

Newcastle Wellbeing Care and Learning: Carers Survey 2016



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

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Introduction

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

Purpose of the survey and national context

From the official survey guidance:

“Local authorities in England with responsibility for providing adult social care services are required to conduct a biennial postal survey of their carers. The Personal Social Services **S**urvey of **A**dult **C**arers in **E**ngland (SACE) asks questions about quality of life and the impact that the services they receive have on their quality of life. It also collects information about self-reported general health and well-being.

“Data collected through the survey by local authorities are sent to the **H**ealth and **S**ocial **C**are **I**nformation **C**entre (HSCIC) and are used as the basis of analyses that are included in national level Official Statistics reports. Data are also used to populate several measures in the **A**dult **S**ocial **C**are **O**utcomes **F**ramework (ASCOF). It is the intention that these data are used to inform policy and decision-making at local, regional and national level; and to improve care, services and outcomes for local populations.”

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

- **1D**: Carer-reported quality of life.
- **1L2**: The proportion of carers who reported that they had as much social contact as they would like.
- **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.
- **3D2**: The proportion of people who use services and carers who find it easy to find information about services.

The information it provides on Newcastle carers' views and experiences will be used to help improve services to carers and cared-for people. Running the survey for a third time also allows us to look for changes in carers' views and experiences since 2012 and 2014.

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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 2016 to draw the sample. Ours was drawn on **24 September 2016**.

Based on the previous survey's response rate, we drew a sample of 816 carers from a total "population" of 2,791 Newcastle carers aged 18 and over 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 **29 October – 30 November 2016**. We sent out one reminder on **10 November 2016**, and received **345** questionnaires returned out of **816** sent out, giving a response rate of **42%**. This gives a margin of error¹ for the entire survey of **+/-4.94** percentage points, given that the total number of service users we drew our random sample from was 2,791². This is within the maximum margin of error specified by the NHS Information Centre, which is +/- 5.00 percentage points.

This means that we can consider that the results from the survey are representative of the entire population of 2,791 carers at 18 and over in Newcastle who were assessed or reviewed during the twelve months prior to the date of extracting the sample (24 September 2016), to within +/-4.94% percentage points either way. As an example of what this means in practice, the percentage of people in the survey who feel that they have as much control over their daily lives as they want is 30.45% - so the "true" figure for the population as a whole lies between 25.62% - 35.28%.

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 2016, as in 2012 and 2014, everyone who took part in the survey did so by returning a questionnaire in English. 134 respondents (39% 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.

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.

² Note that we originally calculated this figure as 2,131, and this figure may have been quoted on some early information about the survey results, but the correct figure is 2,791.

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 Clare Alder, Service Manager for Adult and Older People’s Services so that staff, who are not involved in the delivery of services to the person in question, can make contact with them to discuss the situation and identify the best way forwards to safeguard their wellbeing, and that of the person they care for. 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 the code will be used to identify you”.

Key Findings

National Indicators

Several national performance indicators are reported from the Carers Survey. In 2016 the results were as shown below.

1D – Carer-reported quality of life

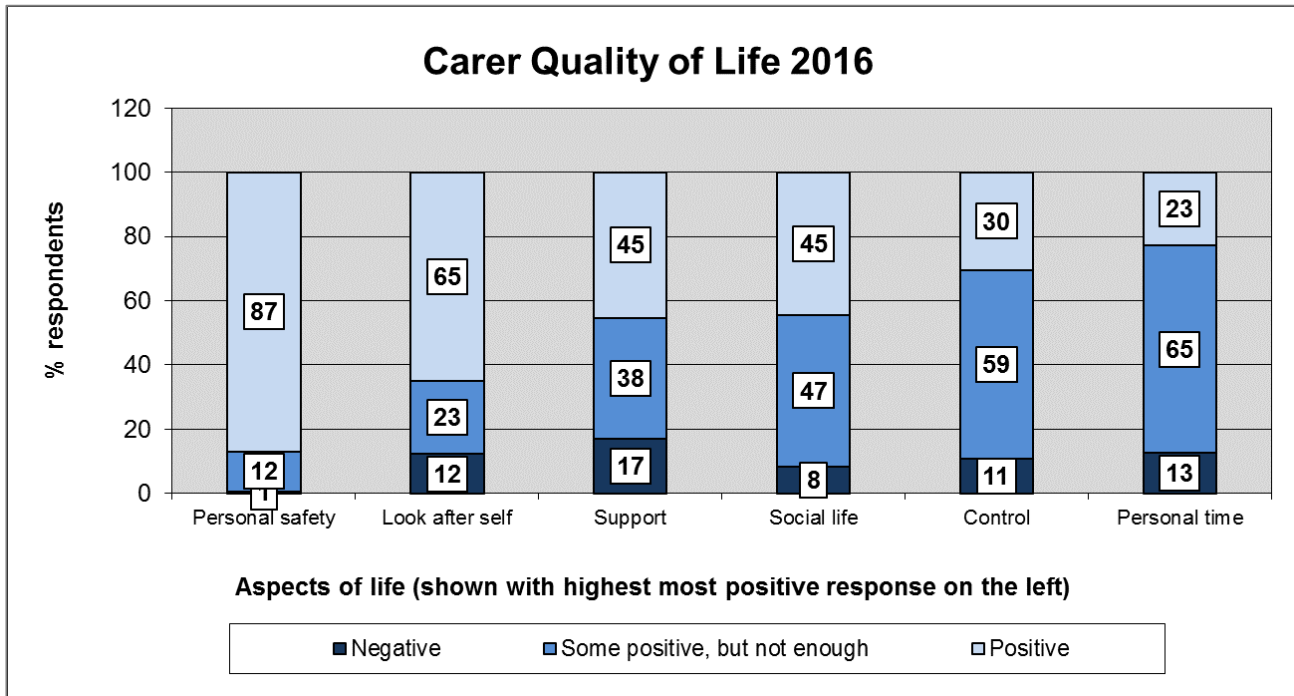
This is a composite measure which combines individual responses to seven questions measuring different outcomes related to overall quality of life: occupation, time and space, control, personal care, safety, social participation and encouragement and support. It is an overarching outcome measure for carers, similar to the equivalent for people who use social care 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 for 2016: **8.3**, or **69%** of the maximum possible score. This is slightly lower than the previous survey's score of **8.4 (70%)**. 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)	71.0	207.0	41.0	319.0
Control (Q8)	93.0	191.0	35.0	319.0
Personal Care (Q9)	205.0	74.0	40.0	319.0
Safety (Q10)	277.0	40.0	2.0	319.0
Social Participation (Q11)	141.0	151.0	27.0	319.0
Encouragement and Support (Q12)	142.0	121.0	56.0	319.0
Total	929.0	784.0	201.0	
Score	1858.0	784.0		
	Numerator	Denominator	1D	
	2642.0	319.0	8.3	69.0%

This is a composite measure; the maximum possible score is 12.0. The figure of **69.0%** shows our score – **8.3** – 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.

In 2014, this figure was **8.4**, and in 2012 it was **8.5**.

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; **87%** of carers said that they had no worries about their personal safety. At the other end of the scale, only **23%** replied “I’m able to spend my time as I want, doing things I value or enjoy”. These results are in line with previous years, with a noticeable drop in positive response for ‘personal time’: **30%** in 2014 had the most positive response, compared to **23%** in 2016.



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 **44.5%**, which is slightly lower than in 2014, when it was **47.0%**, but this is not a significant difference. In 2012 this figure was **51.9%** (note that this figure was not a national indicator in 2012).

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: **44.8%**. This is almost the same as in 2014 (**44.5%**), but significantly lower than 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: **73.2%**. This is significantly lower than in 2014, when this figure was **79.9%**, and in 2012, when it was **80.8%**.

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 have been 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 was **61.3%**, which is significantly lower than in 2014, when it was **67.8%**. It is nearly the same as in 2012, when it was **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.

Action points

Areas which may require attention are as follows:

- **Carers Emergency Card:** it is still the case that the majority of carers (76%) had not heard of the Carers Emergency Card scheme (70% in 2012, 72% in 2014).
- **Social contact and control over daily life:** As shown in the chart on the previous page:
 - **78%** of carers said that they either did some **things they valued** or enjoyed with their time but not enough (65%), or that they did not do anything they valued or enjoyed (13%). This is an increase since 2014, when this figure was 70%.
 - **70%** of carers said that either they had some **control** over their daily life but not enough (59%), or that they had no control (11%). This is an increase since 2014, when this figure was 63%.
 - **56%** of carers said they had either some social **contact** with people they like but not enough (47%), or that they had little social contact and felt socially isolated (8%). This is in line with 2014, when this figure was 54%.
- **Feeling involved in discussions:** Although the majority of carers said that they always or usually felt involved in discussions about the person they care for, 27% of carers said that they only sometimes felt involved, or that they never felt involved. This is an increase compared to 2014, when this figure was 21%.
- **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 (56%). This is in line with the findings from 2014 (52%).

Changes since 2014

The results in 2016 have been similar to those for 2014 and 2012. Areas where there have been changes since the previous survey 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 since 2012, from 53% to 45% in 2014 and 2016.
- **How people spend their time:** In 2014, 30% of carers in the survey said that they could spend their time as they wanted, doing things they value or enjoy. In 2016, this is lower: only 23% said this.
- **Carers' Emergency Card:** In 2012, 70% of carers in the survey had not heard of a Carers Emergency card. In 2016, this percentage was 76%.
- **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 49% in 2012 to 55% in 2016.
- **Control over daily life:** In 2012, 39% of carers in the survey said that they had as much control over their daily life as they wanted. In 2016, this is lower: only 30% said this.
- **Information and advice:** There has been a decrease over the past four years in the percentage of carers in the survey who have tried to find information and advice and say this was very or quite easy: from 68% in 2012 & 2014, to 61% in 2016.
- **Feeling involved:** The percentage of carers whose cared-for person had had discussions about care and support services in last 12 months who said that they always or usually felt involved or consulted in discussions about the support or services provided to the person they care for is significantly lower than in 2014 and 2012: 73%, compared to 80% in 2014, and 81% in 2012.
- **Complaints:** The percentage 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 is lower than in 2014: 60% in 2016, compared to 67%.
- **Length of time being a carer:** Slightly fewer people had been caring for more than a year but less than ten years: 57%, compared to 64% in 2014.
- **Time spent each week caring:** The largest single percentage of carers said that they were caring for 75-99 hours a week (32%), which is a change from 2014, when the largest single percentage said they cared for 100 or more hours a week (23%), with many commenting that they care "24/7". However, in 2012, the largest single percentage of carers said that they were caring for 75-99 hours per week.
- **Direct payments / personal budgets:** Slightly more carers were receiving a direct payment (57%) than in 2014 (52%).

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 percent %	2014%	2012* %	% in sample
Physical support	177	54	57	64	54
Support for memory and cognition	52	16	17	-	15
Learning disability support	39	12	11	13	12
Mental health support	25	8	7	22	9
Social support	28	9	7	1	8
Sensory support	8	2	1	-	3
Total	329	100	100	100	
<i>Missing</i>	16		-	-	-
Total	345		-	-	-

* 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 from 2012 cannot therefore be directly compared to those for 2014 and 2016, and those in the 2012 column are for the closest primary client group to the primary support reason in question, as follows:

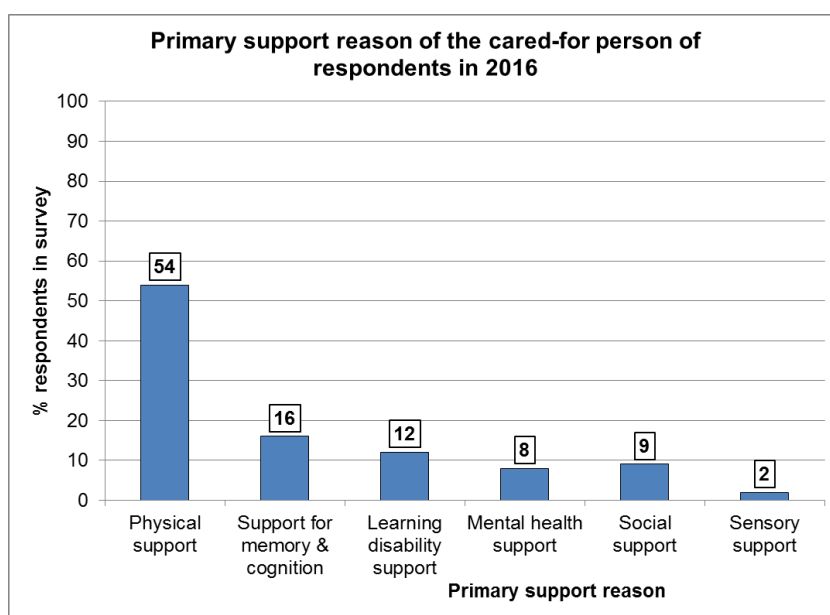
Physical Support = Physical Disability, frailty or sensory impairment – note that under the SALT reporting system, "Sensory Support" is a separate category

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

Just over half of carers in the 2016 survey were caring for someone whose primary support reason was 'physical support' (54%). As shown in the chart, the percentages of **survey respondents** caring for adults with the primary support reasons shown was proportionate to the percentages for each group of people caring for people with these primary support reasons in the **sample**.



Q1. How old is the person you care for?

Q1 Age of cared-for person (in the survey)	Frequency	Valid percent %	2014 %	2012 %	% in sample
18-24	15	5	4	4	1
25-34	17	5	4	5	4
35-44	17	5	3	4	8
45-54	16	5	6	6	21
55-64	24	7	6	8	31
65-74	30	9	11	10	17
75-84	78	24	27	30	13
85 or over	129	40	39	33	5
Total	326	100	100	100	100
<i>Missing</i>	19	-	-	-	
Total	345	-	-	-	

The majority of people being cared for were aged 75 or over (64%).

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

Q2 Cared-for person – client group	Frequency	Valid percent %	2014 %	2012 %
A physical disability	172	51	49	48
Problems connected to aging	162	48	50	43
Dementia	135	40	40	29
Sight or hearing loss	116	34	38	31
Long-standing illness	109	32	34	33
A mental health problem	64	19	17	16
A learning disability or difficulty	57	17	16	2
Terminal illness	14	4	5	4
Alcohol or drug dependency	5	2	1	2
Total*	337	-	-	
<i>Missing</i>	8			
Total	345			

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

The most common response to this question was “a physical disability” (51%), followed by “problems connected to aging” (48%). These were also the most common client groups of cared-for people in 2014 and 2012. Note that this is a question asked directly of the survey respondents, as opposed to the data shown in the ‘primary support reasons’ table above. The data in the primary support reasons table is taken directly from the carers’ Carefirst records.

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 %	2014 %	2012 %
Yes	14	4	4	2
No	318	96	96	98
Total	332	100	100	100
<i>Missing</i>	13			
Total	345			

As in 2014, only 4% of respondents were caring for someone with Asperger's syndrome or autism (in 2012, this was 2%, but this is not a significant change).

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

Q3 Where does the person you care for usually live?	Frequency	Valid percent %	2014 %	2012 %
With me	182	53	45	55
Somewhere else	160	47	55	45
Total	342	100	100	100
<i>Missing</i>	3			
Total	345			

Just over half of carers in the survey replied that the person they cared for lived with them. This is a change from 2014 (when 45% of carers said this), but in line with 2012, when 55% of carers lived with the person they cared for.

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%	2014 %	2012 %
We haven't received any support or services from Newcastle Wellbeing Care and Learning in the last 12 months	84	25	-	-	-
I am extremely satisfied	43	13	17	18	23
I am very satisfied	70	21	28	27	30
I am quite satisfied	81	24	32	38	32
I am neither satisfied nor dissatisfied	36	11	14	12	9
I am quite dissatisfied	13	4	5	2	4
I am very dissatisfied	4	1	2	2	1
I am extremely dissatisfied	5	2	2	2	1
Total	336	100	100	100	100
<i>Missing</i>	9	-	-	-	-
Total	345	-	-	-	-

When carers 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 **under half of carers were extremely or very satisfied: 45%**, the same as in 2014. (This is the figure used to calculate ASCOF indicator 3b.) A further 32% were quite satisfied, 14% were neither satisfied nor dissatisfied, and 9% were quite, very or extremely dissatisfied).

This is a decrease of -11 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	2014 Yes %	2012 Yes %
Equipment or adaptation to their home (such as a wheelchair or handrails)	62	33	4	55	59
Home care / home help	46	49	5	43	42
Lifeline alarm / Telecare	42	52	6	42	34
Day centre or day activities	23	72	5	24	29
They are permanently resident in a care home	21	72	7	19	16
Support or services allowing you to take a break from caring for more than 24 hours	21	75	4	17	20
Support or services to allow you to have a rest from caring for between 1 and 24 hours (such as a sitting service)	14	81	5	17	16
Support or services allowing you to take a break from caring at short notice or in an emergency.	14	80	5	12	15
Personal assistant	14	80	7	12	13
Meals services	5	87	8	6	5
Lunch club	6	87	7	5	5
Other**	14	80	7	11	-

* 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” (62%), followed by “Home care / home help” (46%). These were also the most common options chosen in 2012 and 2014. The most common options among people who replied “other” were:

- Support from voluntary organisations **3%** (10 people)
- Assisted living **2%** (6 people)
- Funding **2%** (6 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	2014 Yes %	2012 Yes %
a. Information and advice	39	58	2	39	47
b. Support from carers groups or someone to talk to in confidence	19	78	3	22	25
c. Support to keep you in employment	4	95	2	4	4
d. Training for carers	3	95	3	2	4

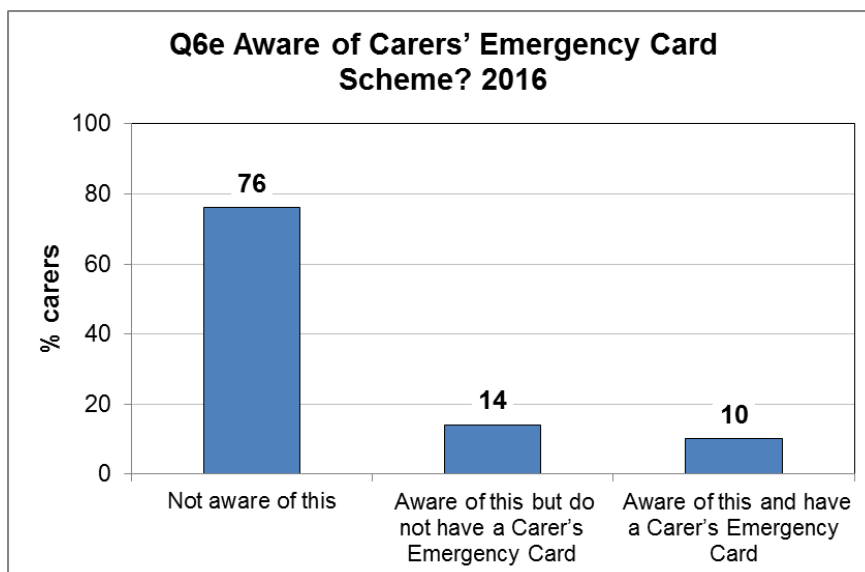
* Respondents could choose as many options as they liked, so percentages total more than 100%.

As in 2012 and 2014, the largest single percentage of carers had used information and advice to help them in their caring role: 39%, which was the same percentage as in 2014.

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.

As in 2012 and 2014, the majority of carers were not aware of the Carers Emergency Card scheme: 76%, compared to 72% in 2014 and 70% in 2012.



Q6e Aware of Carers' Emergency Scheme?	Frequency	Valid percent %	2014 %	2012 %
No, I am not aware of this	238	76	72	70
I am aware of this but I do not have a Carer's Emergency Card	45	14	10	16
Yes, I am aware of this and I have a Carer's Emergency Card	32	10	12	9
Don't know / not sure	-	0	6	4
Total	315	100	100	100
<i>Missing</i>	30	9		
Total	345	-		

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 %	2014 %	2012 %
I'm able to spend my time as I want, doing things I value or enjoy	77	23	30	30
I do some of the things I value or enjoy with my time but not enough	217	65	59	60
I don't do anything I value or enjoy with my time	42	13	11	11
Total	336	100	100	100
<i>Missing</i>	9			
Total	345			

The majority of carers said they did some of the things they wanted to do with their time, but not enough (65%). There has been a small but statistically significant change in responses to this question since the previous survey; from 59% of respondents saying they did some of the things they value or enjoy with their time but not enough in 2014, to 65% in 2016.

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 %	2014 %	2012 %
I have as much control over my daily life as I want	102	30	37	39
I have some control over my daily life but not enough	197	59	56	54
I have no control over my daily life	36	11	7	8
Total	335	100	100	100
<i>Missing</i>	10			-
Total	345			-

Just over half of carers said that they had some control over their daily lives, but not enough (59%). 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 %	2014 %	2012 %
I look after myself	218	65	67	66
Sometimes I can't look after myself well enough	76	23	21	22
I feel I am neglecting myself	41	12	12	13
Total	335	100	100	100
<i>Missing</i>	20			
Total	345			

The majority of carers said they were able to look after themselves, for example getting enough sleep or eating well (65%), and this has not significantly changed since 2012 or 2014.

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 %	2014 %	2012 %
I have no worries about my personal safety	294	87	88	86
I have some worries about my personal safety	42	12	12	13
I am extremely worried about my personal safety	2	1	0	1
Total	338	100	100	100
<i>Missing</i>	7			
Total	345			

Over three-quarters of carers said they had no worries about their personal safety (87%), and this has not significantly changed since 2012 and 2014. The two people who replied that they did not feel at all safe had their details passed on in confidence to Adult Social Care Direct, so this could be discussed with them, in line with the confidentiality guarantee we provide for everyone taking part in the survey³.

³ The full wording of the confidentiality guarantee is: "Your answers will be treated in strict confidence and any help you or the person you look after may get will not be affected by them. You will not be personally identified in the results which are shared with the Department of Health and the Health and Social Care Information Centre. No-one directly involved in providing services to you or the person you care for will see your answers. The code on the form is used to make sure that when you return it we do not send you another one. However, if you say on the form that you are being hurt or harmed by anybody, or you are extremely worried about your personal safety (Question 10), then we will use this code to identify you so that someone from Newcastle Wellbeing Care and Learning (but not anyone directly involved in providing you or

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 %	2014 %	2012 %
I have as much social contact as I want with people I like	150	45	47	52
I have some social contact with people, but not enough	159	47	43	39
I have little social contact with people and feel socially isolated	28	8	11	10
Total	337	100	100	100
<i>Missing</i>	8			
Total	345			

Just under half of carers replied that they had as much social contact as they wanted with people they liked (45%), which is a decrease since 2014 (47%) and 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 %	2014 %	2012 %
I feel I have encouragement and support	149	45	50	53
I feel I have some encouragement and support but not enough	124	38	36	37
I feel I have no encouragement and support	56	17	14	10
Total	329	100	100	100
<i>Missing</i>	16			
Total	345			

Under half of all carers replied that they felt they had encouragement and support in their caring role (45%), which is a slight decline since 2014 (50%) and 2012 (53%).

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.”

Q13. Thinking about the other people you have caring responsibilities for, which of the following best describes your current situation? (Please exclude the person you spend most time helping.)

Q13 Other caring responsibilities	Frequency	Percentage: all respondents %	Percentage: people caring for two or more people %
I don't have caring responsibilities for anyone else	106	33	-
I always have enough time to care for them	102	31	47
I sometimes have enough time to care for them	96	30	44
I never have enough time to care for them	21	7	10
Total	325	100	100
<i>Missing</i>	20		
Total	345		

* This question was not asked in 2012 and 2014.

One-third of carers cared only for one person. Of those who cared for two or more people, just under half (47%) said they always had enough time to care for the other person (the person who is not the main person they care for). However, 10% said they never had enough time to care for the other people they had caring responsibilities for.

Q14. In the last 12 months, has your health been affected by your caring role in any of the ways listed below?

Q14 Health affected by caring role	Frequency	Valid percent %
Feeling tired	233	70
Disturbed sleep	191	57
General feeling of stress	186	56
Short-tempered / irritable	139	42
Feeling depressed	121	36
Physical strain (e.g. back problems)	87	26
Had to see my own GP	76	23
Developed my own health conditions	60	18
Made an existing condition worse	54	16
No, none of these	51	15
Loss of appetite	40	12
Other	2	1
Total	333	100
<i>Missing</i>	12	
Total	345	

* This question was not asked in 2012 and 2014.

The majority of carers replied that their caring role affected their health by causing them to feel tired (70%), followed by disturbed sleep (57%), and a general feeling of stress (56%). Most people who commented on this question described other things than affected their health (nine people), such as aging and high blood pressure, pre-existing health conditions (seven people) such as arthritis and leukaemia, and a description of their situation (six people), such as “disturbed sleep due to my wife’s night-time wanderings”.

Q15. In the last 12 months, has caring caused you any financial difficulties?

Q15 Caring causes financial difficulties	Frequency	Valid percent %
No, not at all	193	59
Yes, to some extent	106	32
Yes, a lot	31	9
Total	330	100
<i>Missing</i>	15	
Total	345	

* This question was not asked in 2012 and 2014.

Over half of carers said that caring had not caused them any financial difficulties (59%). 9% said it had caused them a lot of difficulty.

Section 4: Information and advice quality

Q16. 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.

Q16 Finding information and advice	Frequency	Valid percent %	Valid percent: people who had tried to find information in last 12 months%	2014 %	2012 %
<i>I've never tried to find information or advice</i>	139	42	-	-	-
Very easy to find	26	8	14	18	18
Quite easy to find	91	28	48	50	50
Quite difficult to find	48	15	25	24	24
Very difficult to find	26	8	14	8	8
Total	330	100	100	100	100
<i>Missing</i>	15	-	-	-	-
Total	345	-	-	-	-

Under half of **all** carers said that information or advice was very or quite easy to find: **36%**, compared to **38%** in 2014. Nearly half – **42%**, compared to **43%** in 2014 and **31%** in 2012 – had never tried to find it.

When percentages are calculated using only 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 **61%** (when figures are rounded), which is lower than in 2014 and 2012, when it was **68%** (both years). This is the figure used to report ASCOF indicator 3D. Several people commented on whether it was easy to find information, and an analysis of their comments can be found on the next page. Comments included:

“When mum was in hospital, it would have been useful to have been useful to have information about who to inform. We were fined for informing the office about the change to personal credits later than we should have, not having experience of such benefits we were unaware of what was required.”

“No-one offers information or advice, and if you don't know where to look for it you are totally lost.”

Theme	Number of people		
	2016	2014	2012
I only get information from voluntary organisations	5	-	-
I do not have the time to look for information	2	-	-
I do not need information at present but may in future	2	-	-
I did not get any answers from social services	2	-	-
I go to a carers support group	2	-	-
Information about changes in care services and costs was not well communicated	2	-	-
Staff are not as knowledgeable as they should be	2	-	-
You have to be proactive because no-one provides you with information	2	-	-
Can be difficult to get through to the correct person	2	1	-
<i>Other – comments made by only one person</i>	39	-	-

Q17. 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.

Q17 Helpfulness of information and advice	Frequency	Valid percent %	Valid percent: people who had received information in last 12 months %	2014 %	2012 %
I have not received any information or advice in the last 12 months	134	41	-	-	-
Very helpful	57	17	30	36	45
Quite helpful	113	35	59	53	49
Quite unhelpful	17	5	9	9	4
Very unhelpful	6	2	3	3	1
Total	327	100	100	100	100
<i>Missing</i>	18	-	-	-	-
Total	345	-	-	-	-

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 exactly the same as in the 2014 survey. Over a third of all carers in the survey, **41%**, had not received any information or advice. The most common themes in people's comments when asked about the helpfulness of information and advice about support, services or benefits they had received in the past 12 months were:

- The voluntary sector has helped us **14** people
- Everyone involved has given good advice **4** people

A summary of themes is shown below, and a full list of themes is available on request.

Q17. In the last 12 months, how helpful has the information and advice you have received been?	Number of people		
	2016	2014	2012
Voluntary sector has helped us	14	-	4
Everyone involved has given good advice	4	-	-
The system of paying for care has not been well explained to me	2	-	-
The social worker was friendly but not knowledgeable	2	-	-
The social worker has been helpful	2	6	13
I need more financial advice than I am getting	2	-	1
Health services have not been helpful	2	-	-
Have not looked for information	2	-	-
Council was not that helpful in providing information	2	-	-
<i>Other (comments made by only one person)</i>	37	-	-

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

Q18. 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?

Q18 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 %	2014 %	2012 %
There have been no discussions that I am aware of in the last 12 months	70	21	-	-	-
I always felt involved or consulted	117	35	44	46	51
I usually felt involved or consulted	77	23	29	34	30
I sometimes felt involved or consulted	60	18	23	18	15
I never felt involved or consulted	11	3	4	3	4
Total	335	100	100	100	100
<i>Missing</i>	10		-	-	-
Total	345		-	-	-

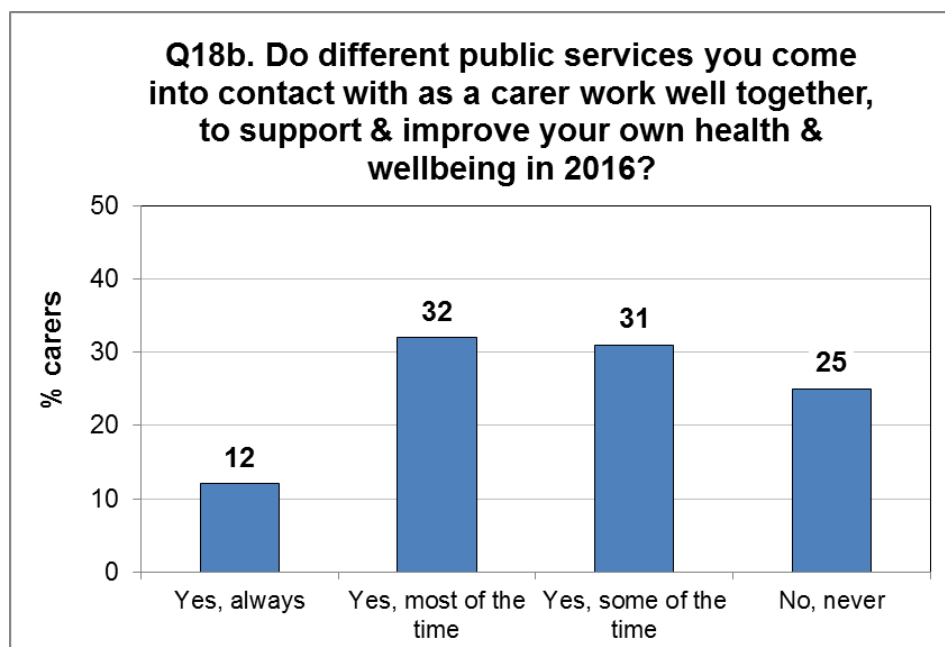
Over half of **all** carers in the survey said that they always or usually felt involved or consulted, as much as they wanted to be, in discussions about the support or services provided to the person they care for (58%). When people who said that there had been no discussions that they were aware of in the last 12 months are removed from the calculation, this total is 73%, which is significantly lower compared to 2014 (80%). This figure (73%) is the figure used when reporting ASCOF indicator 3C.

Q18b. 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?

Q18b Services work well together*	Frequency	Valid percent %	2014 %
Yes, always	29	12	17
Yes, most of the time	79	32	31
Yes, some of the time	77	31	30
No, never	61	25	22
Total	246	100	100
<i>Missing</i>	25		
<i>Don't know or does not apply to me</i>	74		
Total	345		

* This question was not asked in 2012.

Under half of all respondents felt that different public services always or mostly worked well together to support and improve their health and wellbeing (44%). 25% said that this never happened. We asked if carers had any comments about this, and a table showing their views is shown on the next page.



Comments included:

“It gets very confusing [navigating] between the hospital social worker, Newcastle City Council staff, and care workers from private partners of Newcastle City Council”.

“I was not aware of the local council and the health service working together. Council advice was limited, but the health services have at last given practical help and assistance.”

“I feel sometimes it would be of benefit if someone called you to see if you have any problems, or if you are coping.”

Q18b Do you find that different public services you come into contact with as a carer work well together?	No of people who said this
Departments need to communicate better with each other	2
Only one agency provides us with services	2
Advice has been helpful	1
Care homes do not get sufficient supervision from local government	1
Care homes seem to be badly run	1
Council and health services do not work well together	1
Difficult to get through to the correct person	1
Every agency has its own way of doing things	1
Health services were helpful	1
Health visitors are not good at working with other services	1
I do not know who to contact about what	1
I do not like people I do not know watching me care	1
I have told a social worker about my mental health issues, but they did not listen	1
I only receive help that is privately paid for	1
It is confusing to know who works for which service	1
It would be good if someone called to check if you are coping	1
It would be good to be offered a health check	1
Most agencies are good at working together but not all	1
My GP seems unaware of my caring role	1
Services could work better together	1
Services I used to use do not exist due to cuts	1
Services seem to protect each other rather than the care user	1
Social services do not know enough about health services	1
Social services have not provided the services my doctor said I need	1
Social services were helpful	1
Some services are less understanding than others	1
The council were not helpful about arranging a council tax direct debit	1
The EHC I have for the person I care for is not working well	1
The transition from children's services to adult services for the person I care for was not well managed	1
Was not aware of the council and health services working together	1
We provide care, but I am concerned for older people with no families	1
We would like to get more therapy for the person I care for	1

Q18c. 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?

Q18c Know how to make a complaint*	Frequency	Valid percent %	2014 %
Yes, and I feel I could if I wanted to	199	60	67
Yes, but I do not feel I could if I wanted to	20	6	6
No, I do not know how to make a complaint	114	34	27
Total	333	100	100
<i>Missing</i>	12		
Total	345		

* This question was not asked in 2012.

Over half of carers (60%) said that they knew how to make a complaint about care and support services, and felt that they could do this. This is slightly lower than in 2014 (67%), and has been matched by an increase in the percentage replying that they do not know how to make a complaint (34%, compared to 27% in 2014). We asked if carers had any comments about this, and the main themes can be seen in the table below. One comment was:

“I have made complaints to the care service on their poor performance and contacted social services but it has been very ineffective. The care company do not take feedback well and do little to improve their service.”

Q18c Know how to make a complaint – comments	No of people who said this
I have made a complaint but it has not been addressed or resolved	5
I am concerned that if I take my complaint further it could negatively affect the person I care for	3
I am sure I could find out how to	2
I have nothing to complain about	2
I do not feel any complaint I made would be listened to	1
I do not feel involved enough to be able to make a complaint	1
I feel I could address anything that needed improving	1
I have already complained to the Director of Adult Social Care	1
I have enough to do and cannot spare the time to make a complaint	1
I have issues to complain about but am not sure how to	1
I put in a complaint about the care at home service	1
I think I know how to complain	1
I would ask my social worker how to do this	1
I would look this up on the internet	1
I would need a family member to help	1
When I complain I am just advised that I should change care providers	1

Section 6: Carers and the caring role

Q19. In addition to your caring role, please tell us which of the following also applies to you?

Q19 Employment status*	Frequency	Valid percent %	2014 %	2012 %
Retired	178	52	55	54
Not in paid work	57	17	15	15
Employed part-time (working 30 hours or less)	54	16	14	12
Employed full-time	44	13	15	14
Other	18	5	4	7
Doing voluntary work	15	4	3	5
Self-employed part-time	6	2	2	2
Self-employed full-time	5	2	1	3
Total no. of people who answered the question	344	-	-	-
<i>Missing</i>	1		-	-
Total	345		-	-

* 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 and 2014, just over half of carers were retired (52%). There has been no significant change in response to this question since 2012.

Q19b. In addition to your caring role (and employment, if you are employed), please tell us which of the following also applies to you?

Q19b Education and caring*	Frequency	Valid percent %*	2014 %
I am in full-time education or training (<i>studying for 21 or more hours a week during term-time or whilst on a course</i>)	1	0	0
I am in part-time education or training (<i>studying for less than 21 hours during the week during term-time or whilst on a course</i>)	6	2	2
I am not in education or training at present	276	98	98
Total	283	100	100
<i>Missing</i>	62		
Total	345		

* This question was not asked in 2012.

Nearly all carers in the survey said that they were not in education or training (98%), which was also the case in 2014.

Q20. Thinking about combining paid work and caring, which of the following statements best describes your current situation?

Q20 Employment status	Frequency	Valid percent %	Valid percent: people who are in employment %	2014 %	2012 %
I am not in paid employment because of my caring responsibilities	57	18	-	38	49
I am not in paid employment for other reasons (such as being retired)	166	51	-		
I am in paid employment, and I feel supported by my employer	54	16	54	18	15
I am in paid employment, but I don't feel supported by my employer	12	4	12	14	15
I do not need any support from my employer to combine work and caring	25	8	25	12	11
I am self-employed and I am able to balance my work and caring responsibilities	5	2	5	7	4
I am self-employed but I am not able to balance my work and caring responsibilities	4	1	4	6	5
Total	323	100	100	100	100
<i>Missing</i>	22				
Total	345				

As in 2012, the single largest percentage of carers (69%) were not in paid employment for other reasons, such as being retired (51%), which was also the case in the 2012 and 2014 surveys. Of those who were in employment, 54% said they felt supported by their employer.

Q20b. Thinking about combining education and caring, which of the following statements best describes your current situation?

Q20b Education and caring*	Frequency	Valid percent %	2014 %
I am not currently in full- or part- time education because of my caring responsibilities	148	69	22
I am not currently in full- or part- time education, for other reasons	55	26	74
I am in full- or part- time education, but I do not feel supported by my educational establishment	8	4	0
I am in full- or part- time education, and I do not need any support from my educational establishment to combine education and caring	3	1	3
I am in full- or part- time education, and I feel supported by my educational establishment	1	1	1
Total	215	100	100
<i>Missing</i>	130		
Total	345		

* This question was not asked in 2012.

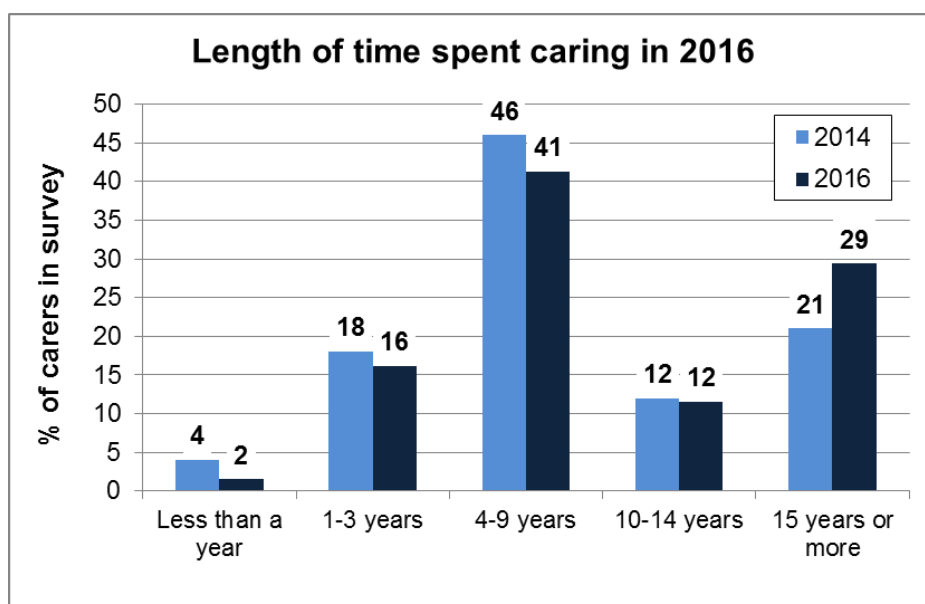
The majority of carers were not in full- or part- time education due to their caring responsibilities (69%, compared to 22% in 2014). 26% of carers said that they were in education due to their caring responsibilities (only 6% were in education).

Q21. About how long have you been looking after or helping the person you care for?

Q21 Length of time spent as a carer	Frequency	Valid percent %	2014 %	2012 %
Less than 6 months	0	0	1	1
Over 6 months but less than a year	5	2	3	3
Over 1 year but less than 3 years	55	16	18	15
Over 3 years but less than 5 years	64	19	19	20
Over 5 years but less than 10 years	76	22	27	20
Over 10 years but less than 15 years	39	12	12	15
Over 15 years but less than 20 years	30	9	6	7
20 years or more	70	21	15	18
Total	339	100	100	100
<i>Missing</i>	6	-		
Total	345	-		

Most carers had been caring for more than one year but less than 10 years (57%). 21% had been caring for 20 years or more. There has been no significant change since 2012.

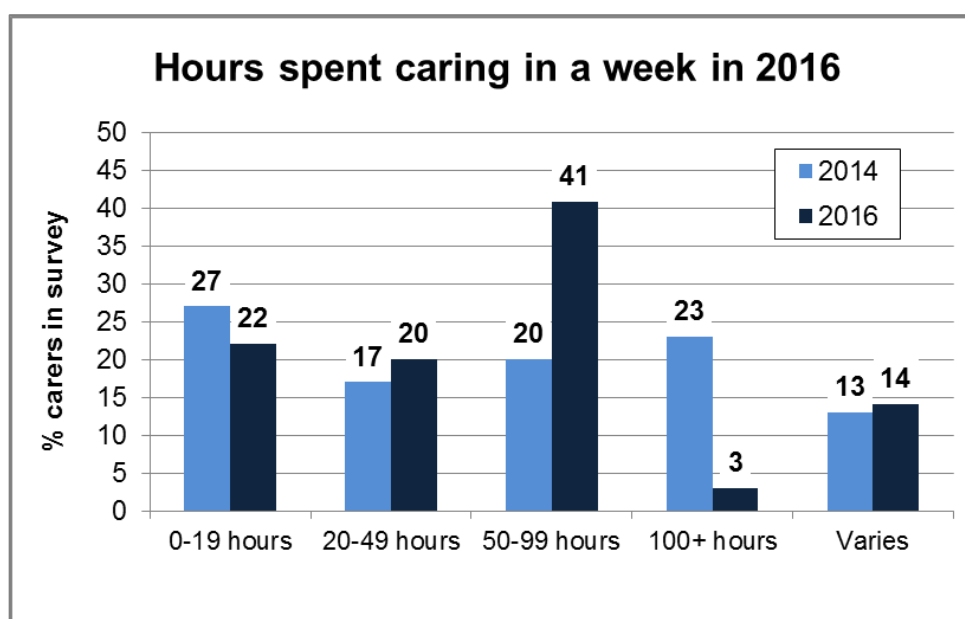
The chart on the right compares the statistics for 2014 and 2016.



Q22. About how long do you spend each week looking after or helping the person you care for?

Q22 Length of time spent caring each week	Frequency	Valid percent %	2014 %	2012 %
0-9 hours per week	44	13	13	13
10-19 hours per week	30	9	14	14
20-34 hours per week	33	10	9	9
35-49 hours per week	34	10	8	7
50-74 hours per week	31	9	5	7
75-99 hours per week	106	32	15	31
100 or more hours per week	10	3	23	4
Varies – Under 20 hours per week	24	7	4	7
Varies – 20 hours or more per week	23	7	9	8
Other	0	0	0	0
Total	335	100	100	100
<i>Missing</i>	10			-
Total	345			-

The largest single percentage of carers said that they were caring for 75-99 hours per week (32%). This is a change from 2014, when the largest single percentage of carers said that they were caring for 100 hours per week or more (23%), but in line with 2012, when the largest single percentage of carers said that they were caring for 75-99 hours per week (31%).



The chart above shows the statistics for 2014 and 2016.

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 the table below. Comments included:

“I live too far away to visit, but I support them daily by phone and other practical ways such as dealing with care company, dealing with post, finances etc. and organising food deliveries.”

“Most of the time my wife can cope, but I like to be there to help and make sure she is okay. She is partly incapacitated.”

“As my mother is now in residential care, the time I spend looking after her is reduced. However, a lot of my time has been taken up sorting finances, etc.”

Q22 Comments on amount of time per week spent caring	No of people who said this
24 hours a day, 7 days a week	16
They are now in residential care	7
I visit them in their care home	5
It has reduced since they went into residential care	4
All day every day except when care worker is there	3
It is like having a full-time job	3
It varies	2
All day every day except when they are at a day centre	1
Description of household	1
Description of tasks	1
I call them each day to check they are okay	1
I care by keeping in touch via phone and dealing with paperwork and finances	1
I care daily but the hours vary	1
I spend a minimum amount of time caring with extra hours as needed	1
I support them to care for themselves	1
I visit a few times a year	1
These are care hours, I spend more hours with them socially	1
These are the hours I spent before they went into residential care	1
They cannot be left alone	1

Q23a. Over the last 12 months, what kinds of things did you usually do for the person you care for?

Q23a Caring tasks	Frequency	Valid percent %*	2014 %	2012 %
Helping with paperwork or financial matters? (Such as writing letters, sending cards, filling in forms, dealing with bills, banking)	299	88	84	86
Keeping him / her company? (Things like visiting, sitting with, reading to, talking to, playing cards or games)	297	88	86	82
Keeping an eye on him / her to see s/he is all right?	296	87	86	83
Other practical help? (Things like preparing meals, doing his / her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital)	296	87	88	88
Helping with dealing with care services and benefits? (Things like making appointments and phone calls, filling in forms)	296	87	86	84
Giving emotional support?	280	83	81	80
Taking him / her out? (Such as taking out for a walk or drive, taking to see friends or relatives)	252	74	76	75
Personal care (Things like dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet)	200	59	60	57
Giving medicines? (Things like making sure s/he takes pills, giving injections, changing dressings)	210	62	59	64
Physical help (Such as helping with walking, getting up and down stairs, getting into and out of bed)	170	50	50	50
Other help?	37	11	10	10
Total	339	-	-	-
<i>Missing</i>	6			-
Total	345			-

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

The most common caring tasks were: “helping with paperwork or financial matters” and “keeping him or her company?” (88%). This is slightly different from 2012 and 2014, when 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. However, in 2012 and 2014 88% of carers did this, and in 2016 this percentage was 87%, so there has been no significant change. Some people commented on the “other help” they gave the person they cared for, and their answers are presented in the table below. The most common themes in people’s comments when asked about the sort of things they usually did for the person they cared for were:

- Supporting attendance at medical and personal care appointments **11 people**

- Description of the tasks above **7 people**
- Checking that care home is meeting their needs **6 people**
- Anything that needs doing **5 people**

“My mum is now in residential care but I visit nearly every day as she needs individual contact to prevent her getting depressed and confused. Little things like hearing aid batteries needing to be replaced are often missed by the busy care home staff.”

The table below shows the main themes in people’s comments:

Q23a Over the last 12 months, what kinds of things did you usually do for the person you care for?	2016	2014
Supporting attendance at medical and personal care appointments	11	5
Description of the tasks above	7	-
Checking that care home is meeting their needs	6	-
Anything that needs doing	5	4
I do all these things	2	-
I support them to do these tasks for themselves	2	-
I take them to social facilities	2	1
Night time care	2	-
Other	2	-
I deal with finances	1	3
I do personal care if the care workers do not arrive	1	-
I do the gardening	1	-
I keep them company	1	-
Keeping them safe	1	1
Spiritual support	1	-
They are in a care home so I do not do any tasks now	1	2

Q23b. Please tell us about anything that you think might affect your ability to care for the person you look after in the future

In 2016 and 2014, we asked carers to tell us about what they thought might affect their ability to care in the future. In both years, the most common answers were “if my health declines” (32 people said this) and “the aging process” (21 people said this). Comments included:

“I am getting sick myself, and should I become ill or have any kind of accident I would not be able to continue in my caring role.”

“My mental and physical health feels at times that it is deteriorating to the point of feeling hopeless, and often angry and frustrated.”

The full list of themes are shown below:

Q23b Things that might affect my ability to care in the future	2016	2014
If my health declines	32	33
The aging process	21	29
If my existing health conditions get worse	14	6
If the condition of the person I care for gets worse	8	5
If I become ill suddenly	6	5
If my mental health gets worse	5	1
If my joint condition gets worse	4	8
Nothing I can think of	4	1
The person I care for has just gone into residential care	4	8
If health problems mean I cannot drive	2	-
If I have to go into hospital	2	-
If the other person I care for gets worse	2	4
Me dying	2	-
My health is already poor	2	-
Right now my health is okay	2	-
The demands of raising a family at the same time as caring	2	-
<i>Other (comments made by only one person)</i>	41	17

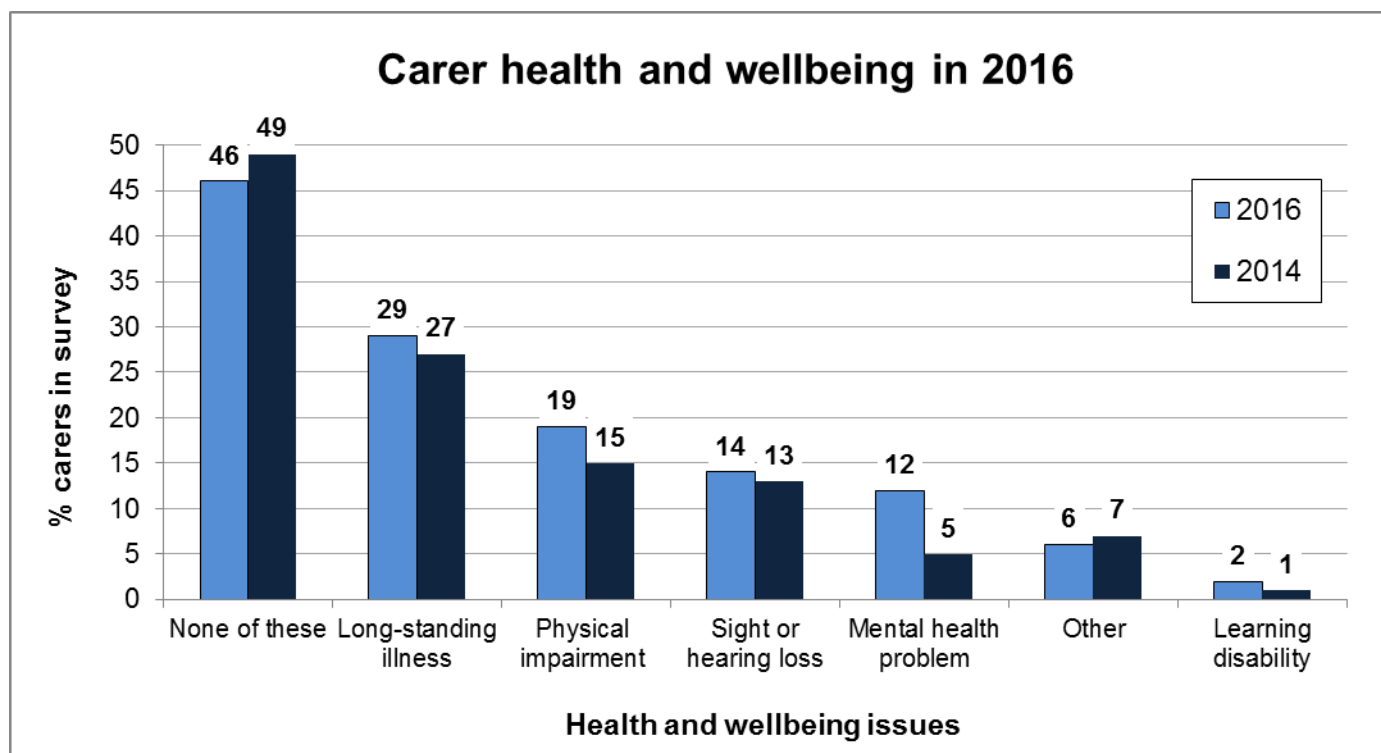
* This question was not asked in 2012.

Q24. Do you have any of the following?

Q24 Carer health and wellbeing	Frequency	Valid percent* %	2014 %	2012 %
None of the above	140	46	49	49
A long-standing illness	89	29	27	27
A physical impairment or disability	57	19	15	19
Sight or hearing loss	44	14	13	14
Other	17	6	7	6
A mental health problem or illness	37	12	5	9
A learning disability or difficulty	6	2	1	2
Total	307	-	-	-
<i>Missing</i>	38	11		-
Total	345	100		-

* 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 (46%). Of those who did, 29% had a long-standing illness and 19% had a physical impairment or disability. These figures are very similar to those from 2012 and 2014. The chart below compares the figures from 2016 and 2014.



Of people who replied “other”, the most common “other” reason was that they were suffering from a longstanding health condition, such as arthritis (12 people) or the after-effects of an earlier illness or accident (five people).

Q24 comments – carer health and wellbeing, “other” conditions	2016
Description of existing situation	30
Longstanding health condition	12
After-effects of earlier illness or accident	5
Aging	2
Physical impairment (bad back)	2

Q25. How many (if any) children aged 18 or under do you have parental responsibility for?

Q25 Number of children	Frequency	Valid percent* %
No children	92	71
1	22	17
2	9	7
3	6	5
4	1	1
5	0	0
6 or more	0	0
Total	130	100
<i>Missing</i>	215	62
Total	345	

* This question was not asked in previous years.

The largest percentage of respondents did not answer this question (62% of all respondents to the survey). This may indicate that they do not have parental responsibility for any children aged 18 or under, but we cannot be certain.

The largest percentage of those who answered the question replied “no children” (71%). Of those who did have parental responsibility for children aged 18 and under, the largest percentage (17% of those who answered the question) had responsibility for one child.

Q26. How old are you?

Q26. Age of carer*	Frequency	Valid percent %	2014 %	2012 %	% in 2016 sample	% in 2016 population**	Difference between respondents & population
18-24	1	0	0	0	1	1	-1
25-34	6	2	1	1	4	4	-1
35-44	6	2	7	6	8	8	-6
45-54	50	17	16	22	21	21	-4
55-64	107	36	31	30	31	31	+5
65-74	69	23	27	19	17	18	+5
75-84	44	15	13	18	13	12	-3
85 and over	26	5	5	5	5	5	-
Total	298	100	100	100	100	100	-
<i>Missing</i>	<i>47</i>						
Total	345						

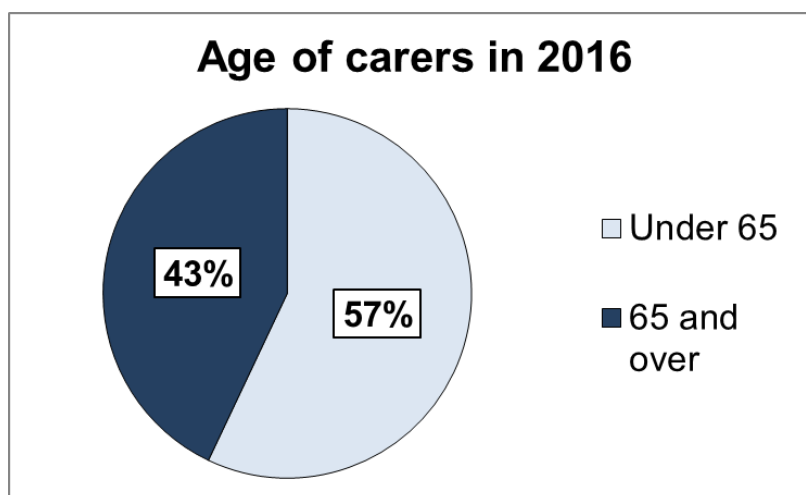
* This information has been taken from a combination of data already held in our records, and respondents' replies to the question in the survey about their age.

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

As in 2012 and 2014, the largest single percentage of carers were aged between 55-64 (36%). Nearly half (43%) were aged 65 and over. As shown above, carers between 55-74 are somewhat overrepresented in the sample, and those aged under 54 somewhat underrepresented.

However, it should be noted that we do not hold any information about age for around 16% of the total

"population" of carers (453 out of 2,791), so these figures are illustrative only. The chart above shows the split between carers aged above and below 65.

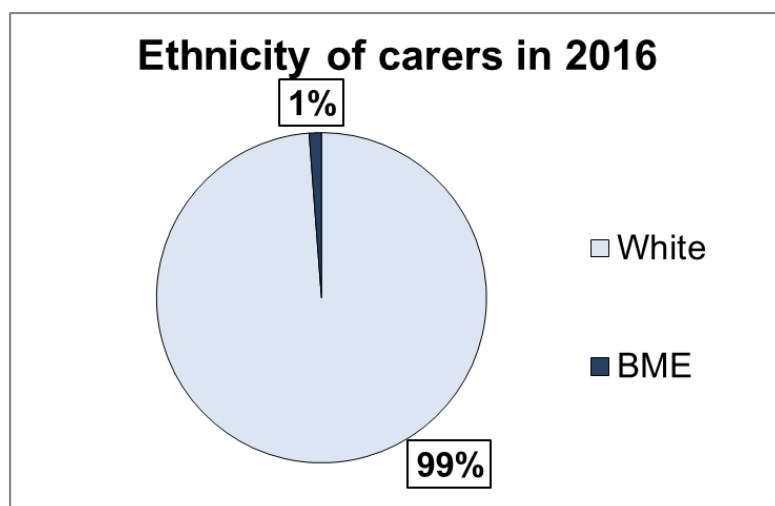


Q27. Ethnic origin of the carer

Q27 Ethnic origin	Frequency	Valid percent %	2014 %	2012 %	% in sample
White	338	99	96	97	93
Asian or Asian British	0	0	2	1	5
Black or Black British	0	0	1	0	0
Chinese	0	0	0	0	0
Mixed	4	1	0	0	1
Other	0	0	0	0	0
Total	342	100	100	100	100
<i>Missing</i>	3				
Total	345				

As in 2012 and 2014, the majority of carers who took part in the survey were from a White ethnic background (99%). This is significantly higher than the percentage of White carers in the sample (93%).

The chart on the right summarises these figures.



Q28. Did anyone help you complete the questionnaire?

Q28 Did anyone help you complete the questionnaire?	Frequency	Valid percent %	2014 %	2012 %
Yes	27	8	8	6
No	313	92	92	94
Total	340	100	100	100
<i>Missing</i>	5			
Total	345			

As in 2012 and 2014, the majority of carers completed the questionnaire without help from anyone else (92%).

Q29. Do you receive a direct payment?

Q29. Do you receive a direct payment?	Frequency	Valid percent %	2014 %	2012 %	% in sample
Yes, I do	190	57	52	1	59
No, I do not	118	35	40	99	41
Don't know or not sure	28	8	8	-	-
Total	336	100	100	100	100
<i>Missing</i>	9			-	-
Total	345			-	-

* 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 (57%), which is in line with both the 2014 figure (52%) and the percentage of carers in the sample who received this (59%). (The change between 2012 and 2014 may be attributed to some carers receiving Direct Payments, but not knowing that this is what the money they were receiving was called.)

Q30. If you do receive a Direct Payment, what do you use it for?

Q30. If you do receive a Direct Payment, what do you use it for?*	Frequency	Valid percent %	2014 %
<i>This does not apply to me because I do not have a Direct Payment</i>	117	42	19
Things that make it easier for you to care (such as paying for travel)	75	27	44
Domestic help or household goods to make it easier for you to care	52	18	23
Activities that improve your quality of life (such as exercise, meeting friends and family, or pursuing a hobby)	60	12	22
Support or services to allow you to have a rest from caring for between 1 and 24 hours (such as a sitting service)	28	10	17
Support or services allowing you to take a break from caring for more than 24 hours	29	10	16
Something else	33	12	14
Support or services allowing you to take a break from caring at short notice or in an emergency	14	5	7
Education , learning or other activities to help you develop skills	4	1	2
Total	282	-	100
<i>Missing</i>	63		-
Total	345		-

* This question was not asked in 2012. Respondents could choose as many options as applied to them, so percentages do not total 100.

As in 2014, 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 (27%). The next most common answer was “domestic help or household goods” (18%). We asked if people had any comments about this, and their answers are shown in the table on the next page. Comments included:

“I use it for gardening which enables me to be home-based for my 'care' but provides exercise and relation too. I am so grateful those I receive this without taking it from 'family funds', as I probably would not enjoy the freedom of choice that I do, knowing those the money has been given for my use.”

“I used it to buy an iPad to make banking and shopping easier, a purchase I really appreciate.”

The three most common uses for direct payments were:

- Transport (15 people)
- Meals out (8 people)
- Respite care (7 people)

Of these, transport and respite care costs were also among the most common reasons for spending direct payments in 2014.

Q26 If you do receive a Direct Payment, what do you use it for?	2016	2014
Transport	15	10
Meals out	8	3
Respite care	7	12
Days out	4	2
Domestic appliances	3	2
Garden maintenance	3	2
Home equipment and aids	3	-
Support worker when the person I care for wants to socialise or go for a short holiday	3	2
Go to hospital appointments	2	-
Groceries	2	-
Happy with the payment	2	-
Holiday	2	4
Extra help in the home	2	3
Purchase extra incontinence pads	2	-
Residential care costs	2	-
Short breaks	2	2
Theatre visits	2	-
Time out and personal care for me	2	3
Visit friends	2	3
Bus fares	1	-
Chiropractor	1	-
<i>Other (comment made by only one person)</i>	25	-

Q31. What carers told us

We asked respondents if they would like to describe any other experiences they wanted to tell us about, or if they had any other comments. The main themes in their comments were:

- Care at home was better when it was run directly by the local authority **4 people**
- I look after two people **3 people**
- The person I care for has gone into residential care **3 people**

Theme	2016	2014	2012
Care at home was better when it was run directly by the local authority	4	1	-
I look after two people	3	3	3
The person I care for has gone into residential care	3	2	-
Applying for financial support and help is too complex and exhausting	2	1	-
Care workers kept arriving late	2	-	-
Carers often understand the person being cared for better than anyone else	2	-	-
Description of the situation	2	-	-
I am awaiting the outcome of an appeal about funding	2	-	-
I am trying to keep the person I care for in their own home	2	-	-
I cannot leave the person I care for alone	2	-	-
I do not have time to do anything for myself	2	1	-
I do not think the person I look after gets adequate care	2	-	-
I get support from my family	2	1	-
I have had to care for two people in succession	2	3	3
I struggle to care for two people at once	2	-	-
Incontinence seriously limits the carer's and cared-for person's quality of life	2	-	-
The care workers are not good at performing their tasks	2	1	-
The hospital's carer's pack still needs some work	2	-	-
The person I care for is happy in residential care	2	1	-
We are still waiting for the equipment we need	2	-	-
<i>Other (comment made by only one person)</i>	155	-	-

Comments included:

“We feel we were given very little help in supporting my mum. We eventually looked for private solutions for things like showering, as the services offered by the council were unreliable. Staff who turned up were pleasant and kind, but often complained about the company they worked for (contracted by the council) in terms of poor pay. As a result, they were constantly changing. Visits were often late or non-existent, and this just added to the stress.”

Q33. In future, what is the best way for the council to provide you with information or correspond with you?

Q33. Preferred methods of communication	Frequency	Valid percent %	2014 %
Standard print	239	86	96
Email	47	17	3
Large print	11	4	2
Other	4	1	0
Explained through BSL interpreter	1	0	0
In another language	0	0	0
Computer disc (CD)	0	0	0
Audio tape or CD	0	0	0
Braille	0	0	0
Total	279	100	100
<i>Missing</i>	66	-	-
Total	345	-	-

* This question was not asked in 2012.

Nearly all carers were happy to receive information in standard print (86%). Of those who specified another preferred format, email was the most popular, as 47 people chose this.

About the carers

Responded to original postal questionnaire or a reminder?

Responded to original or reminder?	Frequency	Valid percent %	2014 %	2012 %
Original	267	78	80	39
Reminder	78	22	20	61
Total	345	100	100	100

Around 78% of the respondents responded to the original, compared to 80% in 2014, and 39% in 2012.

The 2014 figure is more accurate, as in 2012 this was estimated using the date of return. In 2014 and 2016, 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.

Gender

Gender	Frequency	Valid percent %	2014 %	2012 %	% in sample	% in population
Male	116	31	32	34	31	30
Female	223	68	68	66	39	70
Total	339	100	100	100	100	100
<i>Not known</i>	6					
Total	345					

The majority of carers in the survey were female (68%). This is in line with the total population of carers, where 70% are female.

Religion

Religion	Frequency	Valid percent* %	2014 %	% in sample
Christian	74	78	75	72
None	13	14	15	16
Muslim	4	4	5	8
Other	2	2	3	3
Jewish	1	1	1	1
Hindu	0	0	0	1
Sikh	0	0	0	1
Total	94	100	100	100
<i>Not known</i>	251			
Total	345			

* We did not report this information in 2012.

As in 2014, the majority of carers in the survey whose religion was known were Christian (78%), which is in proportion to the sample (72%).

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

Carer assessed jointly or separately?	Frequency	Valid percent %	2014 %	2012 %	% in sample
Jointly	333	97	93	96	97
Separately	12	3	7	4	3
Total	345	100	100	100	100

As in 2012 and 2014, and in line with the sample, nearly all carers had been assessed jointly with the person they care for (97%).

Support involving cared-for person

Support involving cared-for person	Frequency	Valid percent %
Respite services provided	25	3
No respite services provided	790	97
Total	815	100
<i>Unknown</i>	1	0
Total	816	-

The majority of cared-for people (97%) had not had any respite services provided.

Funding status of cared-for person

Funding status of cared-for person	Frequency	Valid percent %
Supported and funded by the local authority	695	89
Full-cost	81	10
Self-funded	2	0
Cared-for person not known to local authority	3	0
Total	781	100
<i>Unknown</i>	35	0
Total	816	

The majority of cared-for people (89%) were supported and funded by the local authority.

Delivery Mechanism of cared-for person

Delivery mechanism of cared-for person	Frequency	Valid percent %
CASSR-managed Personal Budget	505	63
CASSR-commissioned support only	132	16
Direct Payment only	111	14
Part Direct Payment	57	7
Total	805	100
<i>Unknown</i>	11	0
Total	816	

The majority of cared-for people (63%) were receiving a CASSR-managed personal budget.

Reported Health Condition of cared-for person: Asperger Syndrome / High Functioning Autism

Reported Health Condition of cared-for person: Autism	Frequency	Valid percent %
Yes	13	2
No	803	98
Total	816	100

The majority of cared-for people (98%) did not have a diagnosis of Asperger Syndrome or high-functioning autism.

Reported Health Condition of cared-for person: Autism (excluding Asperger Syndrome / High Functioning Autism)

Reported Health Condition of cared-for person: Autism	Frequency	Valid percent %
Yes	7	1
No	809	99
Total	816	100

The majority of cared-for people (99%) did not have a diagnosis of autism (excluding Asperger Syndrome or high-functioning autism).

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?

- a. Dementia
- b. A physical disability
- c. Sight or hearing loss
- d. A mental health problem
- e. Problems connected to ageing
- f. A learning disability or difficulty
- g. Long-standing illness
- h. Terminal illness
- i. Alcohol or drug dependency

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

- a. Yes
- b. No

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

- a. With me
- b. 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?

- a. We haven't received any support or services from Newcastle Wellbeing Care and Learning in the last 12 months
- b. I am extremely satisfied
- c. I am very satisfied
- d. I am quite satisfied
- e. I am neither satisfied nor dissatisfied
- f. I am quite dissatisfied
- g. I am very dissatisfied
- h. 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 or 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

6e: 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.

- a. I'm able to spend my time as I want, doing things I value or enjoy
- b. I do some of the things I value or enjoy with my time but not enough
- c. 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?

- a. I look after myself
- b. Sometimes I can't look after myself well enough
- c. 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.

- a. I have no worries about my personal safety
- b. I have some worries about my personal safety
- c. 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?

- a. I have as much social contact as I want with people I like
- b. I have some social contact with people but not enough
- c. 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?

- a. I feel I have encouragement and support
- b. I feel I have some encouragement and support but not enough
- c. I feel I have no encouragement and support

13. Thinking about the other people you have caring responsibilities for, which of the following best describes your current situation? Please exclude the person you spend most time helping.

- a. I always have enough time to care for them
- b. I sometimes have enough time to care for them
- c. I never have enough time to care for them
- d. I don't have caring responsibilities for anyone else

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

- a. Feeling tired
- b. Feeling depressed
- c. Loss of appetite
- d. Disturbed sleep
- e. General feeling of stress
- f. Physical strain (e.g. back problems)
- g. Short-tempered or irritable
- h. Had to see my own GP
- i. Developed my own health conditions
- j. Made an existing condition worse
- k. Other
- l. No, none of these

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

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

Section 4: Information and advice quality

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

16. 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.

- a. I have not tried to find information or advice in the last 12 months
- b. Very easy to find
- c. Fairly easy to find
- d. Fairly difficult to find
- e. Very difficult to find

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

17. 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.

- a. I have not received any information or advice in the last 12 months
- b. Very helpful
- c. Quite helpful
- d. Quite unhelpful
- e. 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.

18. 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?

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

18b. 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.

- a. Yes, always
- b. Yes, most of the time
- c. Yes, some of the time
- d. No, never
- e. Don't know or does not apply to me

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

18c. 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?

- a. Yes, and I feel I could if I wanted to
- b. Yes, but I do not feel I could if I wanted to
- c. 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.

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

- a. Retired
- b. Employed full-time
- c. Employed part-time (working 30 hours or less)
- d. Self-employed full-time
- e. Self-employed part-time
- f. Not in paid work
- g. Doing voluntary work
- h. Other

19b. In addition to your caring role (and employment, if you are employed), please tell us which of the following also applies to you?

- a. I am in full-time education or training (*studying for 21 or more hours a week during term-time or whilst on a course*)
- b. 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*)
- c. I am not in education or training at present

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

Not in paid work

- a. I am not in paid employment because of my caring responsibilities
- b. I am not in paid employment for other reasons (such as being retired)

In paid employment

- c. I am in paid employment, and I feel supported by my employer
- d. I am in paid employment, but I don't feel supported by my employer
- e. I do not need any support from my employer to combine work and caring

Self-employed

- f. I am self-employed and I am able to balance my work and caring responsibilities
- g. I am self-employed but I am not able to balance my work and caring responsibilities

20b. Thinking about combining education and caring, which of the following statements best describes your current situation?

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

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

- a. Less than 6 months
- b. Over 6 months but less than a year
- c. Over 1 year but less than 3 years
- d. Over 3 years but less than 5 years
- e. Over 5 years but less than 10 years
- f. Over 10 years but less than 15 years
- g. Over 15 years but less than 20 years
- h. 20 years or more

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

- a. 0-9 hours per week
- b. 10-19 hours per week
- c. 20-34 hours per week
- d. 35-49 hours per week
- e. 50-74 hours per week
- f. 75-99 hours per week
- g. 100 or more hours per week
- h. Varies – Under 20 hours per week
- i. Varies – 20 hours or more per week
- j. Other

If other, please specify:

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

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

If other, please tell us more about this:

23b. Please tell us about anything that you think might affect your ability to care for the person you look after in the future:

24. Do you have any of the following?

- a. A physical impairment or disability
- b. Sight or hearing loss
- c. A mental health problem or illness
- d. A learning disability or difficulty
- e. A long-standing illness
- f. Other
- g. None of the above
- h. If you replied "other", please tell us more about this:

25. How many (if any) children aged 18 or under do you have parental responsibility for?

26. How old are you? _____ years

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

- a. **White** (British, Irish, any other White background)
- b. **Mixed** (White and Black Caribbean, White and Black African, White and Asian, any other Mixed background)
- c. **Asian** or **Asian British** (Indian, Pakistani, Bangladeshi, any other Asian background)
- d. **Black** or **Black British** (Caribbean, African, or any other Black background)
- e. **Chinese**
- f. Any **other** ethnic group
- g. If other, tell us more about this.

28. Did someone help you to complete this questionnaire?

- a. Yes
- b. No

29. 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.

- a. Yes, I do
- b. No, I do not
- c. Don't know / not sure

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

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

If something else, please tell us more about this:

31. 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:

32. 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.

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

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

33. In future, what is the best way for the council to provide you with information or correspond with you?

- a. Standard print
- b. Large print
- c. Braille
- d. Audio tape
- e. Computer disc (CD)
- f. Explained through BSL interpreter
- g. In another language (*please tell us which one*)
- h. Email (*please tell us your email address*)
- i. Other (*please tell us about this*)

Information known about the people in the sample

1. Gender
2. Age
3. Ethnicity
4. Religion
5. Method of Assessment of Review
6. Support provided to carer
7. Support involving cared-for person
8. Funding status of cared-for person
9. Delivery mechanism of cared-for person
10. Primary Support Reason of the person being cared for (Physical Support, Sensory Support; Support with Memory and Cognition; Learning Disability Support; Mental Health Support; Social Support)
11. Reported Health Condition of cared-for person – Autism (excluding Asperger Syndrome or High-Functioning Autism)
12. Reported Health Condition of cared-for person – Asperger Syndrome or High-Functioning Autism
13. Responded to the original questionnaire or to a reminder?



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