

Newcastle Wellbeing Care and Learning: Carers Survey 2014 / 15



**Policy and Communications Team
Assistant Chief Executive's Directorate**

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Introduction

This report summarises the findings from the second 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:

“It is important that the Department of Health understands at the national level how well services are meeting user and carer needs. However, information about services is not intended to be used solely to monitor performance through national outcome measures but should also be used locally to inform service delivery and to monitor and develop standards.

We recognise that surveys are an important means for obtaining this information. We understand that some councils may undertake regular feedback via their agreements with service providers but this survey will give an insight into outcomes for carers and provide a consistent basis for comparing results across different areas.

The 2012-13 survey provided additional information on carers and the services they received. This information forms the baseline for a time series to show whether or not these services have improved carers’ ability to care and live a life outside this 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.

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 introduction of new data collections may have an impact on the way in which the survey can be administered locally. However, it is considered vital to continue the biennial survey so that the impact of the strategy on carers can continue to be measured.

The survey provides five outcome measures in the Adult Social Care Outcomes Framework (ASCOF):

- **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.
- **1L2:** The proportion of carers who reported that they had as much social contact as they would like

The information it provides on Newcastle carers’ views and experiences will be used to help improve services to carers and cared-for people. Running the survey for a second time also allows us to look for changes in carers’ views and experiences since 2012.

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Methodology

The survey questionnaires were sent to a random sample of carers who were assessed or reviewed (either separately or jointly with the cared-for person) by Newcastle Wellbeing Care and Learning in the 12 months prior to the date we selected to draw our sample from. The guidance allowed us to choose any date between 1 June – 30 September 2014 to draw the sample. Ours was drawn **on 9 September 2014**. Based on the previous survey's response rate, we drew a sample of 851 carers from a total "population" of 2018 Newcastle carers who had been assessed or reviewed by Newcastle City Council Wellbeing Care and Learning directorate in this time period. In this year we did not remove any carers from the population due to their being in active dispute with the council. (In this situation it is considered that sending them a questionnaire would not be appropriate and would aggravate the situation.)

Responses and margin of error

Questionnaires were sent out between **27 October – 5 December 2014**. We sent out one reminder on **10 November 2014**, and received 361 questionnaires returned out of 851 sent out, giving a response rate of 42%. This gives a margin of error¹ for the entire survey of +/-2.55 percentage points, given that the total number of service users we drew our random sample from was 2018. This is well 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 2018 carers in Newcastle who were assessed or reviewed during the twelve months prior to the date of extracting the sample (9 September 2014), to within 2.55% percentage points either way. For example, the percentage of people in the survey who feel that they have as much control over their daily lives as they want is 36.93%, so the "true" figure for the population as whole lies between 34.38% - 39.48%.

Equality and diversity

We strove to ensure that everyone was able to participate in the survey, using 14-point Arial font for the questionnaires 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 2014, as in 2012, everyone who took part in the survey did so by returning a

¹ 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.

questionnaire in English. 154 respondents (47% of all who responded) asked that we send them a copy of the results, which will be done as soon as the results have been published.

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 Social Care Direct Team Manager, Stuart Pattinson, 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: **8.4** or **70%** of the maximum possible score. The full tables for these questions (Q7-Q12) can be found in section 3 on p.19-21.

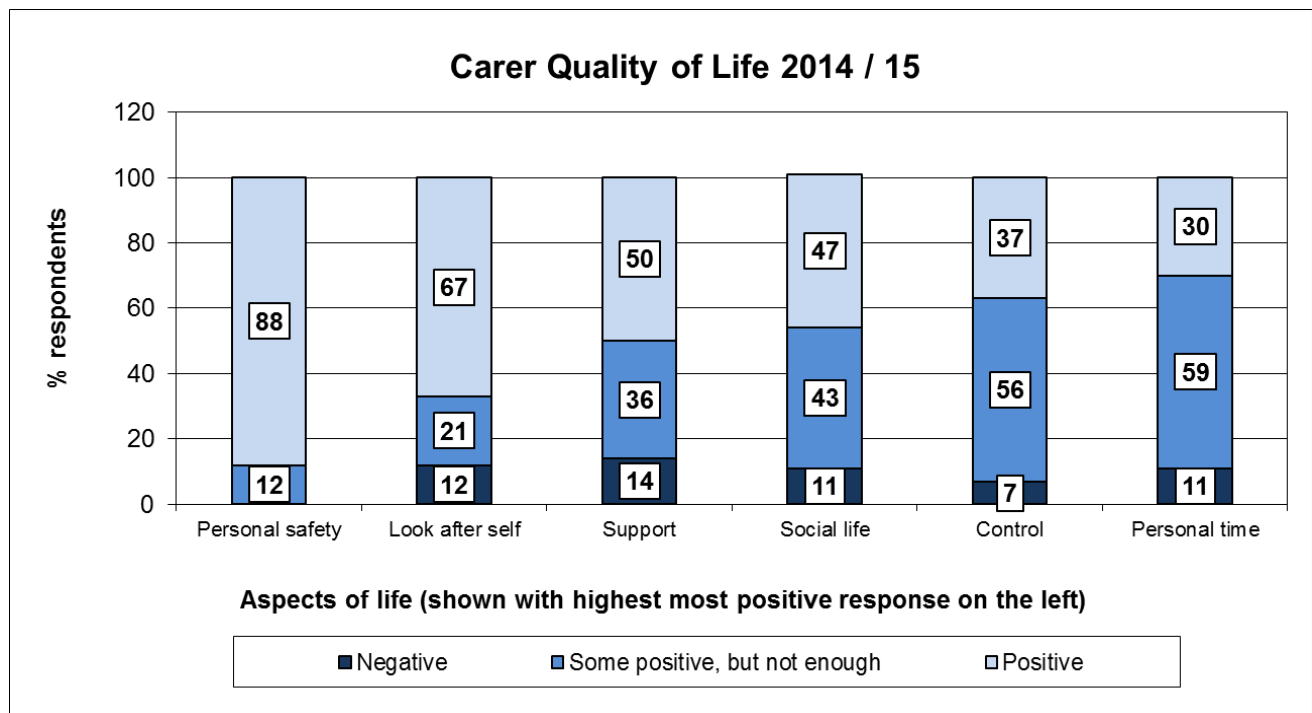
| | No unmet needs | Some needs met | No needs met | Total |
|--|------------------|--------------------|--------------|--------------|
| Occupation (Q7) | 105.0 | 207.0 | 40.0 | 352.0 |
| Control (Q8) | 130.0 | 197.0 | 25.0 | 352.0 |
| Personal Care (Q9) | 234.0 | 74.0 | 41.0 | 349.0 |
| Safety (Q10) | 308.0 | 42.0 | 1.0 | 351.0 |
| Social Participation (Q11) | 166.0 | 150.0 | 37.0 | 353.0 |
| Encouragement and Support (Q12) | 171.0 | 124.0 | 47.0 | 342.0 |
| Total | 1114.0 | 794.0 | 191.0 | |
| Score | 2228.0 | 794.0 | | |
| | Numerator | Denominator | 1D | |
| | 3022.0 | 361.0 | 8.4 | 70.0% |

This is a composite measure. The maximum possible score (calculated in "Max ASCOF") is 12. The percentage in the box shows our score (8.4) 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.

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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; 88% 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 Wellbeing Care and Learning in the last 12 months?”, under half of carers were extremely or very satisfied: **44.5%**. This is a significant decrease from 2012, when this figure was **53.2%**.

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 Wellbeing Care and Learning in the last 12 months. People who said “we have not received any support or services from Newcastle Wellbeing Care and Learning in the last 12 months” have been removed from the calculation.

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: **79.9%**. This is a slight decrease since 2012, when this figure was **80.8%**, but this is not a statistically significant change. (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.)

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: **67.8%**, which is nearly the same as in 2012 (**68.1%**). (Note that this percentage is calculated using the total number of **people who had tried** to find advice or information in the last 12 month, excluding people who had not tried to do this.)

1L2: The proportion of carers who reported that they had as much social contact as they would like

When asked “Thinking about how much social contact you’ve had with people you like, which of the following statements best describes your social situation?”, the percentage of carers who replied “I have as much social contact as I want with people I like” was **47.0%**. This is slightly lower than the figure in 2012, which was **51.9%** (please note that this was not a national indicator in 2012).

Action points

Areas which may require attention are as follows:

- **Overall satisfaction with services used:** There has been a decrease in carers replying that they are very or extremely satisfied overall with care and support services, from 53% in 2012, to 45% in 2014.
- **Carers Emergency Card:** 72% of carers had not heard of the Carers Emergency Card scheme, which is similar to the 2012 survey (70%).
- **Social contact and control over daily life:** As shown in the chart on the previous page:
 - **54%** of carers said they had either some social **contact** with people they like but not enough (43%), or that they had little social contact and felt socially isolated (11%). This is an increase since 2012, when this figure was 49%.
 - **63%** of carers said that either they had some **control** over their daily life but not enough (56%), or that they had no control (7%), as in 2012 (62% said this).
 - **70%** of carers said that they either did some **things they valued** or enjoyed with their time but not enough (59%), or that they did not do anything they valued or enjoyed (11%), as in 2012, when 71% of carers said this.
- **Finding information:** There has been an increase since 2012 in the percentage of carers who have never tried to find information or advice, from 31% to 43%. As in 2012, 32% of carers who had tried to find information said that doing so 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, 16% of carers said that they only sometimes felt involved, or that they never felt involved. However, this is a slight decrease from 2012.
- **Do services work well together?** Slightly more than half of carers said that different public services only sometimes worked well together to support and improve their health and wellbeing, or never worked well together (52%).

Changes since 2012

The results in 2014 have been very similar to those for 2012. Areas where there have been changes are as follows:

- **ASCOF 3(B) Overall satisfaction with services used:** There has been a decrease in carers replying that they are very or extremely satisfied overall with care and support services, from 53% in 2012, to 45% in 2014. This is further explored in Appendix 3 (provided separately).
- **Where the cared-for person lives:** In 2012, just over half of carers said their cared-for person lives with them (55%). In 2014, 45% of cared-for people lived with their carers.
- **Social contact with others:** There has been an increase since 2012 in the percentage of carers who said they had some social contact with people, but not enough, or that they had little social contact and felt socially isolated, from 47% to 51%.
- **Direct payments / personal budgets:** Unlike in 2012, just over half of the carers in the survey were receiving a direct payment (52%). It is possible that that many carers in 2012 were receiving a Direct Payment, but were not certain that this was what the money they were receiving was called, and this may account for the difference between the two years.
- **Time spent each week caring:** The largest single percentage of carers said that they were caring for 100 or more hours a week (23%), with many commenting that they care “24/7”. This is a change from 2012, when the largest single percentage of carers said that they were caring for 75-99 hours per week.
- **Services received:** 60% of carers in the survey had received a service in the past twelve months, which is higher than in the 2012 survey (48%).
- **Information received:** 17% of carers in the survey had received information **only** in the past twelve months (which was funded by the local authority), which is higher than in the 2012 survey (one person).

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.11 A full list of the questions asked can be found in Appendix 1 on p.39, and comments analysis can be found in Appendix 2 (provided separately).

1. About the person you care for

- **Primary client group:** As in 2012, the majority of carers in the survey were caring for someone whose primary support reason was “physical support” (57%).
- **Age of cared-for people:** As in 2012, the majority of people being cared for were aged 75 or over (66%), with 39% being aged 85 or over.
- **Needs of cared-for people:** When carers were asked what conditions the person they cared for had, as in 2012, the most common replies were “problems connected to aging” (50%) followed by “a physical disability” (49% of carers said this).
- **Personal budgets / direct payments:** Slightly over half of carers in the survey were caring for someone who receives a direct payment managed by the local authority (55%).

- **SALT eligibility as long-term supported client:** 78% of people cared for by the carers in the survey were eligible for inclusion in SALT as long-term supported clients.
- **SALT eligibility and in receipt of personal budget or direct payment:** 60% of people cared for by the carers in the survey were eligible for inclusion in SALT, and in receipt of a personal budget or direct payment.
- **Self-funder:** 12% of people cared for by the carers in the survey were self-funding.
- **Where cared-for people live:** In contrast to the previous survey, over half of carers in the survey replied that the person they cared for did not live in their household (55%). In 2012, 45% of cared-for people did not live with their carer.
- **Services used:** The two services used most by the people the carers looked after were “home equipment or adaptation” (55%) or “home care or home help” (43%).

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 (45%); a further 38% were quite satisfied. 12% were neither satisfied nor dissatisfied, and 6% were quite, very or extremely dissatisfied. This is a decrease from 2012, when 53% of carers were extremely or very satisfied overall with the social care and support services used either by themselves or the person they care for.
- **Care and support services used by the carer:** The single largest percentage of respondents had used information and advice to help them in their caring role (39%); 22% had used support from a carers’ group or someone to talk to in confidence. These were the most commonly used support services used by carers in 2012.
- **Carer’s emergency card:** As in 2012, the majority of people (72%) in the survey had not heard of this scheme.

3. The impact of caring and your quality of life

- **Spending time – work and leisure:** As in 2012, the majority of carers said they did some of the things they wanted to do with their time, but not enough (59%).
- **Control over daily life:** As in 2012, just over half of carers said that they had some control over their daily lives, but not enough (56%).
- **Looking after yourself:** As in 2012, the majority of carers said they were able to look after themselves, for example getting enough sleep or eating well (67%).
- **Safety:** As in 2012, over three-quarters of carers said they had no worries about their personal safety (88%).
- **Social contact:** Just under half of carers replied that they had as much social contact as they wanted with people they liked (47%).
- **Encouragement and support:** Just over half of carers replied that they felt they had encouragement and support in their caring role (50%).

4. Information and advice quality

- **Finding information and advice:** As in 2012, the majority of carers who had tried to find information or advice said that it was very or quite easy to find (68%).
 - 43% had never tried to find information or advice. This is higher than in 2012, when this percentage was 31%.
- **Helpfulness of information and advice:** Nearly all carers who had received information or advice said that it was very or quite helpful (89%). This is a five percentage point decrease since 2012. (43% had not received any information or advice in the last 12 months.)
- **Complaints:** The majority of carers said that they knew how to make a complaint about care services and felt that they could do so if they wanted to (67%).

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” (80%). 19% of all carers in the survey said that there had been no such discussions that they were aware of in the last 12 months.
- **Do services work well together?** This is a new question in 2014. Less than half of carers said that different public services worked well together to support and improve their health and wellbeing (48%).

About the carers

We compared the age and gender profile of carers who took part in the survey to the “population” of the 2018 carers from whom we drew our random sample. The percentages 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 65-74 age bracket were slightly over-represented in the survey.

- **Employment:** As in 2012, just over half of carers in the survey were retired (55%).
- **Education:** Only ten carers were in part- or full- time education.
- **Supported in employment:** As in 2012, the largest single percentage of carers said that they were self-employed or retired (38%). Of those who were not, 31% said they felt supported by their employer, and 25% said they were not in paid employment due to their caring responsibilities.
- **Length of time being a carer:** As in 2012, the largest percentage of carers had been caring for more than a year, but less than 10 years (64%). 15% 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 100 or more hours a week (23%), with many commenting that they care “24/7”. This is a change from 2012, when the largest single percentage of carers said that they were caring for 75-99 hours per week.

- **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 keeping an eye on the person to check that they are alright (86%).
- **Taking part in the survey:** As in 2012, the majority of carers completed the questionnaire without help from anyone else (92%).
- **Original or reminder:** 80% of the respondents responded to the original questionnaire.
- **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 15% had a physical impairment or disability.
- **Gender:** As in 2012, the majority (68%) of carers in the survey were female, in line with the gender balance in the total population of carers.
- **Age:** As in 2012, the largest single percentage of carers were aged between 55-64 (31%). Nearly half were aged 65 and over (45%). People aged 65-74 were slightly over represented in the survey; 27% of respondents were in this age group, compared to 19% in the total population of carers.
- **Religion:** 75% of carers whose religion is known described themselves as Christian.
- **Ethnicity:** As in 2012, nearly all (96%) of carers were from a White ethnic background.
- **Direct payments / personal budgets:** Unlike 2012, just over half of the carers in the survey said that they were receiving a direct payment (52%), which is in line with the total population of carers (52% of whom receive a direct payment). It is possible that a significant number of carers in 2012 were receiving a Direct Payment, but were not certain that this was what the money they were receiving was called. This may account for the difference between the two years.
- **What Direct Payments are used for:** The largest single percentage of carers who received a Direct Payment used it to buy things that made it easier for them to care, such as paying for travel (44%). The next most common answer was “domestic help or household goods” (23%).
- **Assessments:** 93% of carers had been assessed jointly with the person they care for, in line with the total population of carers. This has not changed since 2012.
- **Services received:** 60% of carers had received a service in the last twelve months which was funded by the local authority, which is higher than the percentage in 2012, and slightly more than the total population (55%).
- **Information received:** 17% had received information **only** within the last twelve months (which was funded by the local authority), which is line with the total population of carers (17%), and an increase from 0% (one person) in 2012.
- **Preferred format for receiving information:** Nearly all carers (96%) were happy to receive information from Newcastle City Council in standard print.

Frequency tables

Section 1: About the person you care for

Primary support reason of the cared-for person

| Primary support reason of the cared-for person | Frequency | Valid | | % in sample |
|--|------------|------------|------------|-------------|
| | | percent % | 2012* % | |
| Physical support | 450 | 57 | 64 | 57 |
| Support for memory and cognition | 130 | 17 | - | 17 |
| Learning disability support | 84 | 11 | 13 | 11 |
| Mental health support | 58 | 7 | 22 | 7 |
| Social support | 51 | 7 | 1 | 7 |
| Sensory support | 11 | 1 | - | 1 |
| Total | 784 | 100 | 100 | 100 |
| <i>Missing</i> | 67 | - | - | - |
| Total | 851 | - | - | - |

In 2014, the reporting system for statistics about cared-for people and carers changed from RAP (Referrals, Access and Packages of care) to SALT (Short And Long Term support). This meant that people are no longer classified by "Primary Client Group" but by "Primary Support Reason".

The figures for 2014 and 2012 cannot therefore be directly compared, and those in the 2012 column are for the closest primary client group to the primary support reason in question, as follows:

Physical Support = Physical Disability, frailty or sensory impairment – note that under the SALT reporting system, "Sensory Support" is a separate category.

Mental Health Support = Mental health – note that in previous years, this included people with dementia or similar conditions

Learning Disability Support = learning disability.

Social Support = Vulnerable people

The majority of carers in the survey were caring for someone whose primary support reason was 'physical support' (57%). As shown above, the percentages of people in the survey caring for adults with the primary support reasons shown was proportionate to the percentages for each group of people with primary support reasons in the sample.

Personal Budgets / Direct Payments in last 12 months – Cared-for person

| Cared-for person received personal budgets or direct payments in the 12 months prior to extracting the survey sample? | Frequency | Valid percent % | 2012 % | % in sample |
|---|------------|-----------------|------------|-------------|
| Yes | 200 | 55 | 57 | 52 |
| No | 161 | 45 | 44 | 48 |
| Total | 361 | 100 | 100 | 100 |

As in 2012, slightly over half of carers in the survey were caring for someone who receives a direct payment managed by the local authority (55%).

Eligible for inclusion in SALT as long-term supported client – Cared-for person

| Cared-for person is eligible for inclusion in SALT as long-term supported client? | Frequency | Valid percent % | % in sample |
|---|------------|-----------------|-------------|
| Yes | 281 | 78 | 75 |
| No | 80 | 22 | 25 |
| Total | 361 | 100 | 100 |

The majority of cared-for people whom carers in the survey were looking after were eligible for inclusion in SALT as long-term supported clients (78%).

Eligible for inclusion in SALT, and in receipt of a personal budget or direct payment – Cared-for person

| Cared-for person is SALT eligible and in receipt of on-going personal budget or direct payment | Frequency | Valid percent % | % in sample |
|--|------------|-----------------|-------------|
| Yes | 281 | 60 | 55 |
| No | 143 | 40 | 45 |
| Total | 361 | 100 | 100 |

The majority of cared-for people whom carers in the survey were looking after were eligible for inclusion in SALT, and in receipt of a personal budget or direct payment (60%).

Self-funder – Cared-for person

| Cared-for person is a self-funder? | Frequency | Valid percent % | % in sample |
|------------------------------------|------------|-----------------|-------------|
| Yes | 44 | 12 | 11 |
| No | 317 | 88 | 89 |
| Total | 361 | 100 | 100 |

The majority of cared-for people were **not** self-funders (88%).

Q1. How old is the person you care for?

| Q1 Age of cared-for person | Frequency | Valid percent % | 2012 % | change 2012 / 2014 % |
|----------------------------|------------|-----------------|------------|----------------------|
| 18-24 | 14 | 4 | 4 | 0 |
| 25-34 | 13 | 4 | 5 | -1 |
| 35-44 | 11 | 3 | 4 | -1 |
| 45-54 | 22 | 6 | 6 | 0 |
| 55-64 | 21 | 6 | 8 | -2 |
| 65-74 | 39 | 11 | 10 | +1 |
| 75-84 | 94 | 27 | 30 | -3 |
| 85 or over | 138 | 39 | 33 | +6 |
| Total | 352 | 100 | 100 | - |
| <i>Missing</i> | 9 | - | - | - |
| Total | 361 | - | - | - |

The majority of people being cared for were aged 75 or over (66%).

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

| Q2 Cared-for person – client group | Frequency | Valid percent* % | 2012 % | Difference 2012 - 2014 |
|-------------------------------------|------------|------------------|----------|------------------------|
| Problems connected to aging | 181 | 50 | 43 | +7 |
| A physical disability | 174 | 49 | 48 | +1 |
| Dementia | 143 | 40 | 29 | +11 |
| Sight or hearing loss | 138 | 38 | 31 | +7 |
| Long-standing illness | 121 | 34 | 33 | +1 |
| A mental health problem | 60 | 17 | 16 | +1 |
| A learning disability or difficulty | 57 | 16 | 2 | +14 |
| Terminal illness | 19 | 5 | 4 | +1 |
| Alcohol or drug dependency | 2 | 1 | 2 | -1 |
| Total* | 359 | - | - | - |
| <i>Missing</i> | 2 | | | |
| Total | 361 | | | |

* Respondents could choose as many options as they liked, so percentages total more than 100%.

The most common response to this question was “Problems connected to aging” (50%), followed by “a physical disability” (49%).

Q2b. Does the person you care for have Asperger’s Syndrome or autism?

| Q2b Cared-for person – Asperger’s syndrome or autism | Frequency | Valid percent % | 2012 % | Change 2012 / 2014 |
|--|------------|-----------------|------------|--------------------|
| Yes | 13 | 4 | 2 | +2 |
| No | 337 | 96 | 98 | -2 |
| Total | 350 | 100 | 100 | - |
| <i>Missing</i> | 11 | | | |
| Total | 61 | | | |

Only 4% of respondents were caring for someone with Asperger’s syndrome or autism.

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

| Q3 Where does the person you care for usually live? | Frequency | Valid percent % | 2012 % | Change 2012 / 2014 |
|---|------------|-----------------|------------|--------------------|
| With me | 161 | 45 | 55 | -10 |
| Somewhere else | 196 | 55 | 45 | +10 |
| Total | 357 | 100 | 100 | - |
| <i>Missing</i> | 4 | | | |
| Total | 361 | | | |

Over half of carers in the survey replied that the person they cared for lived somewhere else (55%), an increase of 10 percentage points.

PTO

Q4. Overall, how satisfied or dissatisfied are you with the support or services you and the person you care for have received from Newcastle Wellbeing Care and Learning 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% | 2012 % | Change 2012 / 2014 |
|--|------------|-----------------|---|------------|--------------------|
| We haven't received any support or services from Newcastle Wellbeing Care and Learning in the last 12 months | 95 | 27 | - | 14 | +13 |
| I am extremely satisfied | 45 | 13 | 18 | 20 | -7 |
| I am very satisfied | 67 | 19 | 27 | 28 | -9 |
| I am quite satisfied | 95 | 27 | 38 | 27 | - |
| I am neither satisfied nor dissatisfied | 30 | 9 | 12 | 8 | +1 |
| I am quite dissatisfied | 5 | 1 | 2 | 3 | -2 |
| I am very dissatisfied | 6 | 2 | 2 | 1 | +1 |
| I am extremely dissatisfied | 4 | 1 | 2 | 1 | - |
| Total | 347 | 100 | 100 | 100 | - |
| <i>Missing</i> | 14 | - | - | - | - |
| Total | 361 | - | - | - | - |

When people who said “we have not received any support or services from Newcastle Wellbeing Care and Learning in the last 12 months” are removed from the calculation, we see that **just under half of carers were extremely or very satisfied (45%)**. (This is the figure used to calculate ASCOF indicator 3b.) A further 38% were quite satisfied, 12% were neither satisfied nor dissatisfied, and 6% were quite, very or extremely dissatisfied).

This is a decrease of -8 percentage points for the ASCOF 3b indicator since the 2012/3 Carers Survey, when this figure (extremely or very satisfied overall) was 53%.

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 Wellbeing Care and Learning.

| Q5 Usage of support or services | % Yes | % No | % Don't know | % did not choose this option | 2012 Yes % |
|--|------------|------|--------------|------------------------------|------------|
| Equipment or adaptation to their home (such as a wheelchair or handrails) | 55 | 32 | 0 | 13 | 59 |
| Home care / home help | 43 | 41 | 0 | 16 | 42 |
| Lifeline alarm / Telecare | 42 | 42 | 1 | 16 | 34 |
| Day centre or day activities | 24 | 56 | 1 | 19 | 29 |
| They are permanently resident in a care home | 19 | 62 | 1 | 18 | 16 |
| Support or services allowing you to take a break from caring for more than 24 hours | 17 | 68 | 1 | 14 | 20 |
| Support or services to allow you to have a rest from caring for between 1 and 24 hours (such as a sitting service) | 17 | 67 | 1 | 15 | 16 |
| Support or services allowing you to take a break from caring at short notice or in an emergency. | 12 | 73 | 2 | 13 | 15 |
| Personal assistant | 12 | 63 | 1 | 24 | 13 |
| Meals services | 6 | 69 | 1 | 25 | 5 |
| Lunch club | 5 | 71 | 0 | 24 | 5 |
| Other** | 11 | 57 | 5 | 27 | - |
| Total no. of people who answered the question | 352 | - | - | - | - |
| <i>Missing</i> | 9 | - | - | - | - |
| Total | 361 | - | - | - | - |

* Respondents could choose as many options as they liked, so percentages total more than 100%.

** This was not an option in the 2012 survey.

The most common response to this question was “Equipment or an adaptation to their home” (55%), followed by “Home care / home help” (43%). These were also the most common options chosen in 2012. The most common options among people who replied “other” were:

- Sheltered accommodation **2%** (8 people)
- Support from health care staff **2%** (6 people)
- Support from voluntary organisations **2%** (6 people)
- Support for socialising and life skills **1%** (5 people)

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 Wellbeing Care and Learning. 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 | 2012 Yes % |
|--|------------|------|--------------|---------------------------|------------|
| Information and advice | 39 | 55 | 4 | 3 | 47 |
| Support from carers groups or someone to talk to in confidence | 22 | 72 | 1 | 6 | 25 |
| Training for carers | 2 | 88 | 1 | 9 | 4 |
| Support to keep you in employment | 4 | 84 | 1 | 12 | 4 |
| Total no. of people who answered the question | 344 | - | - | - | 424 |
| <i>Missing</i> | 17 | - | - | - | 21 |
| Total | 361 | - | - | - | 445 |

* Respondents could choose as many options as they liked, so percentages total more than 100%.

As in 2012, the largest single percentage of carers had used information and advice to help them in their caring role: 39%, compared to 47% in 2012.

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

This is a scheme run by Newcastle City Council and the British Red Cross where carers can register their details, and can ring the Red Cross in an emergency and ask them to call up an emergency plan which helps assist the cared-for person.

| Q6e Aware of Carers' Emergency Scheme? | Frequency | Valid percent % | 2012 % |
|---|------------|-----------------|------------|
| No, I am not aware of this | 250 | 72 | 70 |
| I am aware of this but I do not have a Carer's Emergency Card | 34 | 10 | 16 |
| Yes, I am aware of this and I have a Carer's Emergency Card | 42 | 12 | 9 |
| Don't know / not sure | 22 | 6 | 4 |
| Total | 348 | 100 | 100 |
| <i>Missing</i> | 13 | | |
| Total | 361 | | |

As in 2012, the majority of carers were not aware of the Carers Emergency Card scheme: 72%, compared to 70% in 2012.

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.

| Q7 Leisure time | Frequency | Valid percent % | 2012 % | Change 2012 / 2014 |
|--|------------|-----------------|------------|--------------------|
| I'm able to spend my time as I want, doing things I value or enjoy | 105 | 30 | 30 | 0 |
| I do some of the things I value or enjoy with my time but not enough | 207 | 59 | 60 | -1 |
| I don't do anything I value or enjoy with my time | 40 | 11 | 11 | 0 |
| Total | 352 | 100 | 100 | - |
| <i>Missing</i> | 9 | | | |
| Total | 361 | | | |

The majority of carers said they did some of the things they wanted to do with their time, but not enough (59%). There has been no significant change in the responses to this question since the previous survey.

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

| Q8 Control over daily life | Frequency | Valid percent % | 2012 % | Change 2012 / 2014 |
|---|------------|-----------------|------------|--------------------|
| I have as much control over my daily life as I want | 130 | 37 | 39 | -2 |
| I have some control over my daily life but not enough | 197 | 56 | 54 | +2 |
| I have no control over my daily life | 25 | 7 | 8 | -1 |
| Total | 352 | 100 | 100 | - |
| <i>Missing</i> | 9 | | - | |
| Total | 361 | | - | |

Just over half of carers said that they had some control over their daily lives, but not enough (56%). There has been no significant change in the responses to this question since the previous survey.

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?

| Q9 Looking after yourself | Frequency | Valid percent % | 2012 % | Change 2012 / 2014 |
|---|------------|-----------------|------------|--------------------|
| I look after myself | 234 | 67 | 66 | +1 |
| Sometimes I can't look after myself well enough | 74 | 21 | 22 | -1 |
| I feel I am neglecting myself | 41 | 12 | 13 | -1 |
| Total | 349 | 100 | 100 | - |
| <i>Missing</i> | 12 | | - | |
| Total | 361 | | | |

The majority of carers said they were able to look after themselves, for example getting enough sleep or eating well (67%), and this has not significantly changed since 2012 (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.

| Q10 Personal safety | Frequency | Valid percent % | 2012 % | Change 2012 / 2014 |
|---|------------|-----------------|------------|--------------------|
| I have no worries about my personal safety | 308 | 88 | 86 | +2 |
| I have some worries about my personal safety | 42 | 12 | 13 | -1 |
| I am extremely worried about my personal safety | 1 | 0 | 1 | -1 |
| Total | 351 | 100 | 100 | - |
| <i>Missing</i> | 10 | | | |
| Total | 361 | | | |

Over three-quarters of carers said they had no worries about their personal safety (88%), and this has not significantly changed since the previous year, when it was 86%. The person 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 survey².

² 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

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

| Q11 Social contact | Frequency | Valid percent % | 2012 % | Change 2012 / 2014 |
|---|------------|-----------------|------------|--------------------|
| I have as much social contact as I want with people I like | 166 | 47 | 52 | -4 |
| I have some social contact with people, but not enough | 150 | 43 | 39 | +4 |
| I have little social contact with people and feel socially isolated | 37 | 11 | 10 | +1 |
| Total | 353 | 100 | 100 | - |
| <i>Missing</i> | 8 | | | |
| Total | 361 | | | |

Just under half of carers replied that they had as much social contact as they wanted with people they liked (47%), which is a slight decrease since 2012 (52%).

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

| Q12 Encouragement and support | Frequency | Valid percent % | 2012 % | Change 2012 / 2014 |
|---|------------|-----------------|------------|--------------------|
| I feel I have encouragement and support | 171 | 50 | 53 | -3 |
| I feel I have some encouragement and support but not enough | 124 | 36 | 37 | -1 |
| I feel I have no encouragement and support | 47 | 14 | 10 | +4 |
| Total | 342 | 100 | 100 | - |
| <i>Missing</i> | 19 | | | |
| Total | 361 | | | |

Half of all carers replied that they felt they had encouragement and support in their caring role (50%), which is a slight decline since 2012 (53%).

about your personal safety (Question 10), then we will use this code to identify you so that someone from Newcastle Wellbeing Care and Learning (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."

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 Wellbeing Care and Learning.

| Q13 Ease of obtaining information | Frequency | Valid percent % | Valid percent: people who had tried to find information in last 12 months% | 2012 Valid percent % | Change 2012 / 2014 |
|---|------------|-----------------|--|------------------------|--------------------|
| <i>I've never tried to find information or advice</i> | 150 | 43 | - | 31% of all respondents | +12 |
| Very easy to find | 36 | 10 | 18 | 18 | 0 |
| Quite easy to find | 99 | 28 | 50 | 50 | 0 |
| Quite difficult to find | 48 | 14 | 24 | 24 | 0 |
| Very difficult to find | 16 | 5 | 8 | 7 | +1 |
| Total | 349 | 100 | 100 | 100 | - |
| <i>Missing</i> | 12 | - | - | - | - |
| Total | 361 | - | - | - | - |

Under half of *all* carers said that information or advice was very or quite easy to find (38%). Nearly half (43%) had never tried to find it.

When percentages are 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, the total for people finding it very or quite easy is **68%**, which is the same as in 2012. This is the figure being used to report the ASCOF indicator 3d. Several people commented on whether it was easy to find information, and a full analysis of their comments can be found in Appendix 2 (provided separately). Comments included:

“As the person I care for was already in a residential home. I was informed rather abruptly that I had to find a nursing home for him. His physical health failed him and he needed more care. I found it difficult to juggle my work while searching for an alternative. However, things worked out quite satisfactorily in the end.”

“I feel as though we have had to learn as we go, there is no set program for benefits or support.”

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 Wellbeing Care and Learning.

| Q14 Helpfulness of information and advice | Frequency | Valid percent % | Valid percent: people who had received information in last 12 months % | 2012 Valid percent % | Change 2012 / 2014 |
|---|------------|-----------------|--|----------------------|--------------------|
| I have not received any information or advice in the last 12 months | 150 | 43 | - | - | - |
| Very helpful | 72 | 21 | 36 | 45 | -9 |
| Quite helpful | 105 | 30 | 53 | 49 | +4 |
| Quite unhelpful | 18 | 5 | 9 | 4 | +5 |
| Very unhelpful | 5 | 1 | 3 | 1 | +2 |
| Total | 350 | 100 | 100 | <i>100</i> | <i>-*</i> |
| <i>Missing</i> | <i>11</i> | <i>-</i> | <i>-</i> | <i>-</i> | <i>-</i> |
| Total | 361 | <i>-</i> | <i>-</i> | <i>-</i> | <i>-</i> |

Over three-quarters of carers who had received information or advice in the last 12 months said that it was very or quite helpful (89%), which is a five percentage point decrease since 2012. Over a third of all carers in the survey (43%) had not received any information or advice.

We also asked if carers had any comments about this, and a full analysis of their view can be found in Appendix 2 (provided separately). Comments included the following:

“It is difficult to obtain information if you don't know what information or advice you need! Organisations could be more proactive. An information sheet in plain language would be very useful to give to people, with contact numbers, names, etc.”

“It is a case of learn as you go. There are no home or phone checks to see if all is well. So if we are not calling the service, the service never calls us.”

“I have found my social worker very informative, and helpful, if she does not know the advice she seeks it for me.”

“I have no idea how the system operates.”

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?

| Q15 Being involved and consulted | Frequency | Valid percent % | Valid percent: people whose cared-for person had had discussions about care and support services in last 12 months % | 2012 % | Change 2012 / 2014 |
|---|------------|-----------------|--|------------|--------------------|
| There have been no discussions that I am aware of in the last 12 months | 66 | 19 | - | - | - |
| I always felt involved or consulted | 125 | 37 | 46 | 51 | -6 |
| I usually felt involved or consulted | 94 | 28 | 34 | 30 | +4 |
| I sometimes felt involved or consulted | 49 | 14 | 18 | 15 | +3 |
| I never felt involved or consulted | 7 | 2 | 3 | 4 | -1 |
| Total | 341 | 100 | 100 | 100 | - |
| <i>Missing</i> | 20 | | - | - | - |
| Total | 361 | | - | - | - |

Nearly two-thirds of *all* carers in the survey 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 (65%). 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 80%, which is not a significant change since 2012 (81%). This figure (80%) is the figure used when reporting ASCOF indicator 3C.

Q15b. Do you find that different public services you come into contact with as a carer, such as the local council and health services, work well together to support and improve your own health and wellbeing?

| Q15b Services work well together* | Frequency | Valid percent % |
|---|------------|-----------------|
| Yes, always | 47 | 17 |
| Yes, most of the time | 85 | 31 |
| Yes, some of the time | 83 | 30 |
| No, never | 60 | 22 |
| Total | 275 | 100 |
| <i>Missing</i> | 16 | |
| <i>Don't know or does not apply to me</i> | 70 | |
| Total | 361 | |

* This question was not asked in 2012.

Slightly under half of all respondents felt that different public services always or mostly worked well together to support and improve their health and wellbeing (48%). 22% said that this never happened. We asked if carers had any comments about this, and a full analysis of their view can be found in Appendix 2 (provided separately). Comments included:

“The system is confused and not "joined up". One service seems to work against the other and this, again, has caused me stress and confusion.”

Q15c. If you wanted to make a complaint about any care and support services that you or the person you care for receive, do you know how to do this?

| Q15c Know how to make a complaint* | Frequency | Valid percent % |
|---|------------|-----------------|
| Yes, and I feel I could if I wanted to | 232 | 67 |
| Yes, but I do not feel I could if I wanted to | 22 | 6 |
| No, I do not know how to make a complaint | 93 | 27 |
| Total | 347 | 100 |
| <i>Missing</i> | 14 | |
| Total | 361 | |

* This question was not asked in 2012.

Two-thirds of carers (67%) said that they knew how to make a complaint about care and support services, and felt that they could do this. We asked if carers had any comments about this, and a full analysis of their view can be found in Appendix 2 (provided separately).

“I do not know if there is a formal procedure, however I would phone social services direct for advice.”

Section 6: Carers and the caring role

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

| Q16 Employment status* | Frequency | Valid percent % | 2012 % | Change 2012 / 2014 |
|--|------------|-----------------|--------|--------------------|
| Retired | 198 | 55 | 54 | +1 |
| Not in paid work | 55 | 15 | 15 | 0 |
| Employed full-time | 54 | 15 | 14 | +1 |
| Employed part-time (working 30 hours or less) | 51 | 14 | 12 | +2 |
| Other | 16 | 4 | 7 | -3 |
| Doing voluntary work | 12 | 3 | 5 | -2 |
| Self-employed part-time | 8 | 2 | 2 | 0 |
| Self-employed full-time | 4 | 1 | 3 | -2 |
| Total no. of people who answered the question | 360 | - | - | - |
| <i>Missing</i> | 1 | | - | |
| Total | 361 | | - | |

* 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”.

As in 2012, just over half of carers were retired (55%). There has been no significant change in response to this question since 2012.

Q16b. In addition to your caring role (and employment, if you are employed), please tell us which of the following also applies to you?

| Q16b Education and caring* | Frequency | Valid percent %* |
|--|------------|------------------|
| I am in full-time education or training (studying for 21 or more hours a week during term-time or whilst on a course) | 1 | 0 |
| I am in part-time education or training (studying for less than 21 hours during the week during term-time or whilst on a course) | 5 | 2 |
| I am not in education or training at present | 251 | 98 |
| Total | 257 | 100 |
| <i>Missing</i> | 104 | |
| Total | 361 | |

* This question was not asked in 2012.

Nearly all carers in the survey said that they were not in education or training (98%).

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 who are not self-employed or retired % | 2012 % | Difference 2012 / 2014 |
|---|------------------|------------------------|---|---------------|-------------------------------|
| <i>I am self-employed or retired</i> | 136 | 38 | - | 49 | -7 |
| I am in paid employment, and I feel supported by my employer | 59 | 18 | 31 | 15 | +1 |
| I am not in paid employment because of my caring responsibilities | 47 | 14 | 25 | 15 | -1 |
| I am not in paid employment for other reasons | 40 | 12 | 21 | 11 | +1 |
| I do not need any support from my employer to combine work and caring | 24 | 7 | 13 | 4 | +3 |
| I am in paid employment, but I don't feel supported by my employer | 20 | 6 | 11 | 5 | +1 |
| Total | 326 | 100 | 100 | 100 | - |
| <i>Missing</i> | 35 | | | | |
| Total | 361 | | | | |

As in 2012, the single largest percentage of carers were self-employed or retired (38%).

Of those who were not, 31% said they felt supported by their employer, and 25% said they were not in paid employment due to their caring responsibilities.

Q17b. Thinking about combining education and caring, which of the following statements best describes your current situation?

| Q17b Education and caring* | Frequency | Valid percent % |
|--|------------|-----------------|
| I am not currently in full- or part- time education, for other reasons | 168 | 74 |
| I am not currently in full- or part- time education because of my caring responsibilities | 50 | 22 |
| I am in full- or part- time education, and I do not need any support from my educational establishment to combine education and caring | 7 | 3 |
| I am in full- or part- time education, and I feel supported by my educational establishment | 3 | 1 |
| I am in full- or part- time education, but I do not feel supported by my educational establishment | 0 | 0 |
| Total | 228 | 100 |
| <i>Missing</i> | 133 | |
| Total | 361 | |

* This question was not asked in 2012.

Just under three-quarters of carers were not in full- or part- time education for reasons other than their caring responsibilities (74%). However, 22% of carers said that they were not in education due to their caring responsibilities (only 4% were in education).

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

| Q18 Length of time spent as a carer | Frequency | Valid percent % | 2012 % | Difference 2012 - 2014 |
|--------------------------------------|------------|-----------------|------------|------------------------|
| Less than 6 months | 3 | 1 | 1 | 0 |
| Over 6 months but less than a year | 9 | 3 | 3 | 0 |
| Over 1 year but less than 3 years | 69 | 18 | 15 | +3 |
| Over 3 years but less than 5 years | 67 | 19 | 20 | -1 |
| Over 5 years but less than 10 years | 96 | 27 | 20 | +7 |
| Over 10 years but less than 15 years | 44 | 12 | 15 | -3 |
| Over 15 years but less than 20 years | 22 | 6 | 7 | -1 |
| 20 years or more | 52 | 15 | 18 | -3 |
| Total | 356 | 100 | 100 | - |
| <i>Missing</i> | 5 | - | | |
| Total | 361 | - | | |

Most carers had been caring for more than one year but less than 10 years (64%). 15% had been caring for 20 years or more. There has been no significant change since 2012.

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

| Q19 Length of time spent caring each week | Frequency | Valid percent % | 2012 % | Difference 2012 - 2014 |
|---|------------|-----------------|------------|------------------------|
| 0-9 hours per week | 46 | 13 | 13 | 0 |
| 10-19 hours per week | 50 | 14 | 14 | 0 |
| 20-34 hours per week | 31 | 9 | 9 | 0 |
| 35-49 hours per week | 26 | 8 | 7 | +1 |
| 50-74 hours per week | 16 | 5 | 7 | -2 |
| 75-99 hours per week | 52 | 15 | 31 | -16 |
| 100 or more hours per week | 81 | 23 | 4 | +19 |
| Varies – Under 20 hours per week | 15 | 4 | 7 | -3 |
| Varies – 20 hours or more per week | 30 | 9 | 8 | +1 |
| Other | 1 | 0 | 0 | 0 |
| Total | 348 | 100 | 100 | - |
| <i>Missing</i> | 13 | | - | |
| Total | 361 | | - | |

The largest single percentage of carers said that they were caring for 100 or more hours per week (23%). This is a change from 2012, when the largest single percentage of carers said that they were caring for 75-99 hours per week (31%). 17 people commented that the person they care for has recently gone into residential care, so their hours are reduced. A full analysis of their comments can be found in Appendix 2 (provided separately).
Comments included:

“Every week is different apart from the regular things, it would vary if there was a hospital appointment. I do the shopping, laundry and cleaning weekly. Time spent on finances and house maintenance varies, also I provide lots of quality time. I do all the jobs needed to keep a house ticking over, the weekly hours vary according to necessity.”

“I don't always just care at her home. I spend a lot of time out doing the shopping, laundry and other types of errands. I am told when the times are that I'm needed most and meet all needs. I am on constant standby to meet her needs, they are many.”

Q20a. Over the last 12 months, what kinds of things did you usually do for the person you care for?

| Q20a Caring tasks | Frequency | Valid percent %* | 2012 %* | Difference 2012 - 2014 |
|--|------------|------------------|---------|------------------------|
| Other practical help? (Things like preparing meals, doing his / her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital) | 312 | 88 | 88 | 0 |
| Keeping an eye on him / her to see s/he is all right? | 306 | 86 | 83 | +3 |
| Keeping him / her company? (Things like visiting, sitting with, reading to, talking to, playing cards or games) | 305 | 86 | 82 | +4 |
| Helping with dealing with care services and benefits? (Things like making appointments and phone calls, filling in forms) | 304 | 86 | 84 | +2 |
| Helping with paperwork or financial matters? (Such as writing letters, sending cards, filling in forms, dealing with bills, banking) | 297 | 84 | 86 | -2 |
| Giving emotional support? | 286 | 81 | 80 | +1 |
| Taking him / her out? (Such as taking out for a walk or drive, taking to see friends or relatives) | 268 | 76 | 75 | +1 |
| Personal care (Things like dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet) | 212 | 60 | 57 | +3 |
| Giving medicines? (Things like making sure s/he takes pills, giving injections, changing dressings) | 210 | 59 | 64 | -5 |
| Physical help (Such as helping with walking, getting up and down stairs, getting into and out of bed) | 177 | 50 | 50 | 0 |
| Other help? | 34 | 10 | 10 | 0 |
| Total | 354 | - | - | - |
| <i>Missing</i> | 7 | | - | |
| Total | 361 | | - | |

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

As in 2012, 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 “keeping an eye on him or her to make sure he or she is alright”

(86%). Some people commented on the “other help” they gave the person they cared for, and their answers are presented in Appendix 2 (provided separately). Comments included:

“I help them to buy birthday and Christmas presents for family members and girlfriends, buying clothes, etc. as needed. I help by explaining everyday things for example newspaper headlines, events on TV, etc.”

We also asked about whether carers felt there was anything that could prevent them from being able to care in future. Their answers are presented in Appendix 2. Comments included:

“I am in my late fifties and worry that I will still be looking after my son in ten years' time. Will my health hold out? My husband had a heart attack last year. Where will my son live?”

“I worry that further deterioration [of the person I care for] will have a significant impact on my ability to care for my relative and maintain a work / life balance. I feel a great deal of pressure from other family members, as they don't seem to be able to relate to her as well as I can.”

About the carers

(Q22 and Q23 related to the age and ethnicity of the carer, and the data g.)

Q24. Did anyone help you complete the questionnaire?

| Q24 Did anyone help you complete the questionnaire? | Frequency | Valid Percent % | 2012 % |
|---|------------|-----------------|------------|
| Yes | 30 | 8 | 6 |
| No | 326 | 92 | 94 |
| Total | 356 | 100 | 100 |
| <i>Missing</i> | 5 | | - |
| Total | 361 | | - |

As in 2012, the majority of carers completed the questionnaire without help from anyone else (92%).

Responded to original postal questionnaire or a reminder?

| Responded to original or reminder? | Frequency | Valid Percent % | 2012 % |
|------------------------------------|------------|--------------------|------------|
| Original | 288 | 80 | 39 |
| Reminder | 73 | 20 | 61 |
| Total | 361 | 100 | 100 |

Around 80% of the respondents had responded after the date when the reminders were sent out. This is higher than in 2012, when this figure was 61%. However, the 2014 figure is more accurate, as in 2012 this was estimated using the date of return. In 2014, questionnaires were marked with an 'R' in front of the ID number on the front of the questionnaire, so that they could be identified as either a reply to the original questionnaire, or to the reminder.

Q21. Do you have any of the following?

| Q21 Carer health and wellbeing | Frequency | Valid Percent* % | 2012 % |
|-------------------------------------|------------|---------------------|-----------|
| None of the above | 152 | 49 | 49 |
| A long-standing illness | 83 | 27 | 27 |
| A physical impairment or disability | 46 | 15 | 19 |
| Sight or hearing loss | 41 | 13 | 14 |
| Other | 22 | 7 | 6 |
| A mental health problem or illness | 16 | 5 | 9 |
| A learning disability or difficulty | 3 | 1 | 2 |
| Total | 310 | - | - |
| <i>Missing</i> | 51 | - | - |
| Total | 361 | - | - |

* 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 15% had a physical impairment or disability. These figures are almost identical to those from 2012.

Of people who replied "other", the most common "other" reason was that they had arthritis (15 people), followed by heart problems (five people). Many carers with long-standing illnesses or medical conditions commented on what they suffered from as shown in the table on the next page.

| Q21 comments – carer health and wellbeing, “other” conditions | 2014 Number of people | 2012 |
|---|--------------------------|------|
| Arthritis | 15 | 20 |
| Heart problems, including having had a heart attack | 5 | 9 |
| Cancer | 5 | 3 |
| Recovering from a recent operation | 4 | - |
| High blood pressure | 4 | 9 |
| Back or neck pain | 4 | 7 |
| Diabetes | 4 | 6 |
| Joint problems, including having had a joint replacement | 4 | 4 |
| Depression | 3 | 7 |
| IBS or other bowel problems | 3 | 2 |
| Asthma | 2 | 6 |
| Anxiety or stress | 2 | 4 |
| COPD or other breathing problem | 2 | 3 |
| Osteoporosis or other bone disease | 2 | 3 |
| Kidney or bladder problems | 2 | 2 |
| Old age | 2 | 2 |
| Other | 1 | 5 |
| Stroke | 1 | 3 |
| Thyroid problems, such as Graves’ disease | 1 | 3 |
| Leg ulcers | 1 | - |
| Migraine | 1 | - |
| Skin problems, such as psoriasis or eczema | 1 | 2 |
| Fibromyalgia | 1 | - |

As in 2012, the most common “other” health issue mentioned by carers was arthritis (15 people), followed by heart problems (5 people).

Gender

| Gender | Frequency | Valid Percent % | 2012 % | % in sample | % in population |
|------------------|------------|-----------------|------------|-------------|-----------------|
| Male | 115 | 32 | 34 | 34 | 34 |
| Female | 242 | 68 | 66 | 66 | 66 |
| Total | 357 | 100 | 100 | 100 | 100 |
| <i>Not known</i> | 4 | | | | |
| Total | 361 | | | | |

The majority of carers in the survey were female (68%). This is in line with the total population of carers, where 66% are female.

Q22. How old are you?

| Age of carer* | Frequency | Valid percent | | % in sample | % in population** | Difference between respondents & population |
|----------------|------------|---------------|------------|-------------|-------------------|---|
| | | % | 2012 % | | | |
| 18-24 | 0 | 0 | 0 | 2 | 1 | -1 |
| 25-34 | 3 | 1 | 1 | 2 | 3 | -2 |
| 35-44 | 24 | 7 | 6 | 9 | 7 | 0 |
| 45-54 | 58 | 16 | 22 | 22 | 22 | -6 |
| 55-64 | 111 | 31 | 30 | 29 | 32 | -1 |
| 65-74 | 96 | 27 | 19 | 18 | 19 | +8 |
| 75-84 | 48 | 13 | 18 | 14 | 13 | -5 |
| 85 and over | 19 | 5 | 5 | 4 | 4 | 0 |
| Total | 359 | 100 | 100 | 100 | 100 | - |
| <i>Missing</i> | 2 | - | - | | | |
| Total | 361 | - | - | | | |

* 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.

** This has been calculated with the number of people whose age is unknown removed from the total.

As in 2012, the largest single percentage of carers were aged between 55-64 (31%). Nearly half (45%) were aged 65 and over. As shown above, carers aged 65-74 are somewhat overrepresented in the sample, and those aged 45-54 somewhat underrepresented. However, it should be noted that we do not hold any information about age for nearly a quarter of the total "population" of carers (429 out of 2018), so these figures are illustrative only.

Religion

| Religion | Frequency | Valid Percent* % | % in sample |
|------------------|------------|------------------|-------------|
| Christian | 69 | 75 | 73 |
| None | 14 | 15 | 16 |
| Muslim | 5 | 5 | 7 |
| Other | 3 | 3 | 3 |
| Hindu | 1 | 1 | 1 |
| Total | 92 | 100 | 100 |
| <i>Not known</i> | 269 | | |
| Total | 361 | | |

* We did not report this information in 2012.

The majority of carers in the survey whose religion was known were Christian (75%) were Christian, which is in proportion to the wider population.

Q23. Ethnic origin of the carer

| Ethnic origin | Frequency | Valid Percent % | 2012 % | % in sample |
|------------------------|------------|-----------------|------------|-------------|
| White | 346 | 96 | 97 | 93 |
| Asian or Asian British | 8 | 2 | 1 | 3 |
| Black or Black British | 4 | 1 | 0 | 0 |
| Chinese | 1 | 0 | 0 | 0 |
| Mixed | 1 | 0 | 0 | 0 |
| Other | 1 | 0 | 0 | 1 |
| Total | 361 | 100 | 100 | 100 |

As in 2012, the majority of carers who took part in the survey were from a White ethnic background (96%). This is slightly higher than the percentage of White carers in the sample (93%), but not significantly so.

(Q24 asked whether anyone had helped the carer to complete the questionnaire.)

Q25. Do you receive a direct payment?

| Q25. Carer receives a direct payment? | Frequency | Valid percent % | 2012* % | % in sample |
|---------------------------------------|------------|-----------------|------------|-------------|
| Yes, I do | 185 | 52 | 1 | 52 |
| No, I do not | 141 | 40 | 99 | 48 |
| Don't know or not sure | 28 | 8 | - | - |
| Total | 354 | 100 | 100 | 100 |
| <i>Missing</i> | 7 | | - | - |
| Total | 361 | | - | - |

* In 2012, "don't know" was not an option for this question.

Just over half of carers in the survey said that they received a direct payment (52%), which is in line with the total population of carers (52% of whom receive a direct payment). This is a very large change since 2012, when this figure was 99%. However, it is likely that the change can be partly accounted for by the possibility that many carers in 2012 were receiving a Direct Payment, but were not certain that this was what the money they were receiving was called. Comments received in reply to question 26 show that there is some confusion among carers about the names of the different benefits that they may be receiving. These can be found in Appendix 2 (provided separately).

Q26. If you do receive a Direct Payment, what do you use it for?

| Q26. If you do receive a Direct Payment, what do you use it for?* | Frequency | Valid percent % |
|--|------------|-----------------|
| Things that make it easier for you to care (such as paying for travel) | 99 | 44 |
| Domestic help or household goods to make it easier for you to care | 52 | 23 |
| Activities that improve your quality of life (such as exercise, meeting friends and family, or pursuing a hobby) | 50 | 22 |
| This does not apply to me because I do not have a Direct Payment | 43 | 19 |
| Support or services to allow you to have a rest from caring for between 1 and 24 hours (such as a sitting service) | 38 | 17 |
| Support or services allowing you to take a break from caring for more than 24 hours | 37 | 16 |
| Something else | 31 | 14 |
| Support or services allowing you to take a break from caring at short notice or in an emergency | 15 | 7 |
| Education, learning or other activities to help you develop skills | 4 | 2 |
| Total | 277 | 100 |
| <i>Missing</i> | 134 | - |
| Total | 361 | - |

* This question was not asked in 2012.

The largest single percentage of carers who received a Direct Payment used it to buy things that made it easier for them to care, such as paying for travel (44%). The next most common answer was “domestic help or household goods” (23%). We asked if people had any comments about this, and these have been analysed in Appendix 2 (provided separately). Comments included:

“I am able to take a holiday with the person I care for and with a lot of friends and ex-work mates, and therefore have a short break, as both of us know them well and they help me care.”

“It is used for alternative therapy to relax such as reflexology and massage, as I get a bad back from carrying mam's shopping and washing, as I do not have access to a car, so I use the bus.”

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

| Carer assessed jointly or separately? | Frequency | Valid percent % | 2012 % | % in sample |
|---------------------------------------|------------|-----------------|------------|-------------|
| Jointly | 327 | 93 | 96 | 93 |
| Separately | 24 | 7 | 4 | 7 |
| Total | 351 | 100 | 100 | 100 |
| <i>Missing</i> | 10 | | - | 19 |
| Total | 361 | | - | - |

As in 2012, nearly all carers had been assessed jointly with the person they care for (93%).

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

| Carer received a service funded by local authority in last 12 months? | Frequency | Valid percent % | 2012 % | % in sample |
|---|------------|-----------------|------------|-------------|
| Yes | 216 | 60 | 48 | 55 |
| No | 145 | 40 | 52 | 45 |
| Total | 361 | 100 | 100 | 100 |

60% of carers had received a service in the last twelve months which was funded by the local authority, which is an increase of 12 percentage points since 2012 (48%) and slightly more than the percentage for the total population of carers (55%).

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

| Carer received information funded by local authority in last 12 months? | Frequency | Valid percent % | 2012 % | % in sample |
|---|------------|-----------------|------------|-------------|
| Yes | 62 | 17 | 0 | 17 |
| No | 299 | 83 | 100 | 83 |
| Total | 361 | 100 | 100 | 100 |

17% of carers had received information only within the last twelve months (which was funded by the local authority), which is an increase from 2012, when only one person had received this.

In future, what is the best way for the council to provide you with information or correspond with you? (Q29)

| Preferred methods of communication | Frequency | Valid percent % |
|------------------------------------|------------|-----------------|
| Standard print | 291 | 96 |
| Large print | 7 | 2 |
| Other – email | 8 | 3 |
| In another language – Arabic | 1 | 0 |
| Computer disc (CD) | 1 | 0 |
| Explained through BSL interpreter | 1 | 0 |
| Audio tape | 0 | 0 |
| Braille | 0 | 0 |
| Total | 305 | 100 |
| <i>Missing</i> | 56 | - |
| Total | 361 | - |

* This question was not asked in 2012.

Nearly all carers were happy to receive information in standard print (96%). Of those who specified another preferred format, email was the most popular – seven people chose this.

We also asked carers at the end of the questionnaire if there were any other experiences they wanted to tell us about, or other comments they wanted to make. Their responses can be found in Appendix 2 (provided separately). Comments included:

“My experience is something of a rollercoaster in terms of caring for my mother, who is generally kind and grateful but occasionally aggressive. Every time I re-adjust my view and temperament in response to an incident, I usually find I am one step behind. Helping to understand dementia does help, and I read articles and books which I find immediately supportive, but putting all the positive ideas and initiatives into practice is another matter. My general mood is that I am concerned for what the future will be.”

“I worry about myself, if and when the time comes that my partner needs to go into a residential care home. I will no longer have Carer's Allowance, and I will no longer have his pension or benefits as they will go with him. I am 57 years old, will not collect my state pension for 10 years, and have been out of the job market for five to six years now. In other words, my life and prospects have been ruined by the need to be a full-time carer since my early fifties. I will probably spend my old age in poverty, even though I worked full-time without a gap from 16-51 years of age. I do have a private pension but have taken it early to help us live now, so it's not worth as much as it might have if had been left.”

Appendix 1 – 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

2b. Does the person you care for have Asperger's Syndrome or autism?

- Yes
- No

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 Wellbeing Care and Learning in the last 12 months?

- We haven't received any support or services from Newcastle Wellbeing Care and Learning 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 Wellbeing Care and Learning.

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
- l. Another form of support or service

If you replied "Another form of support or service", please could you tell us more about this here:

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 Wellbeing Care and Learning. They may be provided by a voluntary organisation, a private agency or Newcastle Wellbeing Care and Learning.

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 Wellbeing Care and Learning. 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 Wellbeing Care and Learning.

- 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 Wellbeing Care and Learning.

- 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. We would be especially interested in hearing about whether the information helped you understand:

- how the system operates,
- the care and support choices available to you and the person you care for, how to access support, and
- how to get access to independent financial advice.

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

15b. Do you find that different public services you come into contact with as a carer, such as the local council and health services, work well together to support and improve your own health and wellbeing? Please tick one box.

- Yes, always
- Yes, most of the time
- Yes, some of the time
- No, never
- Don't know or does not apply to me

If you have any comments about this, please write them here:

15c. 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 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

16b. In addition to your caring role (and employment, if you are employed), please tell us which of the following also applies to you?

- I am in full-time education or training (studying for 21 or more hours a week during term-time or whilst on a course)
- I am in part-time education or training (studying for less than 21 hours during the week during term-time or whilst on a course)
- I am not in education or training at present

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

17b. Thinking about combining education and caring, which of the following statements best describes your current situation?

- I am not currently in full- or part- time education because of my caring responsibilities
- I am not currently in full- or part- time education, for other reasons
- I am in full- or part- time education, and I feel supported by my educational establishment
- I am in full- or part- time education, but I do not feel supported by my educational establishment
- I am in full- or part- time education, and I do not need any support from my educational establishment to combine education and caring

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:

20b. Please tell us about anything that you think might affect your ability to care for the person you look after in the future:

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. Do you receive a Direct Payment? A Direct Payment is a payment made to you or the person you are looking after so that you can buy care or support services for yourself.

- Yes, I do
- No, I do not
- Don't know / not sure

26. If you do receive a Direct Payment, what do you use it for?

- Support or services to allow you to have a rest from caring for between 1 and 24 hours (such as a sitting service)
- Support or services allowing you to take a break from caring at short notice or in an emergency
- Support or services allowing you to take a break from caring for more than 24 hours
- Domestic help or household goods to make it easier for you to care
- Education, learning or other activities to help you develop skills
- Activities that improve your quality of life (such as exercise, meeting friends and family, or pursuing a hobby)
- Things that make it easier for you to care (such as paying for travel)
- This does not apply to me because I do not have a Direct Payment
- Something else

If something else, please tell us more about this:

27. 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

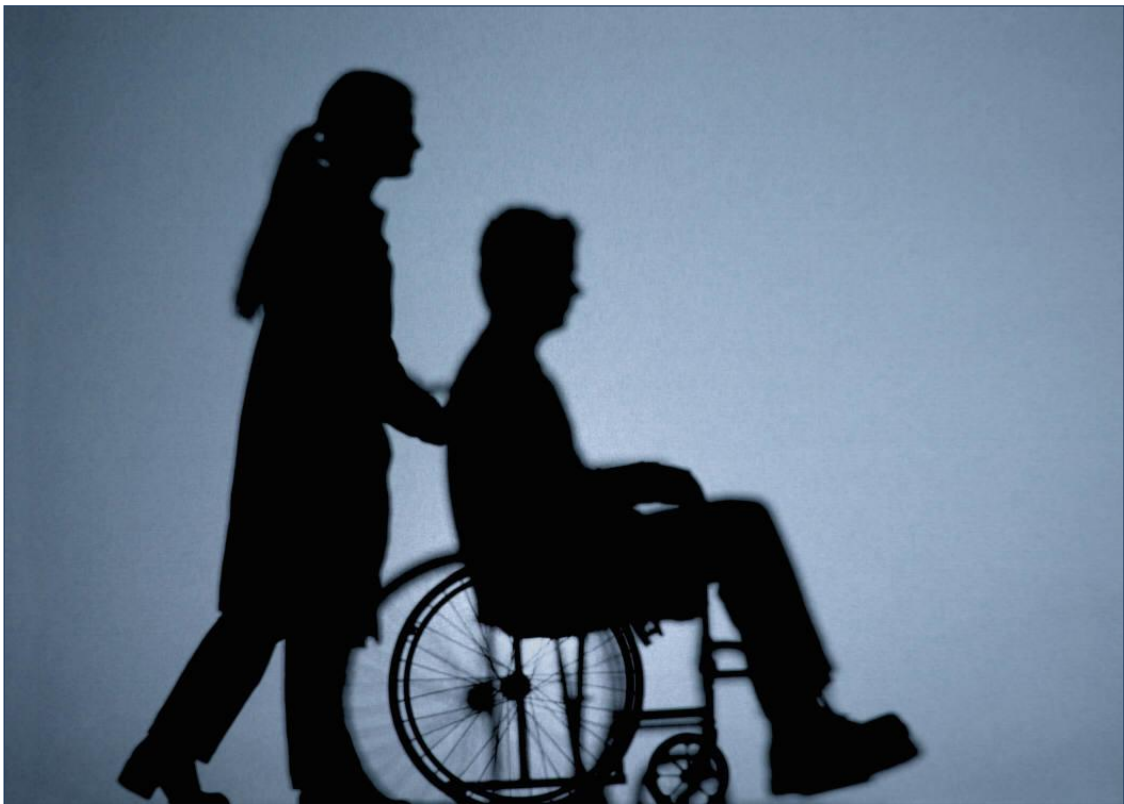
28. We may be asking some people to take part in follow-up research for this study in the next year or so. Would you be happy to be invited to take part in more research? Note that even if you say “yes” there will be no obligation to take part in the future.

- **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. Carer received personal budget or direct payment within 12 months of data extraction
7. Cared-for person eligible for inclusion in SALT as long term supported client
8. Cared-for person is SALT eligible and in receipt of on-going personal budget or direct payment
9. Cared-for person is Self-Funder
10. Carer assessed jointly with the cared-for person or separately
11. Carer received a service in the past 12 months funded by the LA
12. Carer received only information, advice, signposting or other universal services in the last 12 months, funded by the LA



Louise Reeve
Policy and Communications Team
Assistant Chief Executive's Directorate
