

# **Newcastle Adult Services: Carers Survey 2012 / 13**

**Central Policy Unit  
Central Divisions**

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# Index

| <b>Contents</b>  | <b>Page no.</b> |
|--|-----------------|
| <b>Introduction</b>  | 1               |
| Purpose of the survey  | 1               |
| Methodology  | 2               |
| Responses and margin of error  | 2               |
| Equality and diversity   | 2               |
| Safety, wellbeing and confidentiality                                | 3               |
| <b>Key Findings</b>  | 3               |
| National Indicators  | 3               |
| Action points  | 5               |
| Summary of findings  | 5               |
| About the carers   | 6               |
| Findings from earlier research with carers                           | 7               |
| <b>Frequency Tables</b>  | 9               |
| Section 1: About the person you care for                             | 9               |
| Section 2: About your needs and experiences of support               | 13              |
| Section 3: The impact of caring and your quality of life             | 14              |
| Section 4: Information and advice quality                            | 17              |
| Section 5: Arrangement of support and services in the last 12 months | 21              |
| What carers told us  | 26              |
| About the carers   | 31              |
| Appendix 1 – Findings from previous research done with carers        | 36              |
| Appendix 2 – Questions   | 41              |
| Appendix 3 – ASCOF Indicators 1(a) and 1(b) – Definitions            | 49              |

# Introduction

This report summarises the findings from the first NHS Information Centre Carers Survey in Newcastle, which has been run as part of the first national survey of carers in England and Wales.

## Purpose of the survey and national context

From the official survey guidance:

“This survey is being run due to a need to find out more about whether or not services received by carers are helping them in their caring role and their life outside of caring, and also their perception of services provided to the cared-for person. In 2010, the national strategy for carers was refreshed, with the main themes being:

- Supporting people with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.
- Enabling people with caring responsibilities to fulfil their educational and employment potential.
- Personalised support both for carers and those they support, enabling them to have a family and community life.
- Supporting carers to remain mentally and physically well.

Over the period April 2010 to March 2011, provisional figures indicate that 403,000 carers were assessed either separately or jointly with the cared-for person. Of these, an estimated 380,000 carers (94% of those assessed) received a service following their assessment or review.

Very little is known as to whether or not these services have improved carers' ability to care and live a life outside of their caring role. The need to take into account the impact on carers of the provision and quality of services provided to service users is also important.

Carers are a key and important policy area within the Department of Health (DH) and the Care Quality Commission (CQC). The survey aims to collect information about carers' experiences of social care services and support, and will feed into monitoring of the impact of the national carers strategy.”

The survey provides four of the outcome measures in the Adult Social Care Outcomes Framework:

- 1D: Carer reported quality of life.
- 3B: Overall satisfaction of carers with social services.
- 3C: The proportion of carers who report they have been included or consulted in discussions about the person they care for.
- 3D: The proportion of people who use services and carers who find it easy to find information about services.

The information it provides on Newcastle carers' views and experiences will be used to help improve services to carers and cared-for people.

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## Methodology

The survey is sent to a random sample of carers who have been assessed or reviewed (either separately or jointly with the cared-for person) by Newcastle Adult and Culture Services in the 12 months prior to the date we select to draw our sample from. We can choose any date between 1 June – 30 September 2012 to draw the sample. Ours was drawn on 10 September 2012. We drew a sample of 969 carers from a total “population” of 2236 Newcastle carers, of whom 3 were removed from the population for the purposes of the survey, as they were in active dispute with the council and it was felt that sending them a questionnaire would not be appropriate.

## Responses and margin of error

Questionnaires were sent out between **8 October – 30 November 2012**. We sent out one reminder on **22 October 2012**, and received 445 returned questionnaires out of 969 sent out, giving a response rate of 46%. This gives a margin of error<sup>1</sup> for the entire survey of +/- 4.16 percentage points, given that the total number of service users we drew our random sample from was 2236. This is within the maximum margin of error specified by the NHS Information Centre of +/- 5.00 percentage points.

This means that we can consider that the results from the survey are representative of the entire population of 2236 carers in Newcastle who were assessed or reviewed between 10 September 2011 to 10 September 2012 to within 4.16 percentage points either way. For example, the percentage of people in the survey who feel that they have adequate control over their daily lives is 29.13%, so the “true” figure for the population as whole lies between 25.00% - 33.29% (figures have been rounded).

## Equality and diversity

We strove to ensure that everyone was able to participate in the survey, using 14-point Arial font for the printed surveys to maximise ease of reading. Additionally, before sending out the questionnaires, we checked carers’ Carefirst records to determine if they had any special communication requirements such as large print or other language. People requiring large print surveys were sent them on yellow paper in the font size they had specified (or, if no font size was specified, in 18 point font). We also offered all respondents the option of having a face-to-face interview with a researcher if this was what they needed in order to take part, although no-one chose to do this. In 2012, everyone who took part in the survey did so by returning a questionnaire.

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<sup>1</sup> The margin of error is a figure calculated using statistics theory to show how close the percentages calculated from the data collected in the survey are to the “true” satisfaction percentages, which is the figure we would get if, hypothetically, we could ask every single person who received care and support services this question and receive their answer.

## Safety, wellbeing and confidentiality

Where a person gave a reply or made a comment which indicated that there was a reason to be concerned for their personal safety or wellbeing (for example “I am extremely worried about my personal safety”), their details were passed on to the manager of the Safeguarding Adults Unit, Linda Gray, for appropriate action to be taken to safeguard their wellbeing. This is permissible under the terms of the confidentiality guarantee offered to everyone who takes part in the survey:

*“Your answers will be treated as confidential: they will not be passed on to your social worker or anyone else responsible for providing you with services. You will not be personally identified... However, if any of your replies cause us to be concerned about your safety or well-being, someone not directly involved with providing you with services will contact you to discuss this. This is the only circumstance under which it will be used to identify you”.*

## Key Findings

### National Indicators

Several national performance indicators are reported from the Carers Survey, as follows.

#### 1D - Carer-reported quality of life

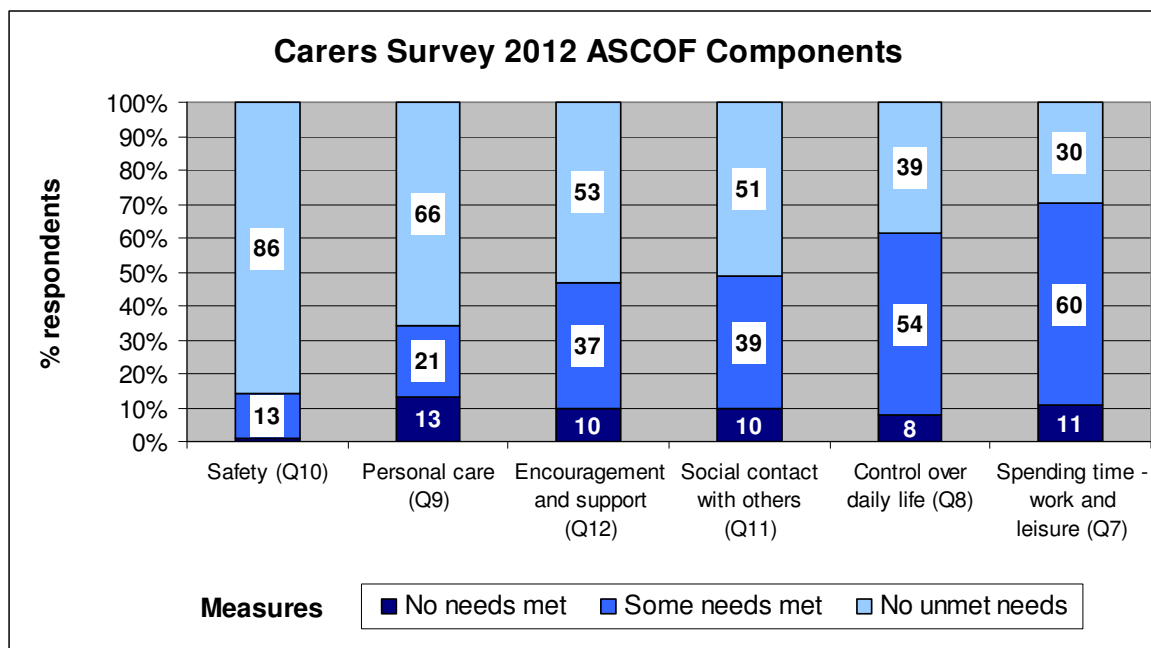
This is a composite measure which combines individual responses to seven questions measuring different outcomes related to overall quality of life which are mapped to seven domains: occupation, time and space, control, personal care, safety, social participation and encouragement and support. It is an overarching outcome measure for carers, similar to the equivalent for people who use services (1A – social care-related quality of life). The table below is the calculation used to produce the 1D indicator score for Newcastle City Council: **8.5** or **71%** of the maximum possible. The full tables for these questions (Q7-Q12) can be found on p.14-16.

|                                 | No unmet needs   | Some needs met     | No needs met | Total       |
|---------------------------------|------------------|--------------------|--------------|-------------|
| Occupation (Q7)                 | 125              | 253                | 46           | 424         |
| Control (Q8)                    | 162              | 227                | 33           | 422         |
| Personal Care (Q9)              | 280              | 92                 | 56           | 428         |
| Safety (Q10)                    | 366              | 56                 | 3            | 425         |
| Social Participation (Q11)      | 216              | 163                | 42           | 421         |
| Encouragement and Support (Q12) | 219              | 152                | 41           | 412         |
| <b>Total</b>                    | <b>1368</b>      | <b>943</b>         | <b>221</b>   | <b>2532</b> |
| <b>Score</b>                    | <b>2736</b>      | <b>943</b>         | <b>0</b>     | <b>3679</b> |
|                                 | <b>Numerator</b> | <b>Denominator</b> | <b>1D</b>    |             |
|                                 | 3679.0           | 433.0              | <b>8.5</b>   | <b>71%</b>  |

This is a composite measure. The maximum possible score (calculated in "Max ASCOF") is 12. The percentage in the box shows our score (8.5) as a percentage of the maximum possible.

Note that respondents had to answer all seven questions to be included in this calculation and any who did not have been removed from the totals – therefore the numbers in the table above are slightly smaller than in the Frequency Tables that appear further on in the report.

The chart below illustrates the contribution each domain makes to the overall ASCOF score. As shown, most carers were satisfied with how safe they felt; 86% of carers said that they had no worries about their personal safety. At the other end of the scale, only 30% replied “I’m able to spend my time as I want, doing things I value or enjoy”.



### 3B - Overall satisfaction of carers with social services

When asked “Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Newcastle Adult and Culture Services in the last 12 months?”, just over half of carers were extremely or very satisfied: **53%**.

Note that this percentage is calculated using the total number of people who said that they and / or the person they care for had received support or services from Newcastle Adult and Culture Services in the last 12 months. People who said “we have not received any support or services from Newcastle Adult and Culture Services in the last 12 months” have been removed from the calculation. (If they were to be included, the “extremely or very satisfied” percentage would be: **48%**.)

### 3C: The proportion of carers who report that they have been included or consulted in discussion about the person they care for

When asked “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?”, the majority of carers said that they always or usually felt included or consulted: **81%**. Note that this percentage is calculated using the total number of people who said that discussions had taken place in the last 12 months; people who said that there had been no discussions that they were aware of in the last 12 months are removed from the calculation. (If they are included, the “always or usually included” percentage is: **68%**.)

### 3D: The proportion of carers who find it easy to find information about services

When asked “In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits?”, the percentage of people finding it very

or quite easy: **68%**. Note that this percentage is calculated using the total number of people who had tried to find advice or information in the last 12 months (excluding people who had not tried to do this). (If they are included, the “very or quite easy” percentage is: **48%**.)

## Action points

Areas which may require attention are as follows:

- **Overall satisfaction:** The majority of carers – 75% – were extremely, very or quite **satisfied** overall with the services they received. Of these, 48% were extremely or very satisfied, and 27% were quite satisfied. We may wish to explore what would be needed to improve the satisfaction ratings of people who were quite satisfied, neither satisfied nor dissatisfied or dissatisfied.
- **Carers Emergency Card:** 70% of carers had not heard of the Carers Emergency Card.
- **Social contact and control over daily life:** As shown in the chart on the previous page:
  - **49%** of carers said they had some social contact with people, but not enough, or that they had little social contact and felt socially isolated.
  - **62%** of carers said they had some control over their daily life but not enough, or that they had no control.
  - **71%** of carers said they did some things they valued or enjoyed with their time but not enough, or that they did not do anything they valued or enjoyed.
- **Finding information:** **31%** of carers said that finding information was very or quite difficult.
- **Feeling involved:** Although the majority of carers said that they always or usually felt involved in discussions about the person they care for, **19%** of carers said that they only sometimes felt involved, or that they never felt involved.

## Summary of findings

Below is a summary of the main findings of the survey. Full frequency tables and can be found in the “Frequency tables” section on p.9. A full list of the questions asked can be found in Appendix 2 on p.41, and comments analysis can be found on p.26.

### 1. About the person you care for

- **Primary client group:** The majority of carers in the survey were caring for someone classified as having a physical disability, frailty and / or sensory impairment (64%).
- **Needs of cared-for people:** When carers were asked what conditions the person they cared for had, the most common reply was “a physical disability” (48% of carers said this), followed by “problems connected to aging” (43%).
- **Personal budgets / direct payments:** Around half of carers in the survey were caring for someone who receives a direct payment managed by the local authority (51%).

- **Age of cared-for people:** The majority of people being cared for were aged 75 or over (63%).
- **Where cared-for people live:** Over half of carers in the survey replied that the person they cared for usually lived with them (55%).
- **Care and support services used by the cared-for person:** The most common type of care and support service used by the cared-for person was “equipment or home adaptation” (59%), followed by “Home care or home help” (42%).

## 2. About your needs and experiences of care and support services

- **Overall satisfaction with services used:** Just under half of carers were extremely or very **satisfied overall** (48%); a further 27% were quite satisfied. 5% were quite, very or extremely dissatisfied.
- **Care and support services used by the carer:** Nearly half of all respondents had used information and advice to help them in their caring role (47%); 25% had used support from a carers’ group or someone to talk to in confidence.
- **Carer’s emergency card:** 70% of people in the survey had not heard of this scheme.

## 3. The impact of caring and your quality of life

- **Spending time – work and leisure:** The majority of carers said they did some of the things they wanted to do with their time, but not enough (60%).
- **Control over daily life:** Just over half of carers said that they had some control over their daily lives, but not enough (54%).
- **Looking after yourself:** The majority of carers said they were able to look after themselves, for example getting enough sleep or eating well (66%).
- **Safety:** Over three-quarters of carers said they had no worries about their personal safety (86%).
- **Social contact:** Just over half of carers replied that they had as much social contact as they wanted with people they liked (51%).
- **Encouragement and support:** Just over half of carers replied that they felt they had encouragement and support in their caring role (53%).

## 4. Information and advice quality

- **Finding information and advice:** The majority of carers who had tried to find information or advice said that it was very or quite easy to find (68%).
  - 31% had never tried to find information or advice.
- **Helpfulness of information and advice:** Nearly all carers who had received information or advice said that it was very or quite helpful (94%).
  - 30% had not received any information or advice in the last 12 months.
- **Complaints:** The majority of people said that they knew how to make a complaint about care services and felt that they could do so if they wanted to (64%).



## 5. Arrangement of support and services in the last 12 months

**Feeling involved:** The majority of carers, whose cared-for person had had discussions about care and support services in last 12 months, said that they always or usually felt involved or consulted, as much as they wanted to be, in discussions about the support or services provided to the person they care for (81%). 17% said that there had been no such discussions that they were aware of in the last 12 months.

### About the carers

We compared the age and gender profile of carers who took part in the survey to the “population” of the 2236 carers from whom we drew our random sample. The percentage of men and women who took part in the survey were proportional to the balance of males and females in the population. However, we found that carers in the 55-64 age bracket were slightly over-represented in the survey, and both younger carers, and the “oldest old” carers (aged 85 and over) were slightly under-represented.

- **Employment:** Just over half of carers in the survey were retired (54%).
- **Supported in employment:** Nearly half of carers said that they were self-employed or retired. Of those who were not, 15% said they felt supported by their employer, and 15% said they were not in paid employment due to their caring responsibilities.
- **Length of time being a carer:** The largest percentage of carers had been caring for over three years but less than 10 years (40%). 18% had been caring for 20 years or more.
- **Time spent each week caring:** The largest single percentage of carers said that they were caring for between 75-99 hours a week (31%).
- **Caring tasks:** The most common caring task was “other practical help”, which includes help in the form of preparing meals, doing shopping, housework, gardening, laundry, household repairs or taking someone to medical appointments. 88% of carers did this. The next most common caring task was helping with paperwork or other financial matters (86%).
- **Taking part in the survey:** The majority of carers completed the questionnaire without help from anyone else (94%).
- **Original or reminder:** Around 61% of the respondents responded after the date when reminders were sent out.
- **Disability or other physical issues:** Just under half of carers said they did not have a long-standing illness, a physical impairment, sensory impairment, mental health problem, learning disability or other similar issue (49%). Of those who did, 27% had a long-standing illness and 19% had a physical impairment or disability.
- **Age:** The largest single percentage of carers were aged between 55-67 (30%). Nearly half were aged 65 and over (42%).
- **Gender:** 66% of carers in the survey were female, in line with the gender balance in the total population of carers.
- **Ethnicity:** 97% of carers were from a White ethnic background.
- **Direct payments / personal budgets:** Almost none of the carers in the survey received a direct payment or personal budget (99%).
- **Assessments:** 96% of carers had been assessed jointly with the person they care for.
- **Services received:** 48% of carers had received a service in the last twelve months which was funded by the local authority.
- **Information received:** One person had received information **only** within the last twelve months (which was funded by the local authority).

## Findings from earlier research with carers

As part of the analysis of findings, the results of this survey have been compared to those from previous local and national research on the experiences of carers. Here is a summary of findings; the full comparison can be found in Appendix 1 on p.36.

- **Newcastle Residents Survey 2012:** This survey found that carers were more likely to have been in touch with the council than other residents. It also found that, generally speaking, their satisfaction levels with council services, and with their local area and the City, tended to be lower. For example, 46% of carers are satisfied with Newcastle City Council, compared to 62% of all residents.
- **Carers Centre Newcastle Annual Client Feedback Survey 2012:** Among the findings of this survey by Carers Centre Newcastle were that carers' main concerns for the future were their own health, loneliness, stress and anxiety, and planning for the future. These concerns were also expressed by carers who took part in our survey.
- **Newcastle Carers Views Surveys – 2006 to 2009:** The findings from these annual local surveys were similar to those from the 2012 survey, indicating that many issues faced by carers in Newcastle have not greatly changed over the past few years. For example, in both the Carers Views surveys and the 2012 Carers Survey, a substantial minority of carers are concerned about whether they look after themselves properly. Similarly, a substantial minority of carers were concerned about not feeling encouraged or appreciated in their caring role, about their feeling lonely or socially isolated, and about not getting enough time to themselves to pursue their own interests or hobbies.
- **“Survey of Carers in Households 2009 / 2010” and “Personal Social Services “Survey of Adult Carers in England 2009 / 10”:** Findings from these two national surveys indicated that carers known to councils tend to have more intensive caring duties, for example providing care for over 35 hours a week. The profile of carers in the PSS Survey of Adult Carers and in our own 2012 survey was similar, with the majority of carers being female and from a White ethnic background, and nearly half being aged 65 or older. Carers in the “Survey of Carers in Households” survey, which was a survey of carers in the general population – whereas the other two surveys are surveys of carers known to local authorities – tended to be younger, with only 25% being aged 65 or older.
- **“Your Views Count” – Newcastle Carers Information Survey 2006:** This survey took place in summer 2006 to inform the development of the Newcastle Carers Strategy 2006, and focussed on carers' views on information. A key finding was that in 2006, 70% of carers in this survey said that it was easy to get hold of information. This is very similar to the result in 2012, where 68% of carers surveyed said that it was very or quite easy to do this.

# Frequency tables

## Section 1: About the person you care for

### Primary client group of the cared-for person

| Primary client group of the cared-for person           | Frequency  | Valid percent % | % in sample |
|--|------------|-----------------|-------------|
| Physical disability, frailty and/or sensory impairment | 279        | 64              | 63          |
| Mental health  | 96         | 22              | 23          |
| Learning disability                                    | 56         | 13              | 13          |
| Vulnerable people                                      | 4          | 1               | 1           |
| Substance misuse                                       | 0          | 0               | 0*          |
| <b>Total</b>   | <b>435</b> | <b>100</b>      | <b>100</b>  |
| <i>Missing</i>   | 10         | -               | -           |
| <b>Total</b>   | <b>445</b> | -               | -           |

\* Four people – 0.4%.

The majority of carers in the survey were caring for someone with a physical disability, frailty and / or sensory impairment (64%).

### Personal Budgets / Direct Payments – Cared-for person

| Cared-for person receives personal budgets or direct payments? | Frequency  | Valid percent % | % in sample |
|--|------------|-----------------|-------------|
| Yes - managed by local authority via Direct Payments           | 224        | 51              | 45          |
| Yes - other  | 26         | 6               | 5           |
| No   | 193        | 44              | 50          |
| <b>Total</b>   | <b>443</b> | <b>100</b>      | <b>100</b>  |
| <i>Missing</i>   | 2          | -               | -           |
| <b>Total</b>   | <b>445</b> | -               | -           |

Around half of carers in the survey were caring for someone who receives a direct payment managed by the local authority (51%).

## Q1. How old is this person?

| Q1 Age of cared-for person | Frequency  | Valid percent % |
|----------------------------|------------|-----------------|
| 18-24                      | 19         | 4               |
| 25-34                      | 23         | 5               |
| 35-44                      | 16         | 4               |
| 45-54                      | 25         | 6               |
| 55-64                      | 34         | 8               |
| 65-74                      | 44         | 10              |
| 75-84                      | 132        | 30              |
| 85 or over                 | 145        | 33              |
| <b>Total</b>               | <b>438</b> | <b>100</b>      |
| <i>Missing</i>             | 7          | -               |
| <b>Total</b>               | <b>445</b> | -               |

The majority of people being cared for were aged 75 or over (63%).

## Q2. Does the person you care for have....?

| Q2 Cared-for person – client group | Frequency  | Valid percent % |
|------------------------------------|------------|-----------------|
| A physical disability              | 210        | 48              |
| Problems connected to aging        | 191        | 43              |
| Long-standing illness              | 144        | 33              |
| Sight or hearing loss              | 139        | 31              |
| Dementia                           | 173        | 29              |
| A mental health problem*           | 69         | 16              |
| Terminal illness                   | 16         | 4               |
| Autism or Asperger's Syndrome**    | 10         | 2               |
| Alcohol or drug dependency         | 7          | 2               |
| <b>Total*</b>                      | <b>442</b> | -               |
| <i>Missing</i>                     | 3          |                 |
| <b>Total</b>                       | <b>445</b> |                 |

\* Respondents could choose as many options as they liked, so percentages do not total 100%.

\*\* This was not an option in the standard questionnaire; we included it for the purposes of local research. When the data was returned to the NHS Information Centre, anyone who replied "Autism or Asperger's Syndrome" was recoded as having replied "A mental health problem" (if they had not already selected this option).

The most common response to this question was "A physical disability" (48%), followed by "problems connected to aging" (43%).

### Q3. Where does the person you care for usually live?

| Q3 Where does the person you care for usually live? | Frequency  | Valid percent % |
|---|------------|-----------------|
| With me   | 239        | 55              |
| Somewhere else                                      | 199        | 45              |
| <b>Total</b>  | <b>438</b> | <b>100</b>      |
| <i>Missing</i>                                      | 7          |                 |
| <b>Total</b>  | <b>445</b> |                 |

Over half of carers in the survey replied that the person they cared for usually lived with them (55%).

### Q4. Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Newcastle Adult and Culture Services in the last 12 months?

| Q4 Overall satisfaction with care and support   | Frequency  | Valid percent % | Valid percent: people who had had services in last 12 months% |
|---|------------|-----------------|---|
| We haven't received any support or services from Newcastle Adult and Culture Services in the last 12 months | 62         | 14              | -   |
| I am extremely satisfied  | 86         | 20              | 23  |
| I am very satisfied   | 112        | 28              | 30  |
| I am quite satisfied  | 119        | 27              | 32  |
| I am neither satisfied nor dissatisfied   | 35         | 8               | 9   |
| I am quite dissatisfied   | 14         | 3               | 4   |
| I am very dissatisfied  | 3          | 1               | 1   |
| I am extremely dissatisfied   | 4          | 1               | 1   |
| <b>Total</b>  | <b>435</b> | <b>100</b>      | <b>100</b>  |
| <i>Missing</i>  | 10         | -               | -   |
| <b>Total</b>  | <b>445</b> | -               | -   |

Just under half of carers were extremely or very satisfied (48%); a further 27% were quite satisfied. 5% were quite, very or extremely dissatisfied. When people who said "we have not received any support or services from Newcastle Adult and Culture Services in the last 12 months" are removed from the calculation, this figure (extremely or very satisfied) is 53%. This is the figure used to calculate **ASCOF indicator 3b**.

**Q5. Has the person you care for used any of the support or services listed below in the last 12 months?**

They may be provided by different organisations, such as a voluntary organisation, a private agency or Newcastle Adult and Culture Services.

| <b>Q5 Usage of support or services</b>   | <b>% Yes</b> | <b>% No</b> | <b>% Don't know</b> | <b>% did not reply "yes", "no" or "don't know"</b> |
|--|--------------|-------------|---------------------|--|
| Equipment or adaptation to their home (such as a wheelchair or handrails)  | 59           | 24          | 0                   | 17   |
| Home care / home help  | 42           | 38          | 0                   | 20   |
| Lifeline alarm / Telecare  | 34           | 41          | 1                   | 24   |
| Day centre or day activities   | 29           | 48          | 0                   | 23   |
| Support or services allowing you to take a break from caring for more than 24 hours                                | 20           | 60          | 2                   | 18   |
| Support or services to allow you to have a rest from caring for between 1 and 24 hours (such as a sitting service) | 16           | 62          | 2                   | 21   |
| They are permanently resident in a care home   | 16           | 57          | 1                   | 27   |
| Support or services allowing you to take a break from caring at short notice or in an emergency.                   | 15           | 65          | 3                   | 17   |
| Personal assistant   | 13           | 57          | 1                   | 30   |
| Lunch club   | 5            | 61          | 1                   | 32   |
| Meals services   | 5            | 62          | 1                   | 32   |
| <b>Total no. of people who answered the question</b>   | <b>442</b>   | -           | -                   | -  |
| <i>Missing</i>   | <b>3</b>     | -           | -                   | -  |
| <b>Total</b>   | <b>445</b>   | -           | -                   | -  |

\* Respondents could choose as many options as they liked, so percentages do not total 100%.

The most common response to this question was "Equipment or an adaptation to their home" (59%), followed by "Home care / home help" (42%).

## Section 2: About your needs and experiences of support

### Q6. 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 Newcastle Adult and Culture Services. Please do not include any unpaid help from family and friends.

| Q6 Support or services used by carer                           | % Yes      | % No | % Don't know | % did not answer question |
|--|------------|------|--------------|---------------------------|
| Information and advice   | 47         | 45   | 3            | 5                         |
| Support from carers groups or someone to talk to in confidence | 25         | 65   | 1            | 9                         |
| Training for carers  | 4          | 80   | 1            | 15                        |
| Support to keep you in employment                              | 4          | 79   | 1            | 17                        |
| <b>Total no. of people who answered the question</b>           | <b>424</b> | -    | -            | -                         |
| <i>Missing</i>   | <i>21</i>  | -    | -            | -                         |
| <b>Total</b>   | <b>445</b> | -    | -            | -                         |

Nearly half of all respondents had used information and advice to help them in their caring role (47%).

### Q6e. Are you aware of the Carers' Emergency Card Scheme?

This is a scheme run by Newcastle City Council and the British Red Cross. Under the scheme, carers register their details and receive a pocket-sized card with unique reference number. If they are delayed in an emergency they ring the British Red Cross and quote the number which enables the charity to call up an emergency plan which helps them assist the cared for person.

| Q6e Aware of Carers' Emergency Scheme?                        | Frequency  | Valid percent % |
|---|------------|-----------------|
| No, I am not aware of this                                    | 299        | 70              |
| I am aware of this but I do not have a Carer's Emergency Card | 68         | 16              |
| Yes, I am aware of this and I have a Carer's Emergency Card   | 40         | 9               |
| Don't know / not sure   | 18         | 4               |
| <b>Total</b>  | <b>425</b> | <b>100</b>      |
| <i>Missing</i>  | <i>20</i>  | -               |
| <b>Total</b>  | <b>445</b> | -               |

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

**Q7. 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.

| <b>Q7 Leisure time</b>  | <b>Frequency</b> | <b>Valid percent %</b> |
|---|------------------|------------------------|
| I'm able to <b>spend my time as I want</b> , doing things I value or enjoy  | 127              | 30                     |
| I do <b>some of the things I value</b> or enjoy with my time but not enough | 263              | 60                     |
| I <b>don't do anything I value</b> or enjoy with my time                    | 46               | 11                     |
| <b>Total</b>  | <b>436</b>       | <b>100</b>             |
| <i>Missing</i>  | 9                | -                      |
| <b>Total</b>  | <b>445</b>       | -                      |

The majority of carers said they did some of the things they wanted to do with their time, but not enough (60%).

**Q8. Which of the following statements best describes how much control you have over your daily life?**

| <b>Q8 Control over daily life</b>                     | <b>Frequency</b> | <b>Valid percent %</b> |
|---|------------------|------------------------|
| I have as much control over my daily life as I want   | 164              | 39                     |
| I have some control over my daily life but not enough | 237              | 54                     |
| I have no control over my daily life                  | 33               | 8                      |
| <b>Total</b>  | <b>434</b>       | <b>100</b>             |
| <i>Missing</i>  | 11               | -                      |
| <b>Total</b>  | <b>445</b>       | -                      |

Just over half of carers said that they had some control over their daily lives, but not enough (55%).



**Q9. 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?**

| <b>Q9 Looking after yourself</b>                | <b>Frequency</b> | <b>Valid percent %</b> |
|---|------------------|------------------------|
| I look after myself                             | 289              | 66                     |
| Sometimes I can't look after myself well enough | 95               | 22                     |
| I feel I am neglecting myself                   | 56               | 13                     |
| <b>Total</b>                                    | <b>440</b>       | <b>100</b>             |
| <i>Missing</i>                                  | 5                | -                      |
| <b>Total</b>                                    | <b>445</b>       | -                      |

The majority of carers said they were able to look after themselves, for example getting enough sleep or eating well (66%).

**Q10. 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.

| <b>Q10 Personal safety</b>                      | <b>Frequency</b> | <b>Valid percent %</b> |
|---|------------------|------------------------|
| I have no worries about my personal safety      | 376              | 86                     |
| I have some worries about my personal safety    | 57               | 13                     |
| I am extremely worried about my personal safety | 4                | 1                      |
| <b>Total</b>                                    | <b>437</b>       | <b>100</b>             |
| <i>Missing</i>                                  | 8                | -                      |
| <b>Total</b>                                    | <b>445</b>       | -                      |

Over three-quarters of carers said they had no worries about their personal safety (86%). People who replied that they did not feel at all safe had their details passed on in confidence to Adult Social Care Direct, so this could be discussed with them, in line with the confidentiality guarantee we provide for everyone taking part in the survey<sup>2</sup>.

<sup>2</sup> The full wording of the confidentiality guarantee is: "Your answers will be treated in strict confidence and any help you or the person you look after may get will not be affected by them. You will not be personally identified in the results which are shared with the Department of Health and the Health and Social Care Information Centre. No-one directly involved in providing services to you or the person you care for will see your answers.

The code on the form is used to make sure that when you return it we do not send you another one. However, if you say on the form that you are being hurt or harmed by anybody, or you are extremely worried about your personal safety (Question 10), then we will use this code to identify you so that someone from Newcastle Adult and Culture Services (but not anyone directly involved in providing you or the person you care for with services) will contact you initially to talk about it. This is the only circumstance under which this code will be used to identify you."

**Q11. Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?**

| <b>Q11 Social contact</b>   | <b>Frequency</b> | <b>Valid percent %</b> |
|---|------------------|------------------------|
| I have as much social contact as I want with people I like          | 224              | 51                     |
| I have some social contact with people, but not enough              | 166              | 39                     |
| I have little social contact with people and feel socially isolated | 43               | 10                     |
| <b>Total</b>  | <b>433</b>       | <b>100</b>             |
| <i>Missing</i>  | 12               | -                      |
| <b>Total</b>  | <b>445</b>       | -                      |

Just over half of carers replied that they had as much social contact as they wanted with people they liked (52%).

**Q12. Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?**

| <b>Q12 Encouragement and support</b>                        | <b>Frequency</b> | <b>Valid percent %</b> |
|---|------------------|------------------------|
| I feel I have encouragement and support                     | 225              | 53                     |
| I feel I have some encouragement and support but not enough | 158              | 37                     |
| I feel I have no encouragement and support                  | 41               | 10                     |
| <b>Total</b>  | <b>424</b>       | <b>100</b>             |
| <i>Missing</i>  | 21               | -                      |
| <b>Total</b>  | <b>445</b>       | -                      |

Just over half of carers replied that they felt they had encouragement and support in their caring role (53%).

## Section 4: Information and advice quality

### Q13. In the past year, 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 Newcastle Adult and Culture Services.

| Q13 Ease of obtaining information              | Frequency  | Valid percent % | Valid percent: people who had tried to find information in last 12 months% |
|--|------------|-----------------|--|
| Very easy to find                              | 54         | 13              | 18   |
| Quite easy to find                             | 148        | 35              | 50   |
| Quite difficult to find                        | 72         | 17              | 24   |
| Very difficult to find                         | 22         | 5               | 7  |
| I've never tried to find information or advice | 132        | 31              | -  |
| <b>Total</b>                                   | <b>428</b> |                 | <b>100</b>   |
| <i>Missing</i>                                 | 17         | -               | -  |
| <b>Total</b>                                   | <b>445</b> | -               | -  |

Nearly half of all carers said that information or advice was very or quite easy to find (48%). 31% had never tried to find it.

When percentages are calculated using the total number of people who had tried to advice or information in the last 12 months (excluding people who had not tried to do this), the total for people finding it very or quite easy is 68%. This is the figure being used to report the ASCOF indicator 3d. Several people commented on whether it was easy to find information, and the main themes from their comments are summarised in the table on the next page. Comments included:

"I have phoned different departments and left messages, no-one returns my calls. Very difficult to speak to a social worker."

"Information is not generally presented, I've had to dig around or ask others. Word of mouth has got me further with finding what I need, as has internet research."

"The most frustrating aspect is the need to constantly follow up GP appointments and feedback from different medical appointments such as hospital, chiropody."

"I needed to find information about choosing a care home for my mother. The social worker at the hospital gave me a list of homes and told me to find the place and not to worry about the cost, [but] the costing and top-up fees, etc., are a major part of finding a home. You need to understand and know about care home charges before finding the home. The hospital just wanted the bed vacated as soon as possible."

"The social worker seemed unaware of the role of direct payments, and did not explain it well. I know more than they do, services do not exist to specifically meet my needs and are designed solely around other elderly people and spouses caring for each other, not a carer who wants to work."

| Theme   | Number of people |
|---|------------------|
| Happy with information given by social worker                                   | 8                |
| Happy with information given by Carers Centre                                   | 5                |
| You have to ask for information rather than people volunteering it              | 4                |
| Different organisations do not share information                                | 3                |
| Financial costs not properly explained.   | 3                |
| People do not return messages when these are left for them, or return them late | 3                |
| Accessing information is easier online  | 2                |
| Already knew a lot about what was available                                     | 2                |
| Difficult to know where to look for information about services                  | 2                |
| You get passed around when you contact the Council                              | 2                |
| Happy with information given by community or voluntary organisation             | 2                |
| Happy with information given by hospital social worker                          | 2                |
| Happy with information given by Social Care Direct                              | 2                |
| <i>Other individual comments</i>  | 30               |

**Q14. 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 Newcastle Adult and Culture Services.

| Q14 Helpfulness of information and advice                           | Frequency  | Valid percent % | Valid percent: people who had received information in last 12 months % |
|---|------------|-----------------|--|
| I have not received any information or advice in the last 12 months | 124        | 30              | -  |
| Very helpful  | 133        | 32              | 45   |
| Quite helpful   | 147        | 35              | 49   |
| Quite unhelpful   | 13         | 3               | 4  |
| Very unhelpful  | 4          | 1               | 1  |
| <b>Total</b>  | <b>421</b> | <b>100</b>      | <b>100</b>   |
| <i>Missing</i>  | 24         | -               | -  |
| <b>Total</b>  | <b>445</b> | -               | -  |

Over half of carers said that information or advice was very or quite helpful (67%). 30% had not received any. Several people commented on whether information received had been helpful, and the main themes from their comments are summarised in the table on the next page. Social workers and Carers Centre Newcastle were mentioned as having been helpful in providing information to carers. Comments included:

“Information on residential care was out of date by the time I received it. I had to continuously call to ask if properties were on the communications list for up-to-date information.”

“It has been difficult to speak to someone with regard to the outcome of the recent tenders for care providers. How the process of change will take place is not clear, it's very worrying for old people.”

“The discussion I had with the hospital social worker was upsetting, and I do not feel they understood, or cared to understand, my mother apart from routine assessment.”

“I receive the Carers Centre newsletter, and there is a lot of information in it which is very useful.”

“With regard to my application for attendance allowance, support from social workers based at the Freeman Hospital and help provided by a representative from Newcastle City Council was very helpful.”

| <b>Theme</b>   | <b>Number of people</b> |
|--|-------------------------|
| Social workers have been very helpful  | 6                       |
| Carers Centre information is very helpful  | 4                       |
| Other  | 4                       |
| Have to go out and look for information  | 3                       |
| Difficult to find up to date information on residential care                       | 2                       |
| Hospital social worker was very helpful  | 2                       |
| Information from the council was not helpful                                       | 2                       |
| Service providers have been very helpful and supportive                            | 2                       |
| Social workers do not always reply to messages or questions                        | 2                       |
| Advice received has sometimes been contradictory                                   | 1                       |
| Difficult to find any information  | 1                       |
| Difficult to find information on outcome for tenders for care providers            | 1                       |
| Difficult to get information if not the next of kin                                | 1                       |
| Don't know   | 1                       |
| Everyone is very helpful   | 1                       |
| Find most information needed on the internet                                       | 1                       |
| Found discussions with social workers distressing and not helpful                  | 1                       |
| Have received information previously   | 1                       |
| Information from First Stop was very helpful                                       | 1                       |
| Interpreter is necessary   | 1                       |
| Need advice on how to spend money effectively                                      | 1                       |
| Need advice on how to support the mental development of the person being cared for | 1                       |
| Not given any information  | 1                       |
| Physical disability team were very helpful   | 1                       |
| Seminar on caring for people with dementia was very helpful                        | 1                       |
| Would be helpful to have an advocate   | 1                       |
| YHN worker was very helpful  | 1                       |

**Q14b. If you wanted to make a complaint about any care services that you or the person you care for receive, do you know how to do this?**

| <b>Q14b. Making a complaint</b>                      | <b>Frequency</b> | <b>Valid percent %</b> |
|--|------------------|------------------------|
| Yes, and I feel I <b>could</b> if I wanted to        | 264              | <b>64</b>              |
| Yes, but I <b>do not feel I could</b> if I wanted to | 38               | <b>9</b>               |
| No, I <b>do not know</b> how to make a complaint     | 109              | <b>26</b>              |
| <b>Total</b>   | <b>411</b>       | <b>100</b>             |
| <i>Missing</i>                                       | <i>34</i>        | -                      |
| <b>Total</b>   | <b>445</b>       | -                      |

The majority of people said that they knew how to make a complaint about care services and felt that they could do so if they wanted to (64%).

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

**Q15. 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?**

| <b>Q15 Being involved and consulted</b>                                 | <b>Frequency</b> | <b>Valid percent %</b> | <b>Valid percent: people whose cared-for person had had discussions about care and support services in last 12 months %</b> |
|---|------------------|------------------------|---|
| There have been no discussions that I am aware of in the last 12 months | 73               | <b>17</b>              | -   |
| I always felt involved or consulted                                     | 183              | <b>43</b>              | <b>51</b>   |
| I usually felt involved or consulted                                    | 106              | <b>25</b>              | <b>30</b>   |
| I sometimes felt involved or consulted                                  | 52               | <b>21</b>              | <b>15</b>   |
| I never felt involved or consulted                                      | 16               | <b>4</b>               | <b>4</b>  |
| <b>Total</b>  | <b>430</b>       | <b>100</b>             | <b>100</b>  |
| <i>Missing</i>  | <i>15</i>        | -                      | -   |
| <b>Total</b>  | <b>445</b>       | -                      | -   |

The majority of carers said that they always or usually felt involved or consulted, as much as they wanted to be, in discussions about the support or services provided to the person they care for (68%). When people who said that there had been no discussions that they were aware of in the last 12 months are removed from the calculation, this total is 81%. This is the figure used to report ASCOF indicator 3c.

## Section 6: About carers

**Q16. In addition to your caring role, please tell us which of the following also applies to you?**

| Q16 Employment status*                               | Frequency  | Valid percent % |
|--|------------|-----------------|
| Retired  | 235        | 54              |
| Not in paid work                                     | 66         | 15              |
| Employed full-time                                   | 62         | 14              |
| Employed part-time (working 30 hours or less)        | 53         | 12              |
| Other  | 30         | 7               |
| Doing voluntary work                                 | 20         | 5               |
| Self-employed full-time                              | 13         | 3               |
| Self-employed part-time                              | 7          | 2               |
| <b>Total no. of people who answered the question</b> | <b>439</b> | <b>-</b>        |
| <i>Missing</i>                                       | 6          | -               |
| <b>Total</b>   | <b>445</b> | <b>-</b>        |

\* Respondents could choose as many options as they liked, so percentages do not total 100%. Responses have been checked and obvious errors removed – for example choosing both “retired” and “employed full-time”.

Just over half of carers were retired (54%).

**Q17. Thinking about combining paid work and caring, which of the following statements best describes your current situation?**

| Q17 Employment status   | Frequency  | Valid percent % | Valid percent: people were not self-employed or retired % |
|---|------------|-----------------|---|
| I am self-employed or retired   | 215        | 49              | -   |
| I am in paid employment, and I feel supported by my employer          | 66         | 15              | 30  |
| I am not in paid employment because of my caring responsibilities     | 66         | 15              | 30  |
| I am not in paid employment for other reasons                         | 47         | 11              | 21  |
| I am in paid employment, but I don't feel supported by my employer    | 22         | 5               | 10  |
| I do not need any support from my employer to combine work and caring | 19         | 4               | 9   |
| <b>Total</b>  | <b>435</b> | <b>100</b>      | <b>100</b>  |
| <i>Missing</i>  | 10         | -               | -   |
| <b>Total</b>  | <b>445</b> | <b>-</b>        | <b>-</b>  |

Nearly half of carers were self-employed or retired. Of those who were not, 15% said they felt supported by their employer, and 15% said they were not in paid employment due to their caring responsibilities.

**Q18. About how long have you been looking after or helping the person you care for?**

| <b>Q18 Length of time spent as a carer</b> | <b>Frequency</b> | <b>Valid percent %</b> |
|--|------------------|------------------------|
| Less than 6 months                         | 6                | 1                      |
| Over 6 months but less than a year         | 12               | 3                      |
| Over 1 year but less than 3 years          | 67               | 15                     |
| Over 3 years but less than 5 years         | 89               | 20                     |
| Over 5 years but less than 10 years        | 88               | 20                     |
| Over 10 years but less than 15 years       | 64               | 15                     |
| Over 15 years but less than 20 years       | 31               | 7                      |
| 20 years or more                           | 79               | 18                     |
| <b>Total</b>                               | <b>436</b>       | <b>100</b>             |
| <i>Missing</i>                             | 9                | -                      |
| <b>Total</b>                               | <b>445</b>       | -                      |

The largest percentage of carers had been caring for over three years but less than 10 years (40%). 18% had been caring for 20 years or more.

**Q19. About how long do you spend each week looking after or helping the person you care for?**

| <b>Q19 Length of time spent caring each week</b> | <b>Frequency</b> | <b>Valid percent %</b> |
|--|------------------|------------------------|
| 0-9 hours per week                               | 51               | 13                     |
| 10-19 hours per week                             | 58               | 14                     |
| 20-34 hours per week                             | 37               | 9                      |
| 35-49 hours per week                             | 28               | 7                      |
| 50-74 hours per week                             | 30               | 7                      |
| 75-99 hours per week                             | 127              | 31                     |
| 100 or more hours per week                       | 14               | 4                      |
| Varies – Under 20 hours per week                 | 28               | 7                      |
| Varies – 20 hours or more per week               | 31               | 8                      |
| Other  | 0                | 0                      |
| <b>Total</b>                                     | <b>404</b>       | <b>100</b>             |
| <i>Missing</i>                                   | 41               | -                      |
| <b>Total</b>                                     | <b>445</b>       | -                      |

The largest single percentage of carers said that they were caring for between 75-99 hours a week (31%).



**Q20. Over the last 12 months, what kinds of things did you usually do for the person you care for?**

| <b>Q20 Caring tasks</b>  | <b>Frequency</b> | <b>Valid percent %*</b> |
|--|------------------|-------------------------|
| <b>Other practical help?</b> (Things like preparing meals, doing his / her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital) | 387              | <b>88</b>               |
| <b>Helping with paperwork or financial matters?</b> (Such as writing letters, sending cards, filling in forms, dealing with bills, banking)  | 379              | <b>86</b>               |
| <b>Helping with dealing with care services and benefits?</b> (Things like making appointments and phone calls, filling in forms)   | 370              | <b>84</b>               |
| <b>Keeping an eye</b> on him / her to see s/he is all right?   | 366              | <b>83</b>               |
| <b>Keeping him / her company?</b> (Things like visiting, sitting with, reading to, talking to, playing cards or games)   | 359              | <b>82</b>               |
| <b>Giving emotional support?</b>   | 350              | <b>80</b>               |
| <b>Taking him / her out?</b> (Such as taking out for a walk or drive, taking to see friends or relatives)  | 331              | <b>75</b>               |
| <b>Giving medicines?</b> (Things like making sure s/he takes pills, giving injections, changing dressings)   | 282              | <b>64</b>               |
| <b>Personal care</b> (Things like dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet)   | 251              | <b>57</b>               |
| <b>Physical help</b> (Such as helping with walking, getting up and down stairs, getting into and out of bed)   | 220              | <b>50</b>               |
| <b>Other help?</b>   | 42               | <b>10</b>               |
| Several people said under 'other' that they carried out the following tasks to help the person they care for:  |                  |                         |
| Advocating, for example checking that someone in residential care is getting adequate nutrition and is well looked-after   | 5                | 1                       |
| Keeping the family updated   | 1                | 0                       |
| Night care   | 1                | 0                       |
| Other unspecified  | 36               | 8                       |
| <b>Total</b>   | <b>439</b>       | <b>-</b>                |
| <i>Missing</i>   | 6                | -                       |
| <b>Total</b>   | <b>445</b>       | <b>-</b>                |

\* Respondents could choose as many options as they liked, so percentages do not total 100%.

The most common caring task was “other practical help”, which includes help in the form of preparing meals, doing shopping, housework, gardening, laundry, household repairs or taking someone to medical appointments; 88% of carers did this. The next most common caring task was “helping with paperwork or other financial matters” (86%).

Some people commented on the “other help” they gave the person they cared for:

“All of the above, [and I am] up through the night as he suffers constipation, and I also make sure he is still breathing.”

“Clearing her home, getting rid of her belongings when she went into care. Making sure the home was looking after her, sorting out finances.”

“Ensuring that all organisations involved in her care take decisions in her best interests, acting as an advocate in financial, care and family matters.”

“Keeping her safe, as she is very vulnerable and can get into difficult situations socially.”

“Making sure that his family abroad keep in touch and updating them with developments in his health.”

“He needs 24 / 7 care to make sure he is safe and does not go out on his own. He cannot make drinks or meals for himself as he does not shut doors, turn lights or fires off, etc.”

“PEG [Percutaneous endoscopic gastrostomy – a feeding tube into the stomach] feeds every four hours during the day.”

“Taking her on holiday, having her staying over for Christmas, New Year, Easter, etc.”

Others made general comments about the care they provided:

“All of the above, to ensure the care team are aware of the needs of my daughter and ensure her safety and well-being in conjunction with her care agency.”

I go to my dad and do what I can for him – shopping, medication, washing and housework. I do what I can to help him stay independent.”

“I rang her every night or morning to see if she was okay.”

“We are neighbours and the best of friends so we do everything together, and are there for one another.”

“Yes, I need to give emotional support, they are upset sometimes. I have to be there for her.”

## What carers told us

We asked respondents if they would like to describe any other experiences they wanted to tell us about, or if they had any other comments. The most common themes in their comments were as shown in the table on the next page. Some comments included:

“I would also like to thank Newcastle Council for its help and support given to us over the years, without this support we would really struggle to care for our son, as he can exhibit very challenging behaviours! We have always felt fully supported by Newcastle. Currently, budget cuts are in evidence. Thankfully, and with great relief, I can say my son continues to be supported. This is a lifeline for us and many thanks.”

“Despite my mother now living in a nursing home, the level of support and commitment from myself remain the same. Whilst kept 'physically' safe by nursing home staff, a person living with dementia still requires a great deal of input from family members. It is very upsetting to witness the deterioration experienced by dementia sufferers and for this reason I find myself spending more and more time with my mother to try and provide her with some quality of life. Dementia suffers 'live for the moment', so despite calling in to see her most days and take her out, in the next minute she will have forgotten it ever took place. Mum moving into a care home has not allowed me to 'regain' my life, it is a constant struggle.”

“Everything is flung back on the carer to do. You can write it into care plans, but if care workers can't or won't do it you have to complain or sort it out. Eventually you feel so hopeless and permanently tired and worn down and have no fight in you, you give up.”

“Carers from a care company visit twice a day, this can be three times in times of ill health. My main concern is that the standard of care is not consistently good. It sometimes appears that, with young carers in particular, the necessary training has either not been given, or not practiced, or the main ideas not embedded. Some carers do as little as possible and do not show much responsibility in how they carry out their job, such visits can be a waste of time and money. It is me who organised someone else to do household cleaning and a second person to do the shopping and one outing per week.”

In April 2012, Carers Centre Newcastle asked carers known to them what their main concerns for their future. The top five concerns were: their health; loneliness; stress and anxiety; planning for the future; being listened to by professionals; and being given enough support and information by professionals.

The questions in the two surveys (ours and the Carers Centre's) were worded differently, so we would not necessarily expect identical results. It is interesting, however, to note that these concerns also appear in responses to our survey. For example, the third most common theme in people's comments in our survey was that caring is very tiring and stressful, and several people commented that they were concerned about the future due to the impact of funding cuts, or because they were worried about their health or that of the cared-for person deteriorating.

| <b>Theme</b>   | <b>No. of people</b> |
|--|----------------------|
| 1. Happy with support provided   | 30                   |
| 2. Description of situation  | 27                   |
| 3. Caring is very tiring and stressful   | 8                    |
| 4. Carer has to take responsibility for everything and sort out any problems   | 5                    |
| 5. Family provide support  | 5                    |
| 6. Other   | 5                    |
| 7. Care providers being changed is stressful for cared-for people  | 4                    |
| 8. Constantly changing care workers is distressing for people with dementia  | 4                    |
| 9. Had to stop work or retire to be able to keep caring  | 4                    |
| 10. Because it is your family you just do it   | 3                    |
| 11. Concerned about the future due to funding cuts   | 3                    |
| 12. Do not feel involved in decision-making  | 3                    |
| 13. Have to care for two people  | 3                    |
| 14. Not kept properly informed about changes to services   | 3                    |
| 15. Organisations providing care and support do not communicate with each other  | 3                    |
| 16. Questionnaire needs to be able to capture experiences of people caring for two adults  | 3                    |
| 17. Standard of care from care workers is not consistently good  | 3                    |
| 18. Allocated hours for care worker visits are often not convenient  | 2                    |
| 19. Can be difficult to access information if you are the carer, due to patient confidentiality or data protection   | 2                    |
| 20. Carers are not paid enough or given enough financial support   | 2                    |
| 21. Caring caused depression   | 2                    |
| 22. Caring is becoming increasingly difficult as the cared-for person's health deteriorates  | 2                    |
| 23. Concerned about the welfare of the cared-for person and the carer as the carer ages  | 2                    |
| 24. Difficult to care for people when they do not realise they have problems (such as dementia)  | 2                    |
| 25. Difficult to navigate through bureaucracy  | 2                    |
| 26. Do not feel older people are respected or supported in Britain   | 2                    |
| 27. Even if a person with dementia is in residential care, carers are still needed to help with their quality of life, for example providing emotional support | 2                    |
| 28. Happy with support from Carers Centre  | 2                    |
| 29. Internal communication in organisations such as the council is often poor  | 2                    |
| 30. Kept an eye on the person and looked after them  | 2                    |
| 31. Need a larger house due to childcare responsibilities for grandchildren  | 2                    |

| Theme   | No. of people |
|---|---------------|
| 32. Need financial support to enable transport to medical appointments, etc.      | 2             |
| 33. Need much better guidance when someone goes into residential care             | 2             |
| 34. People do not get the level of care they really need                          | 2             |
| 35. Unsure how will cope when cared-for person's disease progresses               | 2             |
| 36. You have to ask for information or support rather than people volunteering it | 2             |
| <i>Other individual comments</i>  | 70            |

Other comments included:

“Help from the social worker involved has been invaluable. She has always been here for the whole family with very sound and practical advice, and we are so grateful for all her help.”

“I am not an official carer, I just care for my friend. We go everywhere together, shopping, holidays, eating out and just enjoy each other’s company.”

“I did not realize when my husband was told that he had Alzheimer's disease how it would change our lives forever. As time went on his moods and behaviour changed, also he became agitated, sometimes verbally hostile. I did not realize at the time what it entailed. It’s so soul-destroying for him, I would not wish this on anyone.”

“I find the service provided in Newcastle fragmented as one phone call is never enough, and different departments often give different answers. This causes duplication and is frustrating when you want reasons and answers to issues as they arise. For example, care planning reviews are carried out by three people (not all together).”

“As I am getting older I am more relaxed about my daughter’s independence, until I worry about the financial constraints being faced by the city council and the difficult decisions having to be made. She will be in a wheelchair for her lifetime, but her independent spirit has always been encouraged and her control of her life is of paramount importance, despite her physical constraints.”

## About the carers

### Q24. Did anyone help you complete the questionnaire?

| Q24 Did anyone help you complete the questionnaire? | Frequency  | Valid percent % |
|---|------------|-----------------|
| Yes   | 25         | 6               |
| No  | 415        | 94              |
| <b>Total</b>  | <b>440</b> | <b>100</b>      |
| <i>Missing</i>                                      | 5          | -               |
| <b>Total</b>  | <b>445</b> | -               |

The majority of carers completed the questionnaire without help from anyone else (94%).

### Responded to original postal questionnaire or a reminder?

| Responded to original or reminder? | Frequency  | Valid percent % |
|------------------------------------|------------|-----------------|
| Original                           | 172        | 39              |
| Reminder                           | 263        | 61              |
| <b>Total</b>                       | <b>435</b> | <b>100</b>      |
| <i>Missing</i>                     | 10         | -               |
| <b>Total</b>                       | <b>445</b> | -               |

Around 61% of the respondents had responded after the date when the reminders were sent out. Note that this was calculated by the date when the questionnaires were returned, so it is probably the case that the percentage of people who replied using the original questionnaire should be larger, to allow for people whose “original” questionnaire was not received by the date when the reminders were sent out. In future we will look at whether the way this information is captured can be revised to be more accurate.

### Q21. Do you have any of the following?

| Q21 Carer's client group            | Frequency  | Valid percent % |
|-------------------------------------|------------|-----------------|
| None of the above                   | 202        | 49              |
| A long-standing illness             | 110        | 27              |
| A physical impairment or disability | 77         | 19              |
| Sight or hearing loss               | 58         | 14              |
| A mental health problem or illness  | 38         | 9               |
| Other                               | 23         | 6               |
| A learning disability or difficulty | 8          | 2               |
| <b>Total</b>                        | <b>413</b> | -               |
| <i>Missing</i>                      | 32         | -               |
| <b>Total</b>                        | <b>445</b> | -               |

\* Respondents could choose as many options as they liked, so percentages do not total 100%.

Just under half of carers said they did not have a long-standing illness, a physical impairment, sensory impairment, mental health problem, learning disability or other similar issue (49%). Of those who did, 27% had a long-standing illness and 19% had a physical impairment or disability. Of people who replied “other”, the most common “other” reason was that they were recovering from a recent operation or other medical treatment such as chemotherapy (8 people out of 23 said this). Two others said that they were recovering from a recent illness, such as cancer, and two more people said that they had had joint replacement surgery in the past. Many carers with long-standing illnesses or medical conditions commented on what they suffered from as shown in the table on the next page.

| <b>Condition</b>   | <b>Number of people</b> |
|--|-------------------------|
| Arthritis  | 20                      |
| Heart problems, including having had a heart attack      | 9                       |
| High blood pressure                                      | 9                       |
| Angina   | 8                       |
| Back or neck pain  | 7                       |
| Depression   | 7                       |
| Asthma   | 6                       |
| Diabetes   | 6                       |
| Other  | 5                       |
| Anxiety or stress  | 4                       |
| Hernia   | 4                       |
| Joint problems, including having had a joint replacement | 4                       |
| Cancer   | 3                       |
| COPD or other breathing problem                          | 3                       |
| Osteoporosis   | 3                       |
| Stroke   | 3                       |
| Thyroid problems, such as Graves' disease                | 3                       |
| High cholesterol   | 2                       |
| IBS  | 2                       |
| Kidney problems  | 2                       |
| Old age  | 2                       |
| Sensory impairment – hearing or sight                    | 2                       |
| Skin problems, such as psoriasis or eczema               | 2                       |
| Anaemia  | 1                       |
| Epilepsy   | 1                       |
| Gout   | 1                       |

## How old are you?

| Age of carer*  | Frequency  | Valid percent % | % in sample | % in population | Difference between respondents & population |
|----------------|------------|-----------------|-------------|-----------------|---|
| 18-24          | 0          | 0               | 1           | 1               | -1  |
| 25-34          | 3          | 1               | 3           | 3               | -2  |
| 35-44          | 28         | 6               | 8           | 8               | -2  |
| 45-54          | 97         | 22              | 24          | 22              | 0   |
| 55-64          | 133        | 30              | 26          | 22              | 8   |
| 65-74          | 82         | 19              | 17          | 19              | 0   |
| 75-84          | 79         | 18              | 16          | 17              | 1   |
| 85 and over    | 21         | 5               | 6           | 8               | -3  |
| <b>Total</b>   | <b>443</b> | <b>100</b>      | <b>100</b>  | <b>100</b>      | <b>-</b>                                    |
| <i>Missing</i> | 2          | -               | 13          | 25              | -   |
| <b>Total</b>   | <b>445</b> | <b>-</b>        | <b>-</b>    | <b>-</b>        | <b>-</b>                                    |

\* This information has been taken from a combination of data already held in our records, and respondents' replies to the question in the survey about their age.

The largest single percentage of carers were aged between 55-64 (30%). Nearly half (42%) were aged 65 and over.

It appears that people aged 55-64 are slightly overrepresented in the sample, and that both younger and the "oldest old" (85 and over) carers are slightly underrepresented. It is possible that this may reflect limitations on the time and energy they have available to complete and return the questionnaire; for example, people aged 44 and under are more likely to be combining paid work with caring.

However, it should be noted that we do not hold any information about age for around a quarter of the total "population" of carers (556 out of 2236), so these figures are illustrative only. It is to be hoped that this survey, combined with ongoing work with carers and the people they care for, will help us to build up a more detailed picture of carers in Newcastle.

## Gender

| Gender           | Frequency  | Valid Percent % | % in sample | % in population |
|------------------|------------|-----------------|-------------|-----------------|
| Male             | 148        | 34              | 32          | 35              |
| Female           | 294        | 66              | 68          | 65              |
| <b>Total</b>     | <b>442</b> | <b>100</b>      | <b>963</b>  | <b>1680</b>     |
| <i>Not known</i> | 3          | -               | 8           | 25              |
| <b>Total</b>     | <b>445</b> | <b>-</b>        | <b>971</b>  | <b>2236</b>     |

The majority of carers in the survey were female (66%). This is in line with the total population of carers, where 65% are female.



## Ethnic origin of the carer

| <b>Ethnic origin</b>   | <b>Frequency</b> | <b>Valid Percent %</b> | <b>% in sample</b> |
|------------------------|------------------|------------------------|--------------------|
| White                  | <b>433</b>       | <b>97</b>              | <i>97</i>          |
| White British          | 427              | <b>96</b>              |                    |
| White English          | 2                | <b>1</b>               |                    |
| White Scottish         | 1                | <b>0</b>               |                    |
| White Welsh            | 1                | <b>0</b>               |                    |
| White Cornish          | 1                | <b>0</b>               |                    |
| Gypsy / Romany         | 1                | <b>0</b>               |                    |
| Asian or Asian British |                  |                        | <i>2</i>           |
| Indian                 | 6                | <b>1</b>               |                    |
| Pakistani              | 1                | <b>0</b>               |                    |
| Black or Black British |                  |                        | <i>0</i>           |
| Caribbean              | 1                | <b>0</b>               |                    |
| Chinese                | 0                | <b>0</b>               | <i>0</i>           |
| Mixed                  | 0                | <b>0</b>               | <i>0</i>           |
| Not Stated             | 0                | <b>0</b>               | <i>0</i>           |
| Other                  | 1                | <b>0</b>               | <i>0</i>           |
| <b>Total</b>           | <b>442</b>       | <b>100</b>             | <b>100</b>         |
| <i>Missing</i>         | <i>3</i>         | -                      |                    |
| <b>Total</b>           | <b>445</b>       | -                      |                    |

The majority of carers who took part in the survey were from a White ethnic origin, in line with the sample (97% for both respondents and sample.)

## Personal Budgets / Direct Payments - Carer

| <b>Carer receives personal budgets or direct payments?</b> | <b>Frequency</b> | <b>Valid percent %</b> | <b>% in sample</b> |
|--|------------------|------------------------|--------------------|
| Yes - managed by local authority via Direct Payments       | 1                | <b>0</b>               | <b>0</b>           |
| Yes - other  | 6                | <b>1</b>               | <b>1</b>           |
| No   | 437              | <b>99</b>              | <b>99</b>          |
| <b>Total</b>   | <b>444</b>       | <b>100</b>             | <b>100</b>         |
| <i>Missing</i>   | <i>1</i>         | -                      | -                  |
| <b>Total</b>   | <b>445</b>       | -                      | -                  |

The majority of carers in the survey did not receive a direct payment or personal budget (99%).

**Was the carer assessed jointly with the cared-for person or separately?**

| <b>Carer assessed jointly or separately?</b> | <b>Frequency</b> | <b>Valid percent %</b> | <b>% in sample</b> |
|--|------------------|------------------------|--------------------|
| Jointly                                      | 262              | 96                     | 97                 |
| Separately                                   | 12               | 4                      | 3                  |
| <b>Total</b>                                 | <b>274</b>       | <b>100</b>             | <b>100</b>         |
| <i>Missing</i>                               | 171              | -                      | -                  |
| <b>Total</b>                                 | <b>445</b>       | -                      | -                  |

96% of carers had been assessed jointly with the person they care for.

**Has the carer received a service in the past 12 months which was funded by the local authority? (excluding information).**

| <b>Carer received a service funded by local authority in last 12 months?</b> | <b>Frequency</b> | <b>Valid percent %</b> | <b>% in sample</b> |
|--|------------------|------------------------|--------------------|
| Yes  | 214              | 48                     | 41                 |
| No   | 230              | 52                     | 59                 |
| <b>Total</b>   | <b>444</b>       | <b>100</b>             | <b>100</b>         |
| <i>Missing</i>   | 1                | -                      | -                  |
| <b>Total</b>   | <b>445</b>       | -                      | -                  |

48% of carers had received a service in the last twelve months which was funded by the local authority.

**Has the carer received information only in the past 12 months which was funded by the local authority?**

| <b>Carer received information funded by local authority in last 12 months?</b> | <b>Frequency</b> | <b>Valid percent %</b> | <b>% in sample</b> |
|--|------------------|------------------------|--------------------|
| Yes  | 1                | 0                      | 0                  |
| No   | 443              | 100                    | 100                |
| <b>Total</b>   | <b>444</b>       | <b>100</b>             | <b>100</b>         |
| <i>Missing</i>   | 1                | -                      | -                  |
| <b>Total</b>   | <b>445</b>       | -                      | -                  |

One person had received information only within the last twelve months (which was funded by the local authority).

## Appendix 1 – Findings from previous research with carers

This appendix compares findings from previous research with carers, both nationally and locally, to provide context for the findings from the 2012 Newcastle Carers Survey. This research includes:

- Newcastle Residents Survey 2012
- Newcastle Carers Centre Annual Client Feedback Survey 2012
- Newcastle Carers Views Surveys – 2006 to 2010
- Survey of Carers in Households 2009 / 2010
- Personal Social Services Survey of Adult Carers in England 2009 / 10
- “Your Views Count” – Newcastle Carers Information Survey 2006

### Newcastle Residents Survey 2012

The Newcastle City Council Residents Survey 2012 took place in July 2012, when a random sample of 10,401 addresses in Newcastle were sent a questionnaire about their views on Newcastle City Council, life in their local area, and the city as a whole. 2,383 households replied, giving a response rate of 23%. Of these respondents, 542 identified themselves as carers.

Key findings from the Residents Survey 2012 about carers' views were as follows:

- Carers are more likely to have **been in touch with the council** than residents as a whole; 66% compared to 56% overall.
- Carers tend to be **less satisfied with their local area** than other residents. This is part of a general trend where people's personal circumstances can affect how they perceive their local area; satisfaction rates are also lower for social housing tenants and respondents in poor health.
- Carers feel **less safe** than average when walking in their **local area** after dark; 25% feel unsafe, compared to 21% of all residents.
- More carers disagree that the **Newcastle City Council area** is safe than the average; 22% disagree that it is very or fairly safe, compared to 18% of all residents.
- **Satisfaction with Newcastle City Council** is lower for carers than for all residents; 46% are satisfied, compared to 62% as a whole.
- Carers are as likely to disagree as to agree that the **council offers value for money**; 34% agree and 34% disagree. For all residents, these figures were: 42% agree, and 25% disagree.
- Carers are more likely than non-carers to speak **critically of the council to others**; 41% say they are likely to do this, compared to 25% of all residents.
- Carers are **less likely to trust the Council** than non-carers; 51% say they trust the council, compared to 67% of non-carers.
- Carers are **more likely to feel badly informed** about the council than non-carers: 46% of carers say they feel badly informed, compared to 41% overall.
- Carers are more likely to say that the **Council does not act on the concerns of residents** than non-carers; 55% of carers say this, compared to 44% of non-carers.

## **Carers Centre Newcastle Annual Client Feedback Survey 2012**

This survey is undertaken by Carers Centre Newcastle every year to obtain feedback from carers using their services. The most recent survey took part in April 2012. Questionnaires were sent to carers known to Newcastle Carers Centre, around 200 of whom replied. The Carers Centre have kindly shared the results with us to help analysis our findings. The main findings from the Client Feedback Survey about how carers felt about their lives and about support services was as follows. When asked what their **main concerns for the future** were, carers replied as follows:

- 76% Your own health
- 63% Loneliness, stress and anxiety
- 62% Planning for the future
- 61% Being listened to by professionals
- 60% Being given enough support and information by professionals
- 59% How you will manage to keep caring as you get older
- 53% Money and benefits
- 52% Family relationships
- 36% Costs of care
- 31% Balancing work and care
- 25% Housing issues
- 23% Moving the person you care for into supported housing or a care home

It is interesting to note that many of these concerns were mentioned by carers in their comments at the end of our own survey – see p.26. When asked how services from Carers Centre Newcastle made a difference to their lives, carers replied as follows:

- 86% I feel better emotionally
- 81% I feel less isolated
- 81% I understand the importance of having time for myself
- 75% It helps me think about future
- 74% It helps me communicate with other services or organisations

This suggests that these are areas of importance to carers – feeling better, feeling less isolated, having time for themselves, planning for the future and communicating with other services or organisations – and that where possible, we should consider how services we provide can help carers with them.

## **Newcastle Carers Views Surveys – 2006 to 2009**

The Newcastle Carers Views Survey was sent out alongside the statutory survey of older home care users in spring 2006, 2007, 2008 and 2009. It was not a random sample survey, but instead was sent out with the main survey with a letter attached explaining what we meant by “a carer” and asking the person receiving the main survey to pass the Carers Views Survey on to anyone who matched that description. This means that the data is not representative of all carers in Newcastle, but it does provide an insight into the issues facing carers in the city.

The main findings from the 2006-2009 Carers' Views surveys, and how they compare to the findings from the Newcastle Carers Survey 2012, were as follows.

- **Hours of care:** In each year, the majority of Carers Views survey respondents provided **either** between 0-20 hours (around 44% of carers) or 151-168 hours per week (around 27%). This is a slightly similar pattern to the respondents to the Newcastle Carers Survey 2012, where 27% of carers were providing care for 0-19 hours a week, and 31% were providing care for between 75-99 hours.
- **How long have you been a carer for?** A similar pattern is evident in each year of the Carers Views Survey, with the largest percentages of carers falling into the **1-3 and 4-7 year brackets**, and around 20% providing care for 12 or more years. Similarly, 19% of carers in the Newcastle Carers Survey 2012 had been caring for 1-3 years, 40% had been caring for between 3-10 years, and 18% had been caring for 20 years or more.
- **Caring tasks:** The most common task carried out by carers in the Carers Views Survey was **shopping** (around 90% of carers said that they did this), and, similarly, 88% of carers in the Newcastle Carers Survey 2012 said they provided practical help to the person they care for, including shopping and housework. In both surveys, a majority of carers said that they helped with financial matters and making sure someone is alright.
- **Do carers neglect themselves?** In both the Carers Views surveys and the 2012 Carers Survey, a substantial minority of carers are concerned about **whether they look after themselves properly**. Around 37% of carers in each of the Carers Views Surveys agreed with the statement "I often neglect my own health and don't visit my GP in times of illness", and 35% of carers in the Newcastle Carers Survey 2012, when asked: "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?" replied "Sometimes I can't look after myself well enough" or "I feel I am neglecting myself".
- **Feeling appreciated or encouraged:** Around 30% of respondents to each of the Carers Views surveys did **not** say that they felt appreciated and valued as carers, and 47% of carers in the Newcastle Carers Survey 2012, when asked "Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?", replied either "I feel I have some encouragement and support but not enough" or "I feel I have no encouragement and support".
- **Social contact:** Around 28% of respondents to each of the Carers Views surveys agreed with the statement "I often feel **isolated or lonely**". Respondents to the Newcastle Carers Survey 2012 seemed to find this more of an issue, with 38% replying "I have some social contact with people, but not enough" (when asked "Thinking about how much contact you've had with people you like, which of the following statements best describes your social situation?"). 10% replied "I have little social contact with people and feel socially isolated". This may be due to the fact that the Carers Views Surveys generally contained a higher proportion of people who provided fewer hours of care per week, and thus presumably had more time available for social contact with others.
- **Having time to yourself:** The majority of carers in the Carers Views Surveys **did not agree** that they get sufficient breaks from caring (around 54% of carers in each year either disagreed with this statement or replied "neither agree nor disagree), and nearly

half (49%) agreed that they would like to have more time to themselves to pursue their own interests or hobbies. In the Newcastle Carers Survey 2012, the majority of carers (60%) replied “I do some of the things I value or enjoy with my time but not enough”, and 11% replied “I don’t do anything I value or enjoy with my time” (when asked the question: “Which of the following statements best describes how you spend your time?”).

- **Gender:** In all the surveys – the Carers Views Surveys 2006 – 2009, and the Newcastle Carers Survey 2012 – the majority of carers are **female**, around 66%.
- **Age:** The largest percentage of carers in each of the Carers View Surveys were **aged 50-59**, and in each year, just over half of all carers were aged 60 or over. The Newcastle Carers Survey 2012 has a similar age profile, with 44% of carers being aged 45-64, and 44% being aged 65 and over.
- **Disability:** In each of the Carers Views Surveys, **around half** (48%) of all carers had a long-standing illness, disability or infirmity. This was similar to the Newcastle Carers Survey 2012, where 51% of carers had some form of impairment (long-standing illness, physical impairment or disability, sight or hearing loss, mental health problem or illness, or a learning disability or difficulty).
- **Ethnicity:** The majority of carers in all of the surveys, both the Carers Views Surveys and the Newcastle Carers Survey 2012, are from a **White British** background – around 97%.

### “Survey of Carers in Households 2009 / 2010” and “Personal Social Services Survey of Adult Carers in England 2009 / 10”

In 2010 the NHS Information Centre for health and social care (NHS IC) published two surveys of carers in 2009/10:

- “Survey of Carers in Households - 2009/10 England” – a survey of carers in the **general population**.
- “Personal Social Services Survey of Adult Carers in England - 2009-10” – a survey of **carers known to Councils** with Adult Social Services Responsibilities (CASSRs).

Relevant findings to our survey are that in the survey of carers in households, 30% of carers were providing care for 35 hours or more per week, and 22% of carers were providing care for 50 hours or more per week. The Personal Social Service survey showed that carers known to councils tend to have more intensive caring duties, with 57% providing care for 35 hours or more, and 49% providing care for 50 hours or more.

| <b>Hours per week ↓</b>                  | <b>2009 Households survey of carers in the general population</b> | <b>2009 PSS Survey of carers known to councils</b> | <b>2012 Newcastle Carers Survey (of carers known to Newcastle City Council)</b> |
|--|---|--|---|
| Carers providing 35+ care hours per week | 30%   | 57%  | 64%   |
| Carers providing 50+ care hours per week | 22%   | 49%  | 57%   |

Carers who took part in the 2012 Newcastle Carers Survey appeared to be providing more hours of care per week than carers in either the 2009 carers in households survey or the 2009 PSS Survey of Adult Carers. It is not at present clear whether this is a one-off result or indicative of a genuine increase in hours of care being provided by carers.

When the national results for the Carers Survey are released, this will help us determine if this may be part of a national trend. We should also bear in mind that it may be the case that carers who are caring for more hours may perhaps be more likely to complete the questionnaire. This may be due to their more readily identifying themselves as a carer, or because they have more experience of services being provided to carers and therefore feel more confident answering questions about them. Other findings included:

- **Gender:** Both surveys showed a similar breakdown of carers by gender, where between 60%-66% of carers were female:
  - 2009 Carers in households survey = 60% female
  - 2009 PSS adult carers survey = 66% female
  - 2012 Newcastle carers survey = 66% female
- **Age:** Carers known to councils tend to be older:
  - 2009 Carers in households survey = 25% aged 65 or older
  - 2009 PSS adult carers survey = 49% aged 65 or older
  - 2012 Newcastle carers survey = 42% aged 65 or older
- **Ethnicity:** The ethnic profile was similar in all surveys, with the majority of carers being from a White ethnic background:
  - 2009 Carers in households survey = 92% White
  - 2009 PSS adult carers survey = 91% White
  - 2012 Newcastle carers survey = 97% White

## **“Your Views Count” – Newcastle Carers Information Survey 2006**

This survey took place in summer 2006 to inform the development of the Newcastle Carers Strategy 2006, and focussed on carers’ views on information: whether it was easy to get hold of, where they found it, and what format they preferred it to be in. It was sent out to 2,073 carers in Newcastle via carers support groups, and received 432 replies; a response rate of 21%. Although this is not a random sampling method (and thus the results are not strictly comparable with the 2012 survey), it is useful to compare with as this was a Newcastle-specific survey.

In 2006, 70% of carers in this survey said that it was easy to get hold of information. This is very similar to the result in 2012, where 68% of carers surveyed said that it was very or quite easy to do this.

### **About the carers**

As found in the 2012 Newcastle Carers Survey and the 2009/2010 Carers in Households and PSS Carers Surveys, the majority of carers in the “Your Views Count” survey were female (73%), and the largest age group was people aged 65 and over (43%). Interestingly, a larger proportion of people in the 2006 survey had been caring for 16 or

more years; 40%, compared to 25% in the 2012 survey. It is not clear if this is due simply to change over time, or caused by a difference in the sampling method.



## **Appendix 2 – Questions asked, and information about respondents**

### **1. How old is the person you care for?**

(If you don't know their exact age, please give an approximate one.)

### **2. Does the person you care for have any of the following?**

- 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
- Autism or Asperger's Syndrome

The final option, "Autism or Asperger's Syndrome" was added by ourselves.

### **3. Where does the person you care for usually live?**

- With me
- Somewhere else

### **4. Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Newcastle Adult and Culture Services in the last 12 months?**

- We haven't received any support or services from Newcastle Adult and Culture Services in the last 12 months
- I am extremely satisfied
- I am very satisfied
- I am quite satisfied
- I am neither satisfied nor dissatisfied
- I am quite dissatisfied
- I am very dissatisfied
- I am extremely dissatisfied

**5. Has the person you care for used any of the support or services listed below in the last 12 months? They may be provided by different organisations, such as a voluntary organisation, a private agency or Newcastle Adult and Culture Services.**

Possible answers for each option:

- Yes
- No
- Don't know

- a. Support or services allowing you to take a break from caring at short notice or in an emergency.
- b. Support or services allowing you to take a break from caring for more than 24 hours
- c. Support or services to allow you to have a rest from caring for between 1 and 24 hours (such as a sitting service)
- d. Personal assistant
- e. Home care / home help
- f. Day centre or day activities
- g. Lunch club
- h. Meals services
- i. Equipment or adaptation to their home (such as a wheelchair or handrails)
- j. Lifeline Alarm / Telecare
- k. They are permanently resident in a care home

## **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 Newcastle Adult and Culture Services. They may be provided by a voluntary organisation, a private agency or Newcastle Adult and Culture Services.

**6. 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 Newcastle Adult and Culture Services. Please do not include any unpaid help from family and friends.

Possible answers for each option:

- Yes
- No
- Don't know

- a. Information and advice
- b. Support from carers groups or someone to talk to in confidence
- c. Training for carers
- d. Support to keep you in employment

### **Q6e: Are you aware of the Carers' Emergency Card Scheme?**

This is a scheme run by Newcastle City Council and the British Red Cross. Under the scheme, carers register their details and receive a pocket-sized card with unique reference number. If they are delayed in an emergency they ring the British Red Cross and quote the number which enables the charity to call up an emergency plan which helps them assist the cared for person.

- a. Yes, I am aware of this and I have a Carer's Emergency Card
- b. I am aware of this but I do not have a Carer's Emergency Card
- c. No, I am not aware of this
- d. Don't know / not sure

## **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.

### **7. 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.

- 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

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

- 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

### **9. 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?**

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

### **10. 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.

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

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

- 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

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

- 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

## **Section 4: Information and advice quality**

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

**13. 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 Newcastle Adult and Culture Services.**

- 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

If you would like to tell us more about this, please do so here:

**14. 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 Newcastle Adult and Culture Services.**

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

If you would like to tell us more about this, please do so here:

**14b. If you wanted to make a complaint about any care services that you or the person you care for receive, do you know how to do this?**

- Yes, and I feel I could if I wanted to
- Yes, but I do not feel I could if I wanted to
- No, I do not know how to make a complaint

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

The next question is about organising the support and services for you and the person you care for.

**15. 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?**

- 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: About yourself**

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

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

- 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

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

- 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

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

- 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

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

- 0-9 hours per week
- 10-19 hours per week
- 20-34 hours per week
- 35-49 hours per week
- 50-74 hours per week
- 75-99 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:

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

- **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?**

If other, please tell us more about this:

**21. Do you have any of the following?**

- 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

**22. How old are you? \_\_\_\_\_ years**

**23. To which of these groups do you consider you belong?**

- White** (British, Irish, 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, or any other Black background)
- Chinese**
- Any **other** ethnic group

**24. Did someone help you to complete this questionnaire?**

- Yes
- No

**25. 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**

**26. We may be asking some people to take part in follow-up research for this study in the next year or so. Would you be happy to be invited to take part in more research? Note that even if you say “yes” there will be no obligation to take part in the future.**

- Yes**, I have written my name, address and phone number in the space below
- No**

If you would be happy to be contacted for this purpose please provide your contact details here.

**Information known about the people in the sample**

1. Gender
2. Age
3. Ethnicity
4. Religion
5. Primary Client Group of the person being cared for (Physical Disability, Frailty and Sensory Impairment; Mental Health; Learning Disability; Substance Misuse; Vulnerable People)

6. Whether carer is in receipt of personal budgets or direct payments
7. Whether cared-for person is in receipt of personal budgets or direct payments
8. Whether cared-for person is a self-funder
9. Whether the carer was assessed jointly with the cared-for person, or separately
10. Whether the carer received a service in the past 12 months funded by Newcastle City Council
11. Whether the carer received information in the past 12 months funded by Newcastle City Council



## Appendix 3 – ASCOF Indicators Definitions

### (1D) Carer-reported quality of life

**Domain /  
Outcome  
Rationale**

1. Enhancing quality of life for people with care and support needs  
*Carers can balance their caring roles and maintain their desired quality of life*  
This measure gives an overarching view of the quality of life of carers based on outcomes identified through research by the Personal Social Services Research Unit. This is the only current measure related to quality of life for carers available, and supports a number of the most important outcomes identified by carers themselves, to which adult social care contributes.

**Definition /  
Interpretation**

**This measure is deferred in 2012/13 and will be published for the first time using 2012/13 data.**

This is a composite measure which combines individual responses to seven questions measuring different outcomes related to overall quality of life which are mapped to 7 domains (occupation, time and space, control, personal care, safety, social participation and encouragement and support).

This is an overarching outcome measure for carers, similar to the equivalent for people who use services (1A – social care-related quality of life).

The seven questions, drawn from the Carers Survey, are:

- *Occupation* - Q18. Which of the following statements best describes how you spend your time?
- *Time and space* - Q19. 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?
- *Control* - Q20. Which if the following statements best describes how much control you have over your daily life?
- *Personal care* - Q21. 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?
- *Safety* - Q22. Thinking about your personal safety, which of the statements best describes your present situation?
- *Social participation* - Q23. Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation?
- *Encouragement and support* - Q24. Thinking about encouragement and support in your caring role, which of the following statements best describes your present situation?

Note that these are the question numbers and wording for the 2009/10 survey and may change for 2012/13 *pending review and rationalisation of the Carers Survey during 2012/13*.

Each of the questions has three possible answers, which are equated with having no unmet needs in a specific life area or domain (the ideal state), having some needs met and having no needs met.

Responses to the questions indicate whether the carer has unmet needs in any of the seven areas. The measure is calculated to give an overall score based on respondents' self-reported quality of life, using a combination of the questions above. All seven questions are given equal weight.

#### *Interpretation*

The measure gives an overall indication of the reported outcomes for carers – it does not, at present, identify the specific contribution of councils' adult social care towards those outcomes.

**Risk  
adjustment**

A range of factors may be considered to adjust the measure to improve comparability between councils. Some example are:

- The intensity of the caring role

- Age of carer
- Characteristics of the cared-for person

## Formula

$$\left(\frac{X}{Y}\right) * 100$$

Where:

**X:** Each respondent is assigned a score based on their answers to the seven questions above. Each of the questions has four answers which are equated with having no unmet needs in a specific life area or domain, having some needs met and having no needs met.

- No needs met (the last answer option for each question) = 0
- Some needs met (2nd answer option) = 1
- No unmet needs (1st answer option) = 2

The numerator is then a sum of the scores for all respondents who have answered all the seven questions.

**Y:** The number of respondents who answered all the seven questions.

## Exclusions

Any respondents who failed to answer any of the seven questions above are excluded from the calculation of the indicator. For example, a respondent who answered six of the questions but did not answer any one will be excluded from the indicator calculation.

## Worked example

The table below represents the responses of 105 carers who answered all seven questions.

|                           | No unmet needs | Some needs met | No needs met | Total |
|---------------------------|----------------|----------------|--------------|-------|
| Occupation                | 45             | 45             | 15           | 105   |
| Time and Space            | 65             | 35             | 5            | 105   |
| Control                   | 33             | 52             | 20           | 105   |
| Personal Care             | 65             | 38             | 2            | 105   |
| Safety                    | 85             | 20             | 0            | 105   |
| Social Participation      | 58             | 35             | 12           | 105   |
| Encouragement and Support | 22             | 36             | 47           | 105   |
| Total                     | 373            | 261            | 101          |       |

The numerator for the indicator is  $[(373*2) + (261*1) + (101*0)] = 1,007$

The denominator for the indicator is 105.

Therefore the indicator value is  $1007/105$  which equals 9.6.

## Disaggregation available

### Client groups:

### Frequency of collection

### Return format

### Data source

### Decimal places

### Longer-term development options

**Equalities:** Age, Gender, Ethnicity, Religion, Sexual orientation

Carers

Biennial

Numeric

Carers Survey

**One**

The Carers Survey is subject to review in 2012/13 to look at the potential for reducing length and burden, and the final version will be subject to agreement by ADASS and other stakeholders for collection in 2012/13. There is potential for moving to annual collection if burden can be reduced significantly, subject to the agreement of local government.

We will also look to develop a 'value-added' measure which quantifies the contribution of social services to carers' quality of life, as we will for people

using services.

**Further guidance**

Guidance for 2012/13 onwards can be found via the generic user survey guidance page online.

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**(3B) Overall satisfaction of carers with social services**

**Domain / Outcome**

3. Ensuring people have a positive experience of care and support.  
*People who use social care and their carers are satisfied with their experience of care and support services.*  
*(Overarching measure)*

**Rationale**

This measures the satisfaction with services of carers of people using adult social care, which is directly linked to a positive experience of care and support. Analysis of user surveys suggests that this question is a good predictor of the overall experience of services and quality.

**Definition / Interpretation**

This measure is deferred in 2012/13 and will be published for the first time using 2012/13 data.

The relevant question drawn from the Carers Survey is question 7: "Overall, how satisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?", to which the following answers are possible:

- 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

The measure is defined by determining the percentage of all those responding who identify strong satisfaction – i.e. by choosing the answer "I am extremely satisfied" or the answer "I am very satisfied".

Note that this is the question number and wording for the 2009/10 survey and may change for 2012/13 pending review and rationalisation of the Carers Survey during 2012/13.

**Risk adjustment**

While this question asks directly about services, it is potentially subject to influence of exogenous factors. For example a previous study of home care users suggested that better perceptions of home care were related to amongst other things receiving less than 10 hours home care (a proxy for need) and receiving help from others. Further analysis will be required to explore this and establish whether risk adjustment should be applied.

**Formula**

$$\left( \frac{X}{Y} \right)$$

Where:

X: In response to the question above, those individuals who selected the response "I am extremely satisfied" or "I am very satisfied".

Y: All those that responded to the question.

**Exclusions**

People who select the response "We haven't received any support or services from Social Services in the last 12 months" will not be counted in either the numerator or the denominator

**Worked**

The number of carers who said "I am extremely satisfied" or "I am very

|  |  |
|--|--|
| <b>example</b>                         | satisfied" was 112.<br>In total the number of carers who responded to the question was 160 but 7 gave a response of "We haven't received any support or services from Social Services in the last 12 months".<br>The indicator value is $[(112/(160-7))*100] = 73.2\%$ |
| <b>Disaggregation available</b>        | <b>Equalities:</b> Age, Gender, Ethnicity, Religion, Sexual orientation  |
| <b>Client groups:</b>                  | Carers   |
| <b>Frequency of collection</b>         | Biennial (to be first conducted in 2012/13)  |
| <b>Return format</b>                   | Percentage   |
| <b>Data source</b>                     | Carers Survey  |
| <b>Decimal places</b>                  | One  |
| <b>Longer-term development options</b> | The Carers Survey will be reviewed to look at potential for reducing length and burden. There is potential for moving to annual collection if burden can be reduced significantly, subject to agreement.   |
| <b>Further guidance</b>                | Guidance for 2012/13 onwards can be found via the generic user survey guidance page online.  |

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**(3C) The proportion of carers who report that they have been included or consulted in discussion about the person they care for**

|                                    |  |
|------------------------------------|--|
| <b>Domain / Outcome</b>            | 3. Ensuring people have a positive experience of care and support.<br>Carers feel that they are respected as equal partners throughout the care process.   |
| <b>Rationale</b>                   | Carers should be respected as equal partners in service design for those individuals for whom they care – this improves outcomes both for the cared for person and the carer, reducing the chance of breakdown in care. This measure reflects the experience of carers in how they have been consulted by both the NHS and social care.  |
| <b>Definition / Interpretation</b> | This measure is deferred in 2012/13 and will be published for the first time using 2012/13 data.<br>The relevant question drawn from the Carers Survey is Q37: "In the last 12 months, do you feel you have been involved or consulted as much as you want to be, in discussion about the support or services provided to the person you care for?", to which the following answers are possible: <ul style="list-style-type: none"> <li>• There have been no discussion that I am aware of, in the last 12 months</li> <li>• I always felt involved or consulted</li> <li>• I usually felt involved or consulted</li> <li>• I sometimes felt involved or consulted</li> <li>• I never felt involved or consulted</li> </ul> Note that this is the question number and wording for the 2009/10 survey and may change for 2012/13 pending review and rationalisation of the Carers Survey during 2012/13.<br>The measure is defined by determining the percentage of all those responding who choose the answer "I always felt involved or consulted" and "I usually felt involved or consulted". |
| <b>Risk adjustment</b>             | None   |
| <b>Formula</b>                     |  |

$$\left(\frac{X}{Y}\right) * 100$$

Where:

X: In response to the above question, all those individuals who selected the response "I always felt involved or consulted" and "I usually felt involved or consulted".

Y: All those that responded to the question.

Further consideration will be given to what responses should be included in the numerator of this measure and confirmed before 2012/13 when this measure comes into operation.

**Exclusions**

People who select the response "There have been no discussions that I am aware of, in the last 12 months" will not be counted in either the numerator or the denominator.

**Worked example**

The number of carers who said "I always felt involved or consulted" (and "I usually felt involved or consulted") was 129.

In total the number of carers who responded to the question was 160 with 7 giving a response of "There have been no discussion that I am aware of, in the last 12 months".

The indicator value is  $[(129/(160-7))*100] = 84.3\%$

**Disaggregation available**

**Equalities:** Age, Gender, Ethnicity, Religion, Sexual orientation

**Client groups:**

Carers

**Frequency of collection**

Biennial (to be first conducted in 2012/13)

**Return format**

Percentage

**Data source**

Carers Survey

**Decimal places**

One

**Longer-term development options**

The Carers Survey will be reviewed to look at potential for reducing length and burden. There is potential for moving to annual collection if burden can be reduced significantly, subject to agreement.

**Further guidance**

Guidance for 2012/13 onwards can be found via the generic user survey guidance page online.

**(3D) The proportion of people who use services and carers who find it easy to find information about services**

**Domain / Outcome**

3. Ensuring people have a positive experience of care and support.

People know what choices are available to them locally, what they are entitled to, and who to contact when they need help.

**Rationale**

This measure reflects social services users' and carers' experience of access to information and advice about social care in the past year. Information is a core universal service, and a key factor in early intervention and reducing dependency.

Improved and/or more information benefits carers and the people they support by helping them to have greater choice and control over their lives. This may help to sustain caring relationships through for example, reduction in stress, improved welfare and physical health improvements. These benefits accrue only where information is accessed that would not otherwise have been accessed, or in those cases where the same information is obtained more easily.

**Definition / Interpretation**

This measure is part deferred in 2012/13 and will be published for the first time in full in 2012/13.

This measure is comprised of a combination of questions in the Adult Social Care Survey and Carers Survey.

The question from the Adult Social Care Survey is Question 12: "In the past

year, have you generally found it easy or difficult to find information and advice about support, services or benefits?”, to which the following answers are possible:

- Very easy to find
- Fairly easy to find
- Fairly difficult to find
- Very difficult to find
- I’ve never tried to find information or advice

This portion of the measure is defined by determining the percentage of all those responding who select the response “Very easy to find” and “fairly easy to find”.

The relevant question drawn from the Carers Survey is Question 31: “In the last 12 months, have you found it easy or difficult to find information and advice about support, services or benefits? Please include information and advice from different sources, such as voluntary organisations and private agencies as well as Social Services”. The following answers are possible:

- 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

Note that this is the question number and wording for the 2009/10 survey and may change for 2012/13 pending review and rationalisation of the Carers Survey during 2012/13.

This portion of the measure is defined by determining the average percentage across the two surveys of all those responding who select the response “Very easy to find” and “fairly easy to find”.

The Adult Social Care Survey will be annual whereas the Carers Survey will, at least initially, be biennial. Therefore, in years where only one survey is conducted (including 2012/13) the data from the ASCS will constitute the whole measure. In years where both are conducted (including 2012/13), each part of the measure will be given equal weight, as set out in the “formula” section below.

None

**Risk  
adjustment**

**Formula**

**In 2012/13:**

$$\left(\frac{X}{Y}\right) \times 100$$

Where:

X: In response to Question 12 of the ASCS, those individuals who selected the response “Very easy to find” and “fairly easy to find”.

Those respondents who were sent the version of the questionnaire for people with learning disabilities will be treated in the same way, as this questionnaire has been designed to be equivalent to the non-learning disabilities version.

Y: All those that responded to the question.

For both the numerator (X) and denominator (Y), weighted data should be used to calculate the measure. The data from the survey will be weighted by the NHS Information Centre to take account of the stratified sampling technique that has been used when conducting the survey. The weights are automatically calculated within the survey data return along with the ASCOF outcome measures. Further details of how to use the weights when analysing the survey data are available in Appendix I of the guidance for the 2011-12 Adult Social Care Survey.

**From 2012/13 onwards:**

$$\frac{\left[\left(\frac{X}{Y}\right) \times 100\right] + \left[\left(\frac{A}{B}\right) \times 100\right]}{2}$$

X and Y are as above.

A: The sum of all those who in response to the above question of the Carers Survey, selected the response “Very easy to find” and “fairly easy to find”. In years where the Carers Survey has not been completed (since this is initially a biennial collection), the most recent value for the carers element should be carried over and counted in the second of these parts in the numerator. In these years, only the changes in the service user element (drawn from the ASCS) will be identifiable.

B: The sum of all those that responded to the above question of the Carers Survey.

The overall measures from 2012/13 onwards will therefore be the average of the score on the ASCS and the Carers Survey.

**Exclusions**

People who select the response “I’ve never tried to find information or advice” for the ASCS or “I have not tried to find information or advice in the last 12 months” for the Carers Survey will not be counted in either the numerator or the denominator.

**Worked example**

**For 2012/13 when only data for users is available:**

The number of users who select the responses “Very easy to find” or “fairly easy to find” was 191.

In total the number of users who responded to the question was 350 of whom 8 gave a response of “I’ve never tried to find information or advice”.

(Data weighted to reflect the stratified sampling technique that has been used when conducting the survey)

The indicator value is  $[(191/(350-8)) \times 100] = 55.8\%$

**From 2012/13 Onwards:**

The number of respondents to the Adult Social Care Survey who select the responses “Very easy to find” or “fairly easy to find” was 191.

In total the number of users who responded to the question was 350 of whom 8 gave a response of “I’ve never tried to find information or advice”.

The score for the ASCS is  $[(191/(350-8)) \times 100] = 55.8\%$

(Data weighted to reflect the stratified sampling technique that has been used when conducting the survey)

The number of respondents to the Carers Survey who select the responses “Very easy to find” or “fairly easy to find” was 93.

In total the number of users who responded to the question was 220 of whom 8 gave a response of “I have not tried to find information or advice in the last 12 months”.

The score for the Carers Survey is  $[(93/(220-8)) \times 100] = 43.9\%$

The average of the score for the ASCS and the score for the Carers Survey is  $[(55.8+43.9)/2] = 49.9$

The indicator value is 49.9%.

**Disaggregation available**

**Equalities:** Age, Gender, Ethnicity, Religion, Sexual orientation

|  |  |
|--|--|
| <b>Client groups:</b>                  | Carers   |
| <b>Frequency of collection</b>         | Biennial (to be first conducted in 2012/13)  |
| <b>Return format</b>                   | Percentage   |
| <b>Data source</b>                     | Carers Survey  |
| <b>Decimal places</b>                  | One  |
| <b>Longer-term development options</b> | The Carers Survey will be reviewed to look at potential for reducing length and burden. There is potential for moving to annual collection if burden can be reduced significantly, subject to agreement. |
| <b>Further guidance</b>                | Guidance for 2012/13 onwards can be found via the generic user survey guidance page online.  |

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