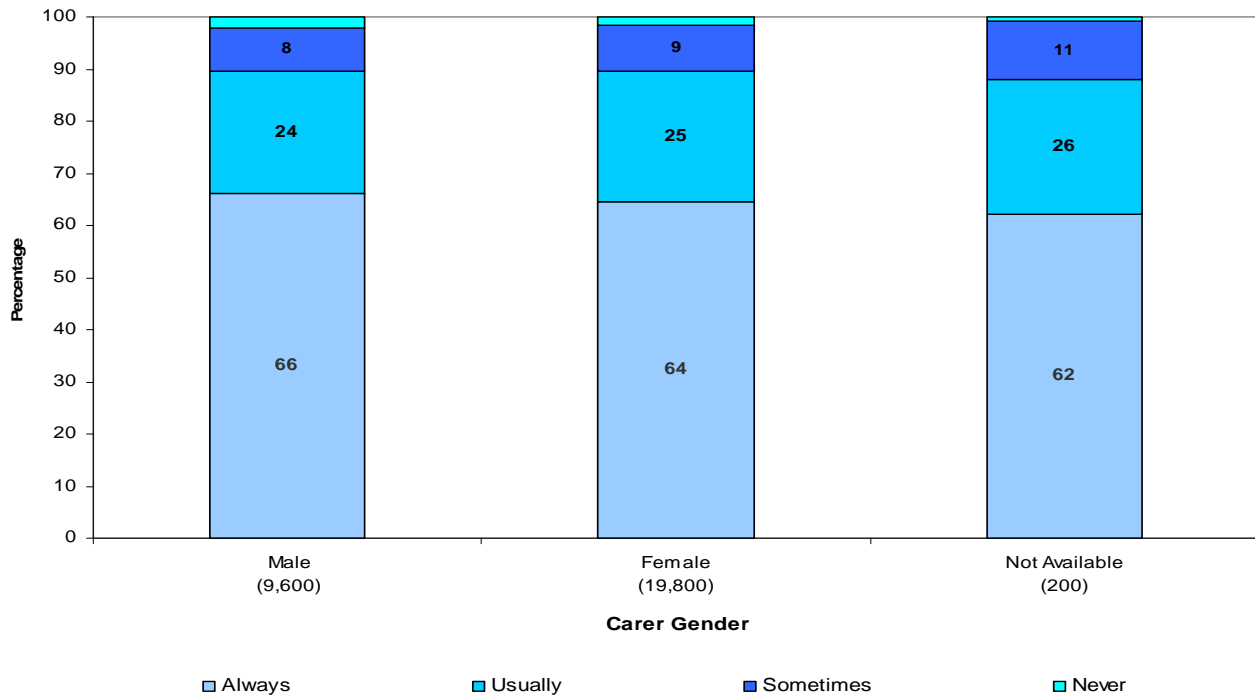
Figure 4.8 Carers treated with respect when in contact with professionals at an NHS hospital (Q42) by gender



1. Figures may not add up to 100 per cent due to rounding

Similarly to figure 4.8, **figure 4.9** shows there was little relationship between the gender of the carer and whether they were treated with respect by professionals at a GP surgery or health centre. 90 per cent of both males and females reported that they were either always or usually treated with respect.

Figure 4.9 Carers treated with respect when in contact with professionals at a GP surgery/health centre (Q44) by gender



1. Figures may not add up to 100 per cent due to rounding

5. Coverage

Introduction

The eligible population was defined as those carers (aged 18+) who had been assessed or reviewed, either separately or jointly with the cared for person, by social services during the past 12 months when the sample was. In addition, councils were asked to include carers who were named on the file of carers who had been assessed or reviewed in the last 12 months when the sample was chosen. These carers were referred to as “carers known by association”.

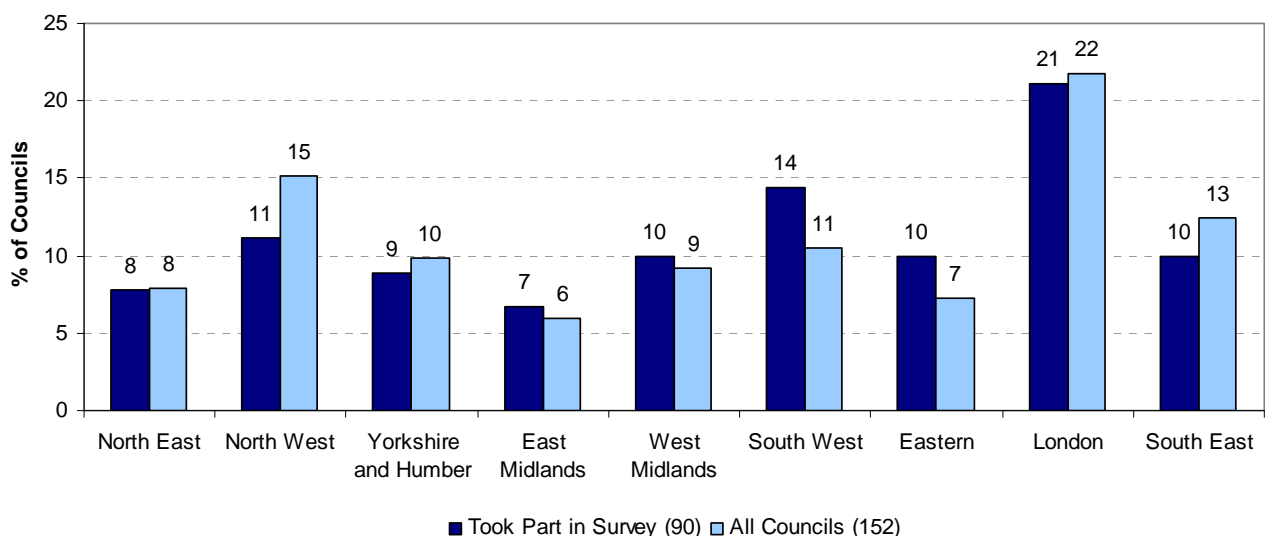
However, a pilot survey conducted in February 2009 had shown that not all councils held enough detailed information to identify carers known by association, so not all councils were able to include this further group of carers.

Councils Taking Part

Councils had the option of deciding whether to take part in this survey as it was voluntary. In total 90 out of the 152 councils (59%) did decide to take part in the survey. Those who declined were asked to give their reasons with the majority mentioning lack of resources or that they were already carrying out local work in this area. Of those 90 councils taking part in the survey, 41 (46%) were able to include carers known by association.

Figure 5.1 shows that the councils taking part in the survey were broadly representative regionally of all councils although there were slightly fewer councils in the North West compared to the national distribution, and slightly more in the South West and Eastern regions.

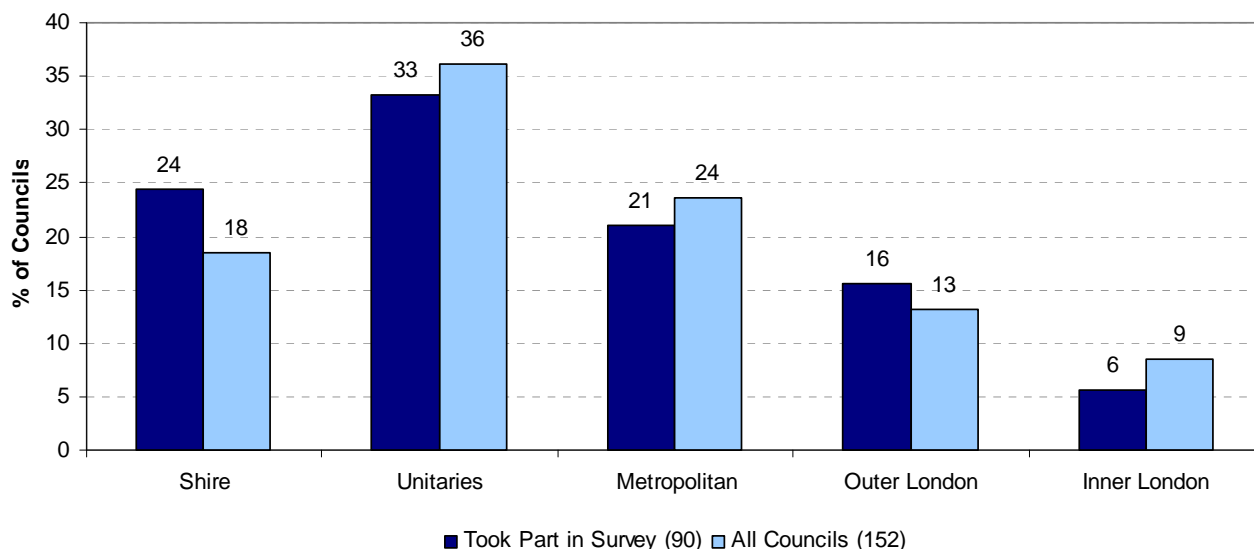
Figure 5.1: Percentage distribution of councils Taking Part in the Survey by Region



1. Figures may not add to 100 due to rounding.

Figure 5.2 shows that the councils taking part in the survey were also broadly representative by type of councils although there were slightly more Shire councils and councils in Outer London compared to the national distribution, and slightly fewer Unitaries, Metropolitan and councils in Inner London.

Figure 5.2: Percentage distribution of councils Taking Part in the Survey by Council Type



1. Figures may not add to 100 due to rounding.

An exercise was undertaken to examine any potential bias caused by only having a sample of councils taking part. Results to two of the key questions in the survey on satisfaction with services received and overall quality of life were reweighted to be representative of all councils in England. The results can be seen in tables 5.1 and 5.2 and show that the largest change in any of the results was 0.3 percentage points and therefore, the results from the 90 councils who took part in the survey can be taken to be representative of England as a whole.

Table 5.1: Answers to “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?” (Q7) reweighted for differences by region and council type

England 2009-10		Percentages		
		Adjusted for:		
Satisfaction	Unadjusted	Regional Differences	Council Type Differences	
Extremely Satisfied	17.5	-0.2	0.0	
Very Satisfied	36.2	-0.2	-0.2	
Fairly Satisfied	28.9	0.1	0.0	
Neither	9.0	0.1	0.0	
Dissatisfied	8.3	0.2	0.2	

1. Based on 29,900 responses of carers who had received services.
2. Figures may not add to 100 due to rounding.

Table 5.2: Answers to Overall quality of life of the carer (Q17) reweighted for differences by region and council type

Quality of Life	Unadjusted	Adjusted for:	
		Regional Differences	Council Type Differences
So good, it could not be better	1.6	0.0	0.1
Very good	11.5	0.1	0.2
Good	22.9	0.1	0.0
Alright	47.4	-0.2	-0.3
Bad	11.2	0.0	-0.1
Very bad	3.1	0.0	0.1
So bad, it could not be worse	2.1	0.0	0.1

1. Based on 33,500 responses.
2. Figures may not add to 100 due to rounding.

Selection of Sample

In total, the questionnaire was distributed to approximately 87,800 carers out of an eligible population of 175,600.

Figure 5.3 shows that 71 per cent of carers sampled had received an assessment or review in the last year while 20 per cent were on the file of a carer who had been assessed or reviewed (ie. a carer known by association) but it was not known from council records how or whether the remaining 9 per cent had been assessed.

Figure 5.3: Sample Selected by Whether and How Carer Was Assessed

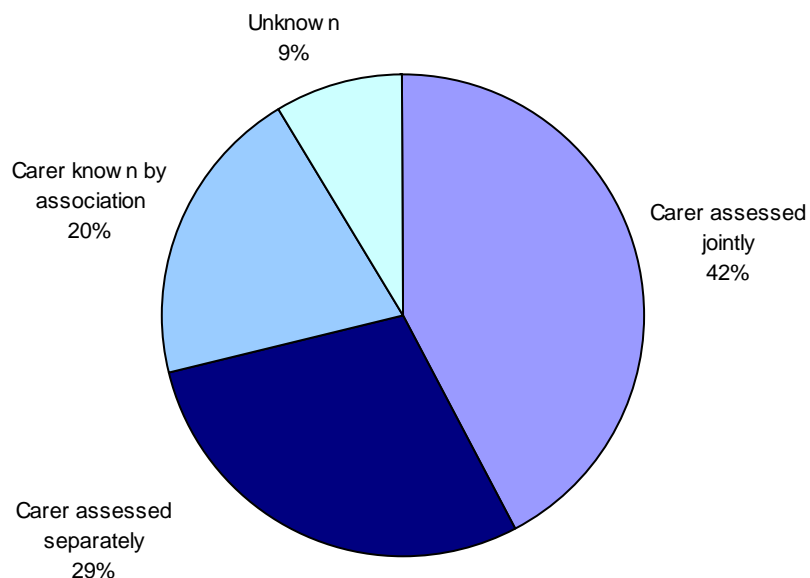
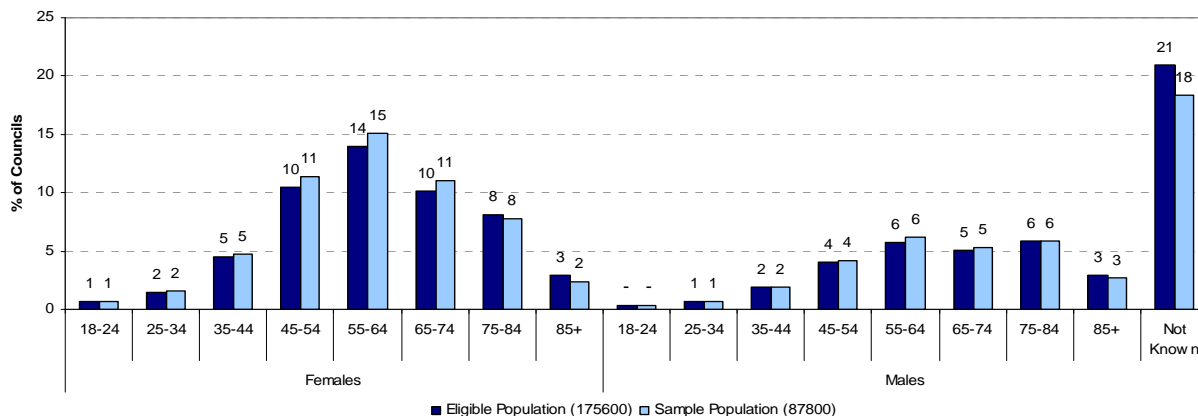


Figure 5.4 shows the distribution of the eligible population of carers and those selected for the sample and therefore sent questionnaires, broken down by age and gender. The two distributions are very similar showing that the sample was selected correctly and no noticeable bias was introduced at this stage.

There were a large percentage of carers where either the age or gender was unknown. This reflects the fact that not all these carers will have gone on to receive services or information and those known by association will not even have had an assessment. The demographic records of some of these carers may be of poor quality.

Figure 5.4: Breakdown of eligible population and those sampled by age and gender



1. Figures may not add to 100 due to rounding.

Response rates

A user is classed as a respondent if they responded to one or more questions, allowing carers to express their views on areas they feel strongly about without having to complete the entire questionnaire.

35,200 carers responded with answers to one or more questions out of the 87,800 who were sent questionnaires and **table 5.3** shows this represented 40 per cent of those surveyed. The majority of the questionnaires returned were administered by post. Carers were offered the option of returning blank questionnaires to show that they did not want to receive reminder letters and 6 per cent of those sampled took up this option.

Table 5.3: Method of collection for total respondents and non respondents¹

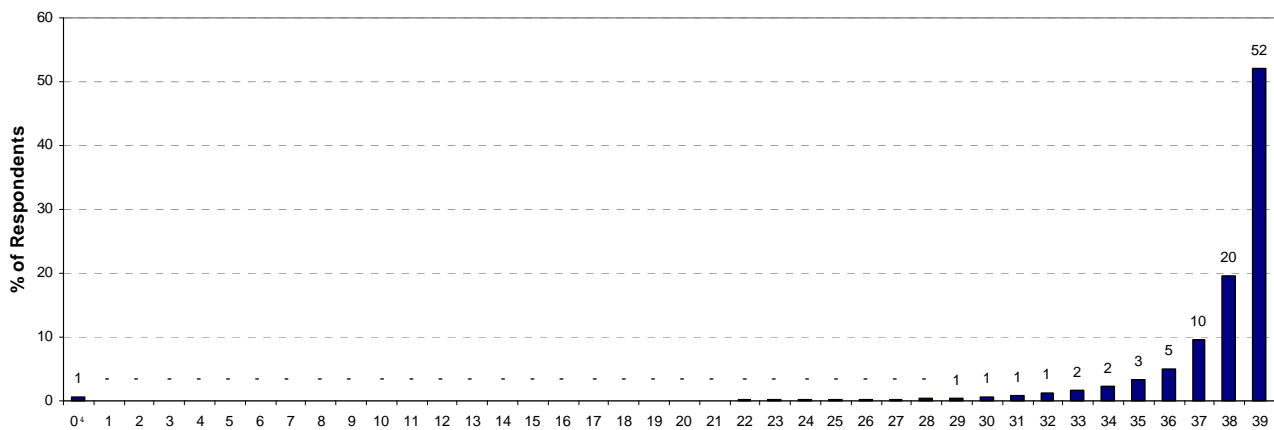
England 2009-10		Percentages
Method of Collection		Respondents and Non Respondents
Response ²	Post	40
	Face-to-face	-
	Telephone	-
Non-Response	Blank Questionnaire Returned	6
	Nothing Returned	54

1. Based in 87,800 carers sampled.
2. Around 200 carers were flagged on the LA returns as responders but had not actually answered any questions. This has a negligible effect on the response rate at national level.
3. Figures may not add to 100 due to rounding.

An additional complication in this survey was that there were 58 questions in total but 19 of these were optional in that councils could choose whether to include them or not. Analysis of the number of questions answered in this section therefore is restricted to the 39 mandatory questions so it is comparable across councils. In addition, 5 councils did not include all the mandatory questions so they have also been removed from this analysis.

Figure 5.5 shows that 52 per cent of respondents answered all questions in the questionnaire and an additional 20 per cent of respondents only left one question unanswered. 90 per cent of respondents answered at least 35 out of the 39 mandatory questions.

Figure 5.5: Number of questions from the questionnaire answered by respondents^{1,2,3}



- Less than 0.5 per cent
1. Based on 33,000 respondents.
 2. Does not include 3 demographic questions on age, gender or ethnicity as these could be answered from council records and also does not include the optional questions.
 3. Excludes 5 councils who did not include all of the mandatory questions.
 4. Around 200 carers were flagged on the LA returns as responders but had not actually answered any questions. This has a negligible effect on the response rate at national level.
 5. Figures may not add up to 100 per cent due to rounding

Table 5.4 shows that there is some relationship between the degree of satisfaction and the number of questions the respondent chose to answer. Of those respondents that answered 21 to 30 questions, 22 per cent said they were extremely satisfied compared to 17 per cent

of those who answered all 39 questions. The differences for those answering 1 to 20 questions were not found to be significant.

Table 5.4: The number of questions answered by respondents by degree of satisfaction

England 2009-10		Percentages ¹ and Rounded Numbers					Total Respondents
Number of Questions Answered	Degree of Satisfaction						
	Extremely Satisfied	Very Satisfied	Fairly Satisfied	Neither	Dissatisfied ²		
1 to 20	21	34	25	9	11	200	
21 to 30	22	35	25	9	8	600	
31 to 36	19	36	27	9	8	3,700	
37 to 38	18	36	29	9	8	8,300	
39	17	37	30	9	8	15,300	

1. Figures may not add up to 100 per cent due to rounding

2. Includes "Quite Dissatisfied", "Very Dissatisfied" and "Extremely Dissatisfied".

Response rates for different groups

It is important to look at response rates (the percentage of people responding) for different groups as a low response rate for a reasonably large group can lead to the sample being biased and therefore the results will not fully reflect the eligible population.

Figure 5.6 shows that the response rate for carers known by association was lower at 34 per cent than those who had had an assessment or review in the previous 12 months (46 per cent for those assessed separately and 40 per cent for those who had a joint assessment with the cared for person). This is to be expected as anecdotal feedback from councils has suggested that they are less confident of the accuracy of their records for carers known by association. Some councils have also indicated that the person nominated as a "carer" on the cared for persons record may simply be the next of kin and not have any significant caring responsibilities. Therefore, they may not have thought the questionnaire was relevant for them which will explain the lower response rate. This is partially demonstrated in **table 5.5** where 23 per cent of carers known by association cared for fewer than 20 hours per week compared to 13 per cent of carers who had an assessment separately from the cared for person. However, it is not very different from carers who had a joint assessment with the cared for person where 22 per cent cared for fewer than 20 hours per week.

Others have said that they were not confident of some of the information on carers known by association and therefore basic information such as address details may not be up to date which would obviously result in non-response.

Figure 5.6: Response Rate by Whether the Carer was Assessed

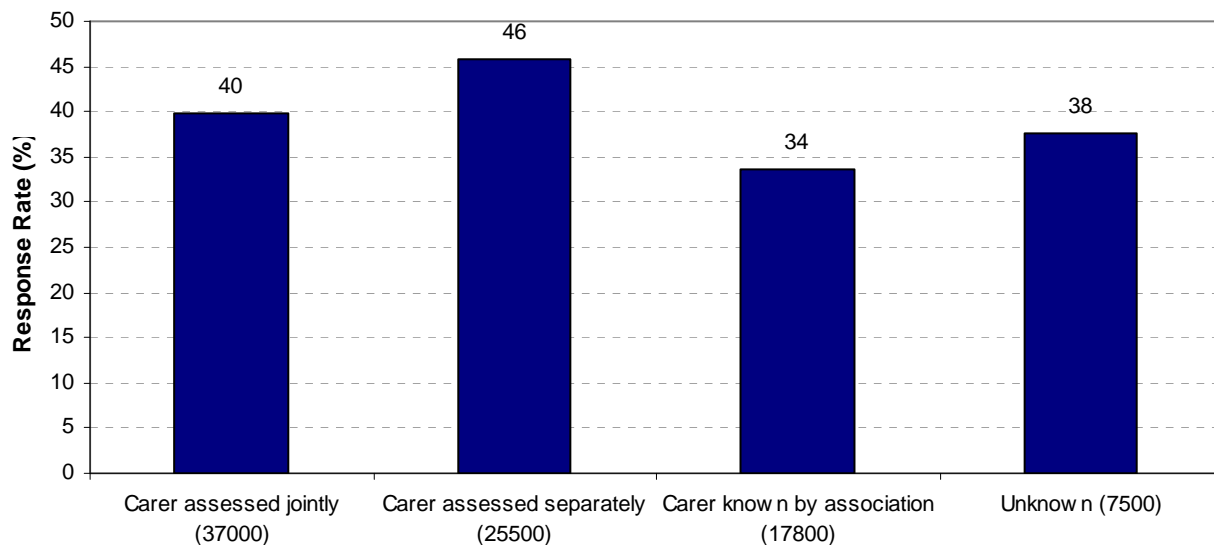


Table 5.5: Number of Hours per Week Spent Caring by Whether Carer was Assessed

England 2009-10							Percentages ¹ and Rounded Numbers			
How and whether carer was assessed	0-9 hrs	10-19 hrs	20-34 hrs	35-49 hrs	50-99 hrs	100+ hrs	Varies less than 20	Varies 20 or more hrs	Other	Total Respondents
Carer assessed jointly	9	10	9	8	11	34	3	8	7	13,600
Carer assessed separately	4	6	7	8	13	41	2	8	9	11,000
Carer known by association	9	11	8	9	12	32	3	8	7	5,400
Unknown	7	8	9	7	14	37	3	9	6	2,600

1. Figures may not add up to 100 per cent due to rounding

Response rates by gender, age and ethnicity are difficult to assess. There were optional questions included in the survey to capture this demographic information, but councils who did have reliable data about the carer available from their own systems were instructed to remove the questions. This was to reduce burden on the respondent and on the councils themselves when completing the data return. As an added complication, some councils may have had reliable information on their systems about carers they assessed but not those who were known by association. Therefore, the demographic data on their data return may be a mixture of system and respondent data.

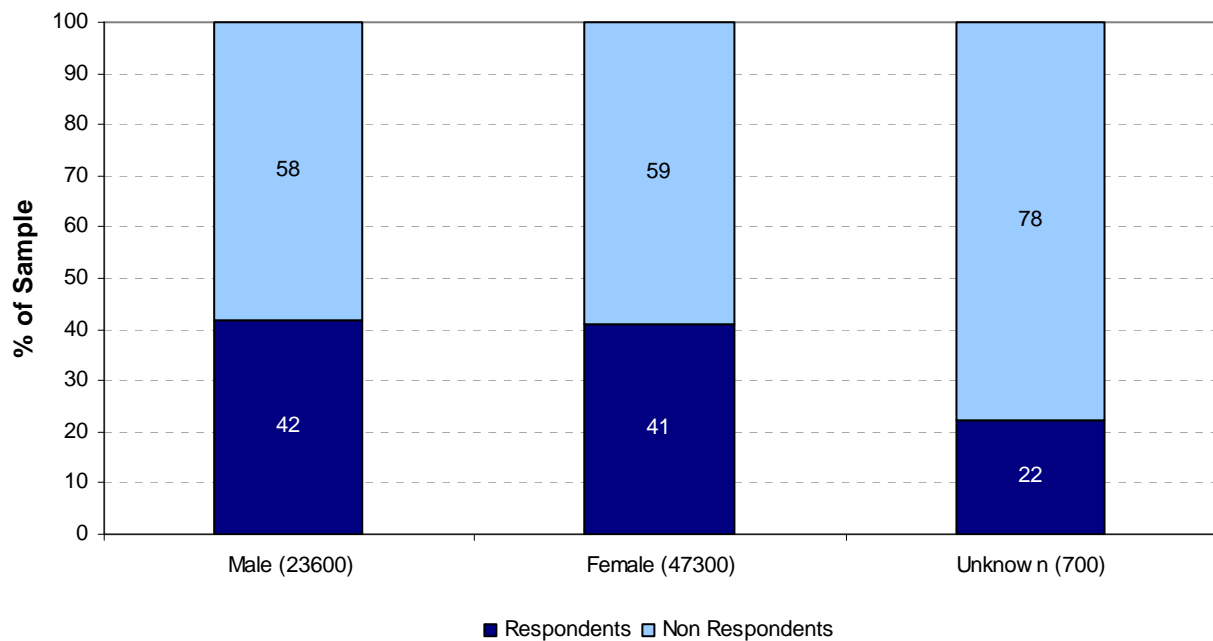
This causes problems when trying to calculate a response rate because for example, if the council does not know the age of their carers then they will only be able to provide the ages for all those who respond. This will bias an analysis of response rates by age by inflating those for known age groups and deflating the response rate where age is unknown, as all those who start off as age unknown move out of this group when they respond to the survey and are placed in the relevant age group.

The following analysis of response rates by gender, age and ethnicity attempts to get around this problem by removing councils from the analysis who have less complete demographic

data. This is arbitrarily taken to be those where the “unknown” category makes up more than 10 per cent of their sample.

There was little difference in response rates between men and women as shown in **figure 5.7**. The response rate for those with unknown gender was much lower at 22 per cent but 44 per cent of those where the gender was unknown were either carers who were known by association with the cared for person, or whether they were assessed was unknown from the council's systems. As mentioned previously those carers known by association have a lower response rate than those who have received an assessment or review and potential reasons were also given previously.

Figure 5.7: Respondents and Non Respondents by Gender



1. Figures may not add up to 100 per cent due to rounding

Figure 5.8 shows that the response rate for younger carers is lower as only 19 per cent of carers aged 25 to 34 and 21 per cent of those aged 18 to 24 responded, compared to 53 per cent of carers aged 75 to 84. However, the lowest response rates were for the smaller groups but as only 4 per cent of carers in this response rate analysis were aged 18 to 34 this is unlikely to have biased the results of the survey. Again, those with unknown age have a low response rate but potential reasons for this were discussed previously.

Figure 5.8: Response Rate by Age

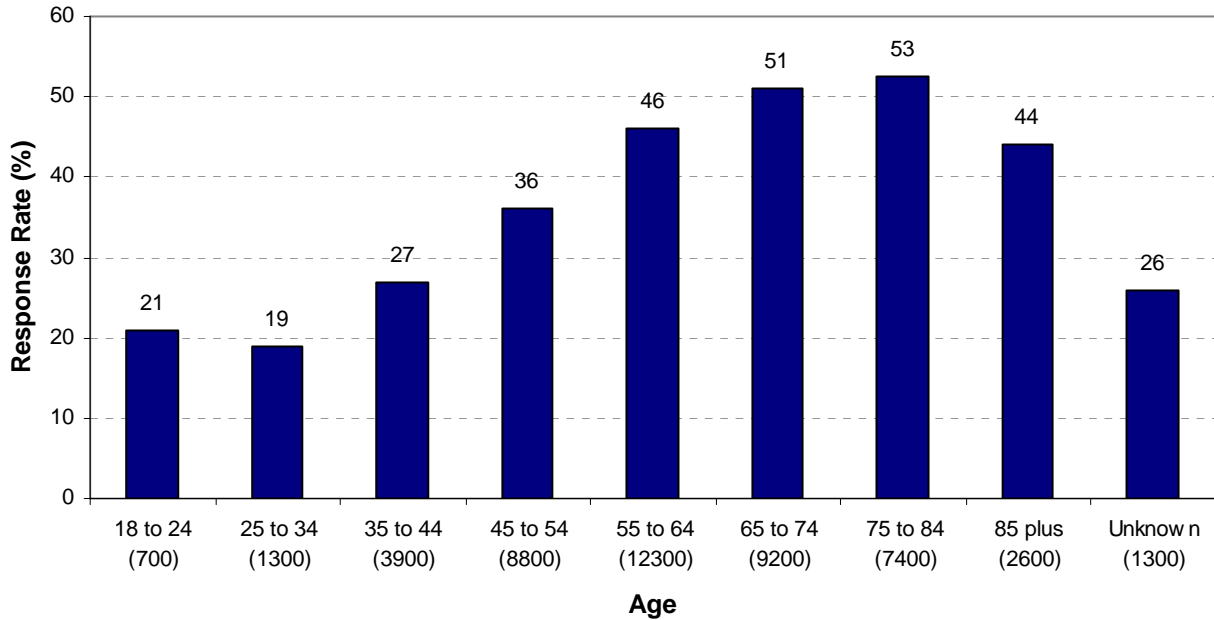


Figure 5.9 shows that the response rate for carers in black or minority ethnic groups is lower as for example, only 32 per cent of carers in the Black group responded compared to 49 per cent of carers in the White ethnic group. Again however, the lowest response rates are for the smaller groups as 88 per cent of those with a known ethnic group in this response rate analysis were from the White ethnic group. Again, those with unknown or not stated ethnic group have a low response rate but potential reasons for this were discussed previously.

Figure 5.9: Response Rate by Ethnicity

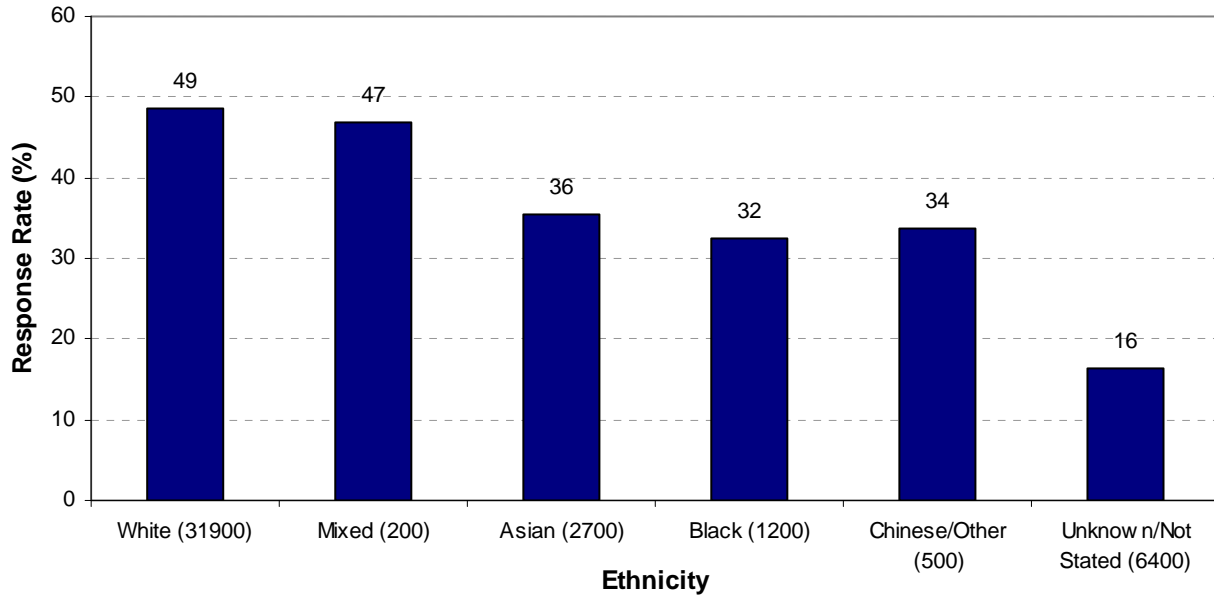
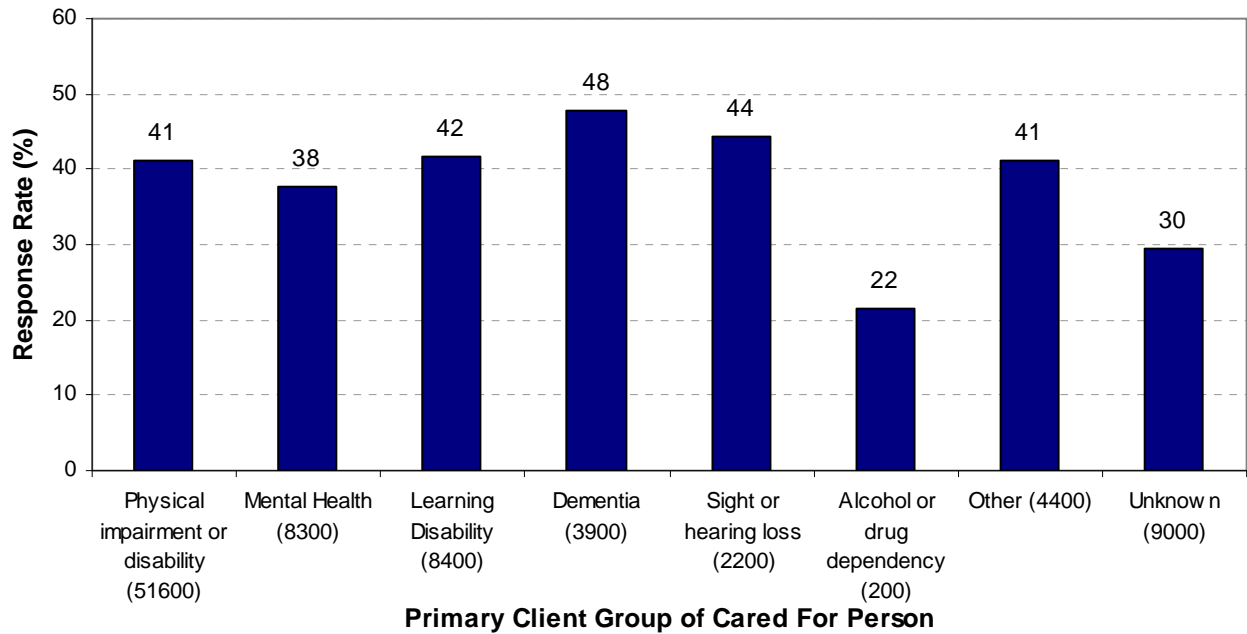


Figure 5.10 shows that the response rate by primary client group of the cared for person was fairly even across the groups although it was quite low for carers of those with an alcohol or drug dependency but they are a very small group. Primary client group was taken from council records and not from the questionnaire so the issues which affected the calculation of response rates by age, gender and ethnicity do not apply.

Figure 5.10: Response Rate by Primary Client Group of Cared for Person



Appendix A: Editorial Notes

Introduction

This section outlines the methodology for the survey and discusses interpretation and robustness of the data.

Overview of Methodology

The survey was designed by the Social Services User Survey Group (SSUSG)⁴ which contains representatives from the NHS Information Centre (NHS IC), Department of Health, Care Quality Commission, Personal Social Services Research Unit and Councils with Adult Social Services Responsibilities. For this particular survey, a representative from Carers UK also joined the group.

The survey was based on evidence gathered from previous Carers surveys, notably a pilot version of this survey which was conducted in April 2009⁵ and a survey of Adult Carers in Kent⁶.

Councils had the option of deciding whether to take part in this survey as it was voluntary. In total 90 out of the 152 councils (59%) did decide to take part in the survey and more information about how representative these 90 councils were is given in section 5.

On behalf of SSUSG, the NHS IC took responsibility for providing councils with survey guidance, questionnaires, letters to send to carers, translations of the questionnaires into foreign languages, large print versions, telephone and face-to-face scripts as well as a data return for councils to provide the data to the NHS IC for analysis⁷. Councils then carried out the survey in line with the guidance by selecting carers from their records, sending a questionnaire to them and then coding up the returned questionnaires which were then sent to the NHS IC.

The eligible population was defined as those carers (aged 18+) who had been assessed or reviewed, either separately or jointly with the cared for person, by social services during the past 12 months when the sample was chosen (the survey fieldwork was carried out in November 2009). In addition, councils were asked to include carers who were named on the file of carers who had been assessed or reviewed in the last 12 months when the sample is chosen. These carers were referred to as “carers known by association”.

However, the pilot survey had shown that not all councils held enough detailed information to identify carers known by association, so not all councils were able to include this further group of carers.

⁴ More information about SSUSG including papers for meetings can be found at <http://www.ic.nhs.uk/services/social-care/review-approval-and-development/ssusg>

⁵ A report on this pilot survey can be found in the papers of the meeting of 16 July 2009 of SSUSG which can be found at <http://www.ic.nhs.uk/services/social-care/review-approval-and-development/ssusg/ssusg-papers--16-july-2009>

⁶ The results from this survey have not yet been published.

⁷ All of these documents can be found at <http://www.ic.nhs.uk/services/social-care/social-care-collections/user-surveys/user-survey-guidance-2009-10/user-survey-guidance-carers-2009-10>

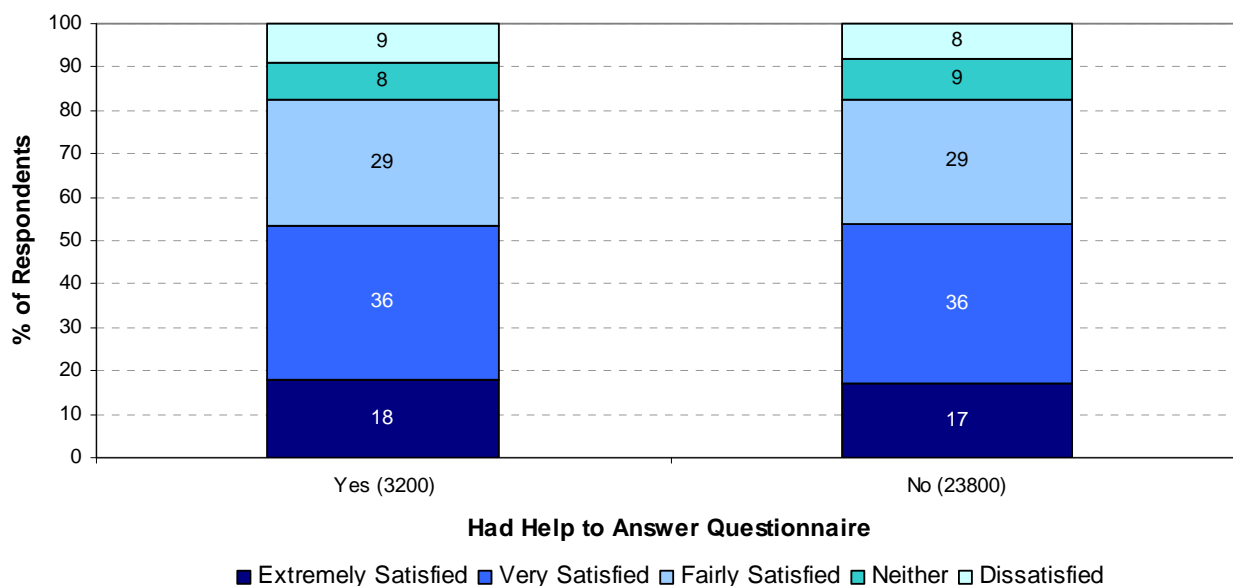
For most councils the forms were distributed in November 2009 and 98 per cent of carers were sent forms in the post and a further 1 per cent were offered telephone interviews and the remaining 1 per cent were offered face-to-face interviews.

Councils were provided with a sample questionnaire which is re-produced in **Appendix C** although councils were able to include additional questions and local branding. Councils also had flexibility to remove some of the questions as 19 out of the 58 questions were optional. Councils should have kept the remaining 39 questions although 5 councils did also remove one or more of these questions. 23 councils (26%) reported that they included additional questions.

If Carers were caring for more than one person, then they were asked to answer the questions in respect of the person they spent the most time helping.

Carers were also able to seek help in answering the questionnaire from friends or relatives if necessary but were advised not to ask for help from staff from Social Services who may have had involvement in their caring role. **Figure A.1** shows that there is little relationship between satisfaction and whether the carer had help which suggests the helpers have not had any influence on the carers views expressed in the questionnaire.

Figure A.1: Satisfaction (Q7) by Whether Carer Had Help to Answer Questionnaire (Q56)



1. Figures may not add up to 100 per cent due to rounding.
 2. Includes quite dissatisfied, very dissatisfied and extremely dissatisfied.

Response Rates

Response rates play an important part in the overall value of surveys. Confidence in the estimates derived from the survey will be affected by non-response bias and statistical sampling error if response rates are low (see separate sections on Non-Response Bias and Confidence Intervals). The council tables (Appendix D) show the response rates achieved for

the survey questions. Overall, the response rate achieved was 40 per cent and section 5 gives more details of how this differed for different subgroups of carers.

Response rates per council ranged from a maximum of 84 per cent to a minimum of 25 per cent. Care should be taken when interpreting results for councils with low response rates. Full council response rates can be seen in Appendix D.

Non-Response Bias

Typically, we might expect people who do not reply to surveys to be more satisfied. This means that the lower the achieved response rate, the more likely it is for the results to be subject to non-response bias (probably giving a lower figure for satisfaction than the true figure). Of the 90 councils who took part in the survey, 39 councils achieved a response rate which would enable an estimate of 50 per cent from their results to have a confidence interval of less than 4 percentage points. 50 councils did not achieve this level of precision and therefore care should be taken when interpreting their results. The remaining one council did not provide sufficient information about their eligible sample and therefore a confidence interval could not be calculated.

Of the 50 councils who did not meet the required level of precision, 34 councils would achieve a precision of between 4 and 5 percentage points for an estimate of 50 per cent from their results, a further 10 would achieve a precision of between 5 and 6 percentage points and the remaining 6 councils would achieve a precision of more than 6 percentage points.

Confidence Intervals

Surveys produce statistics that are estimates of the real figure for the whole population which would only be known if the entire population was surveyed. Therefore estimates from sample surveys are always surrounded by a confidence interval which assesses the level of uncertainty caused by only surveying a sample of carers. The 95% confidence interval gives the range in which you would expect the true value to fall 95 times if 100 samples were selected.

Care needs to be taken in making comparisons with England averages. If the confidence interval for a council level estimate does not overlap with the confidence interval for the equivalent England estimate then it is likely that the values are genuinely different. Similarly if the confidence intervals for estimates for two different councils or two different years do not overlap then it is likely that they are genuinely different.

It is Best Value good practice for service specific surveys for the 95% confidence interval for indicators to be no more than plus or minus 4 per cent. That is, we want to be 95% confident that the true figure is within plus or minus 4 percentage points of the figure obtained from the sample. So this means that if the survey gives an answer of 50 per cent, for example, we can be confident that the true figure is between 46 per cent and 54 per cent.

Differences discussed in the commentary of this report between different categories of respondents are significant to a 95% level, ie. we are 95% confident they are real differences but there is a 5% chance they are the result of sampling variation.

Calculating Confidence Intervals

A standard formula for the calculation of a 95% confidence interval (CI) for the estimate of a proportion p from a sample survey is:

$$\pm 1.96 \times \sqrt{\left(\left(\frac{p(1-p)}{n}\right)\left(\frac{N-n}{N}\right)\right)}$$

where:

p is the sample proportion

n is the number of people who responded to a question (ie. the sample size minus the number of non-responses to the survey and the particular question being analysed)

N is the size of the eligible population

This formula includes the finite population correction factor and assumes n is reasonably large.

One council did not provide any information about the size of their eligible population so confidence intervals could not be calculated for the results for that council. The confidence intervals for the England estimates were calculated including the results from this council as it was found to have negligible impact when they were removed.

As an example, it can be applied to calculate confidence intervals for estimates derived from the question "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?" (Question 17) where:

p is the proportion of people who answered "So good it could not be better" or "Very good"

n is the sum of those that responded to the question

N is the size of the eligible population

Example

Council A has 1024 eligible carers and surveyed 637 of them, 410 questionnaires were returned by users. The responses received to the question "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?" were:

<u>Response</u>	<u>Number of Carers</u>
So good, it could not be better	28
Very good	181
Good	101
Alright	63
Bad	31
Very bad	3
So bad, it could not be worse	1
Did not respond to the question	2
Did not take part in the survey	227

The proportion of people who answered "So good it could not be better" or "Very good" for Council A is 51.2% ($p = 0.512$, 209 divided by 408).

The 95% confidence interval is plus or minus 3.8%. This is calculated by inserting the values of p , n and N below into the formula for calculating confidence intervals.

$p = 0.512$

$n = 408$ ($=28+181+101+63+31+3+1$)

$N = 1024$

More details and a further worked example along with a Confidence Interval Calculator can be found at appendix E.

It should also be noted that the figures reported as being representative of England are from the 90 councils who volunteered to take part in the survey (see section 5 for comparison of these 90 councils by region and council type compared to all 152 in England). The formula for the confidence intervals given previously does not take into account the fact that not all councils took part. Therefore confidence intervals quoted for England are likely to be underestimates of the true value.

Appendix B: Related Publications

This publication can be downloaded from the NHS Information Centre website at:

www.ic.nhs.uk/pubs/psscarersurvey0910

User Experience Surveys

Other User Experience Surveys carried out by the NHS Information Centre can be found at:

<http://www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information>

Previous User Experience Surveys carried out by the Department of Health can be found at:

http://www.dh.gov.uk/en/Publicationsandstatistics/Statistics/StatisticalWorkAreas/Statisticalsocialcare/DH_4086765

Other Social Care Reports

Publications relating to social care activity, finance, staffing and user experience surveys can be found at www.ic.nhs.uk/statistics-and-data-collections/social-care/adult-social-care-information.

Data from some of our other social care reports can be accessed directly via our National Adult Social Care Intelligence Service (NASCIS). NASCIS is an online portal which contains standard reports for each council as well as the capacity to carry out further analysis of social care data. The online analytical tool can be found at <http://nascis.ic.nhs.uk/>

Recent Reports

“Community Care Statistics 2008-09: Social Services Activity Report, England” which is available at www.ic.nhs.uk/pubs/carestats0809asr

“Personal Social Services: Expenditure and Unit Cost, England, 2008-09 [NS]” which is available at www.ic.nhs.uk/pubs/pss0809exp

“Personal Social Services Staff of Social Services Departments at 30 September 2009, England. [NS]” which is available at www.ic.nhs.uk/pubs/pssstaffsept089

“Personal Social Services: Home Care Users Aged 65 or over, England - Councils with Adult Social Services Responsibilities tables, provisional, 2008-09” which is available at www.ic.nhs.uk/pubs/psshcu0809

“Personal Social Services Survey of Adults Receiving Community Equipment and Minor Adaptations in England, 2007-08” is available at www.ic.nhs.uk/pubs/pssadultsequip0708

“Community Care Statistics: Grant Funded Services for Adults, England – 2008/09” which is available at <http://www.ic.nhs.uk/pubs/carestats0809gfs>

“Registered Blind and Partially Sighted People, year ending March 2008” is available at www.ic.nhs.uk/pubs/blindpartiallysighted08

“Registered Deaf and Hard of Hearing People, year ending March 2007” is available at

<http://www.ic.nhs.uk/statistics-and-data-collections/social-care/disability/people-registered-as-deaf-or-hard-of-hearing-year-ending-31-march-2007-england-ns>

National Indicator Set

A number of the data items collected on RAP and ASC-CAR are used in the calculation of the National Indicator Set (NIS). Commentary on these indicators is set out in the report *“Social Care and Mental Health Indicators from the National Indicator Set - further analysis, final, England 2008-09”* is available at

www.ic.nhs.uk/pubs/socmhi08-09

Historical performance assessment data was published by the Care Quality Commission (CQC) formerly the Commission for Social Care Inspection (CSCI). Associated council data are available via the Care Quality Commission website at

<http://www.cqc.org.uk/guidanceforprofessionals/socialcare/councils/performanceassessment/socialservicesperformanceassessmentframeworkindicatorsadults2008-09.cfm>

Data for Child Social Services

Information on social care for children is available at

<http://www.everychildmatters.gov.uk/socialcare/>

Data for the UK

Information within this report relates to England data, similar publications for Wales, Scotland and Northern Ireland can be found via the following links:

The Welsh Assembly Government

<http://wales.gov.uk/topics/health/publications/socialcare/reports/?lang=en>

The Scottish Government

[http://search1.scotland.gov.uk/Scotland?n=All&\\$rcexpanded=false&action=search&q=Social+Care](http://search1.scotland.gov.uk/Scotland?n=All&$rcexpanded=false&action=search&q=Social+Care)

Department of Health, Social Services and Public Safety

http://www.dhsspsni.gov.uk/index/stats_research/stats-cib-3/statistics_and_research-cib-pub/adult_statistics-1.htm

Appendix C: Blank Copy of Base Questionnaire

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 (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"/>

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 D: Council Tables and Confidence Interval Tools

Table	Content
U1	Profile of answers for all questions by council
U2	Profile of answers for all questions by demographics
U3	Response rates by council
U4	Confidence Intervals for all questions by council
U5	Confidence Interval Calculator

These annexes are in the form of an excel spreadsheet which can be found at:
www.ic.nhs.uk/pubs/psscayersurvey0910

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Comments

If you have any comments on this report they would be welcomed. Please complete the online feedback form which can be found at www.ic.nhs.uk/pubs/psscarersurvey0910.

Any questions concerning any data in this publication, or requests for further information, should be addressed to:

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