



CARING FOR OTHERS SURVEY

2012-2013

Analysis Report

2013-03-27 Carers Report 201213 v0.6

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SUMMARY AND KEY MESSAGES

The majority of carers we are supporting are over 45 and over, female and most are retired or not working. On the whole they live with the person they care for. Around 66% of them are affected by a condition or illness in their own right. Most of these people have been caring for 3 years or more and spend up to 20 hours per week doing so.

In terms of issues which affect their quality of life, having things to do which they value and enjoy outside of caring and having control over their daily lives, are areas where people are indicating they have the highest level needs.

The responses also tell us that:

- Carers say that being involved or consulted in discussions about the person they care for is most important to them – the 15% of carers said they only felt involved sometimes and 4% never felt involved.
- Having support in an emergency or crisis situation is the second most important consideration for carers. However, very few of those surveyed reported using this service (7%).
- Assessing their needs as carers and identifying appropriate support to help them care is also a key aspect.
- Carers want good quality, professionally delivered, information and advice – communicated face to face, via telephone or via leaflets.
- Information and advice about the illness or condition affecting the person they care for is what carers want to know about most – signposting to other specialist organisations or information sources (for dementia / stroke / cancer / aging generally etc) would help with this and be fairly easy to do.
- There is much scope for improving the satisfaction level of carers. Concentrating on the areas above, which carers are telling us are important, has the potential to improve satisfaction levels.

PURPOSE OF THE REPORT

This report presents data from the 2012-2013 Carers Survey as robust evidence of the views of carers in Cumbria. It has the potential to inform commissioning and well as improvement or existing practice and service delivery. As an overview analysis of the responses received it aims to provide information to:

- allow monitoring of what we are achieving for local carers in their view
- identification of key areas for service development and improvement
- enable development of front-line practice in relation to Adult Social Care (ASC) staff
- support forward planning, commissioning and market development
- share with providers, partner organisations and stakeholders to support development and improvement in the work they do for local people

The data can also supplement and inform the Directorate Business Review (DBR) across some of the 7 principles of social care: personalisation, prevention, protection, plurality, partnership, productivity and people.

The following sections contain some basic analysis accompanied by narration. Further work could be done to 'dig deeper' into individual questions (e.g. around safety) or to cross tabulate the results by different characteristics and questions. An example of this might be investigating whether reported quality of life is correlated to services carers or the people they care for have used. However, consideration would need to be given as to how any breakdown affects the validity of results e.g. by focusing on a very small sample of data.

PROFILE OF CARERS

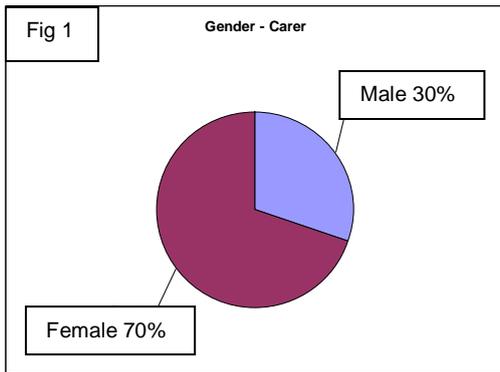


Fig. 1 shows the gender split for carers in the overall sample as 70% female compared to 30% male.

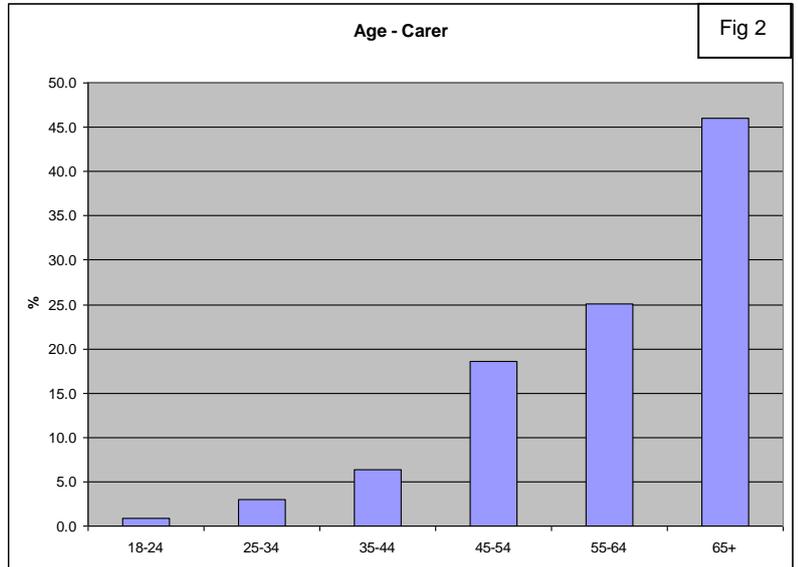


Fig. 2 shows that 46% of carers were aged 65 or over. A further 25% were aged between 55 and 64 years.

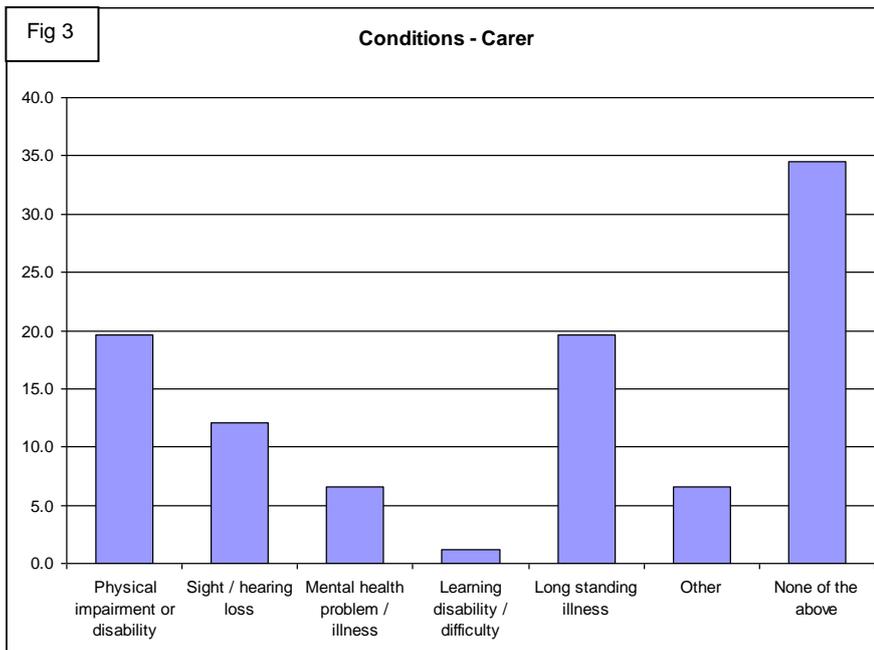
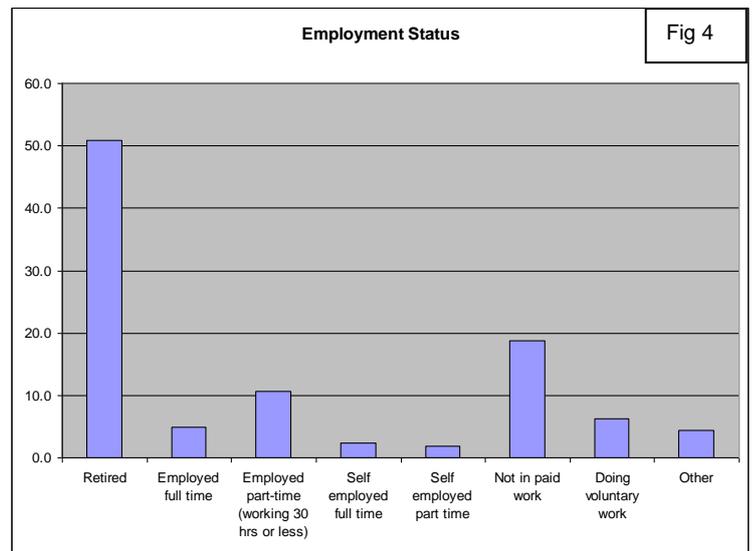


Fig 3 relates to any conditions or illness affecting the carer. Respondents could tick as many answers as was applicable. Around 35% said 'none of the above'.

Of the 227 people who indicated they were affected by a condition or illness around 66% indicated being affected by one and 25% by two of the options. Just over 9% of carers indicated three or more of the options were applicable to them. Physical impairment or disability and long standing illness were the most common responses.

Fig 4 – Employment status. Not surprisingly, given the carer age profile, over 50% of responses indicated the carer was retired. It was possible for people to select more than one response to this question and, where this occurred, it was most commonly a combination of ‘retired’ and ‘doing voluntary work’ or retired and ‘not in paid’ work.

Just less than 20% of carers reported being in paid employment of some kind (including those who were self-employed). Around 11% stated they were part-time and 5% full-time. The remaining 4% were self employed on either a full or part-time basis.



The survey also included a question around how supported people in employment felt. As the numbers in full or part-time employment were small (around 20%), and some people indicated they did not feel they needed support from their employer, it is difficult to draw conclusions from the responses with any certainty. However, of the 52 applicable responses about 40 indicated they felt supported by their employer whereas 12 didn't.

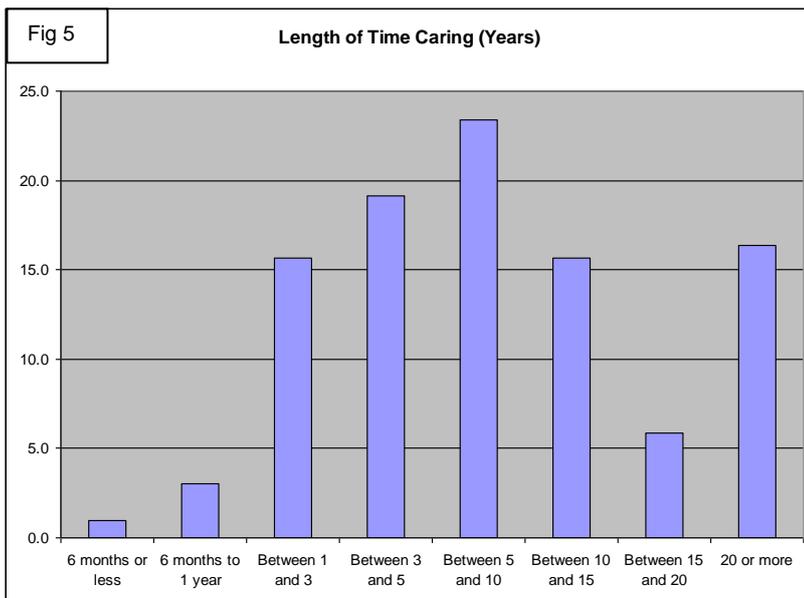
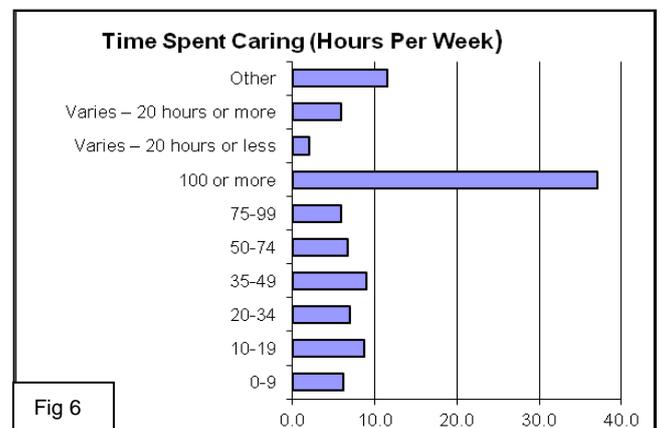
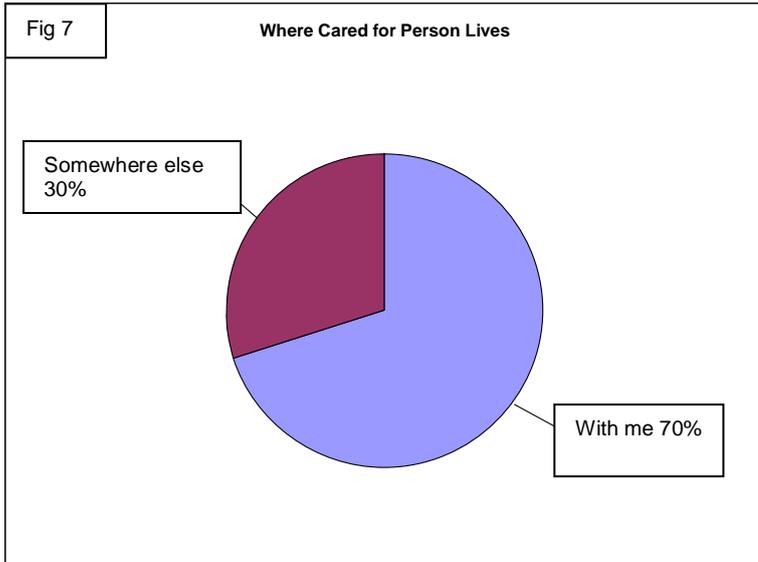


Fig 5 shows the breakdown of length of time respondents had been looking after or helping the cared for person.

The low numbers of those reporting caring for less than a year could potentially be explained by the fact that the survey was sent to those people who had had a carers assessment or review and so were perhaps less likely to be ‘new’ to caring. There is a noticeable drop in the number of people in the 15-20 years category this was also the case in 2009 when a similar survey was carried out. It is unclear as to why this might be.

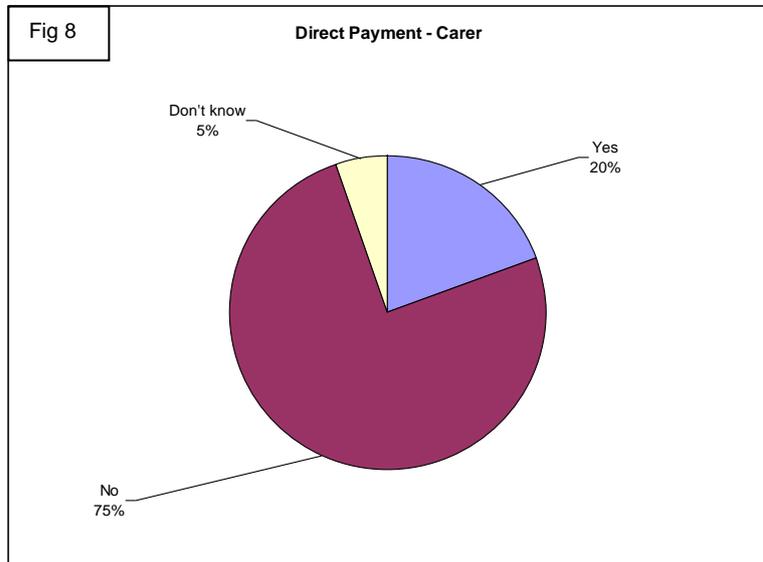
In terms of time spent caring per week most carers (37%) reported caring for 100 hours or more with very few (2%) spending 20 hours or less. As can be seen in Fig 6 percentages across the remaining specified options were very similar at between 6% and 9%. The ‘other’ category was most commonly accompanied by 24/7 or ‘all the time’ as a response and so could be included with the 100 hours or more figures bringing this up to around 49%.





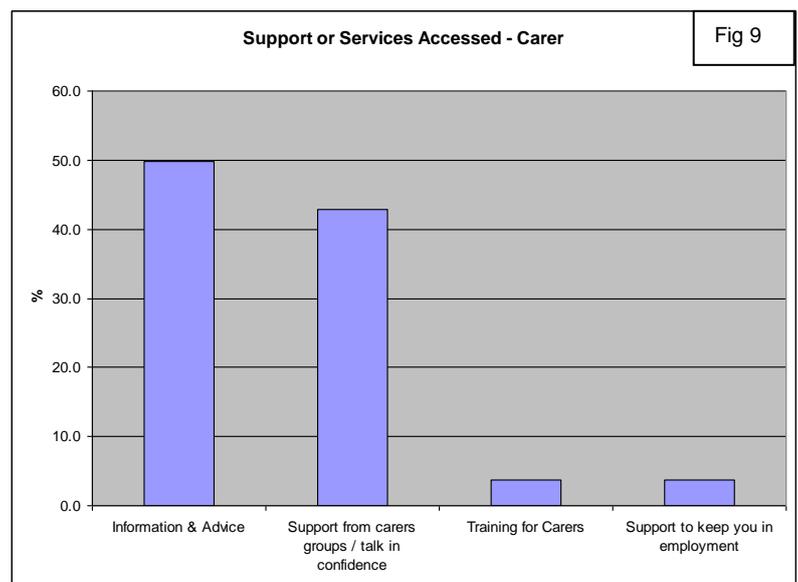
As can be seen in Fig 7, 70% of carers who responded live with the person they are looking after or helping. It might be useful to try and understand whether this figure is representative of carers who receive an assessment as a whole. If it isn't then we may not be reaching those carers who live 'somewhere else' effectively. Analysis of the responses from the Adult Social Care Survey (ASCS) from 2011-12, excluding those people in residential care, shows that 47% of people say they get help from someone who lives with them whilst 51% of people receive help from someone who lives in another household.

Fig 8 shows that only 20% of carers reported being in receipt of Direct Payment in relation to their caring role.



a

Fig 9 shows that 50% of the responses indicated that the carer had accessed information and advice to help them in their caring role. 40% related to accessing support from a carers group or someone to talk to in confidence. Given all those who responded should have received either a carers assessment or review of their needs as a carer these figures seems low. Very few respondents report having been supported to stay in employment – given the age profile this and employment status this is perhaps to be expected. Respondents could select more than one answer option and 49% of people who answered the question reported accessing two.



PROFILE OF CARED FOR PERSONS

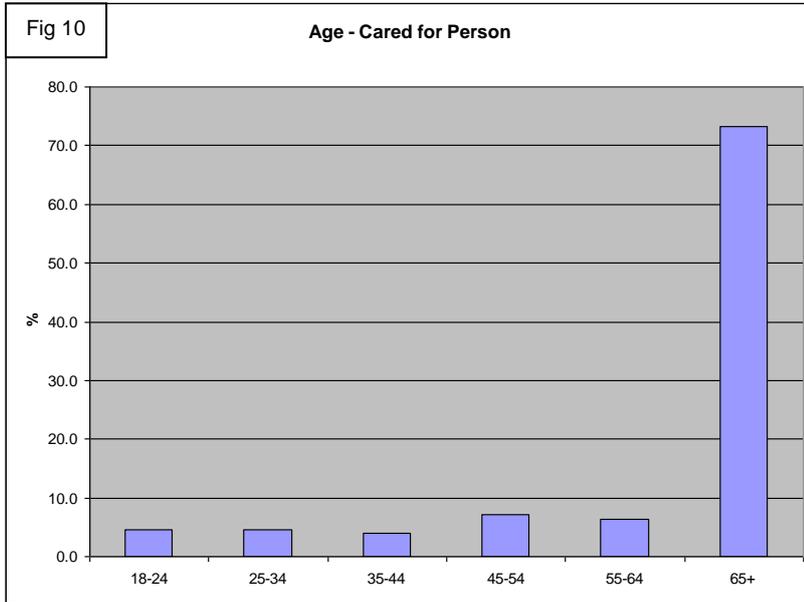
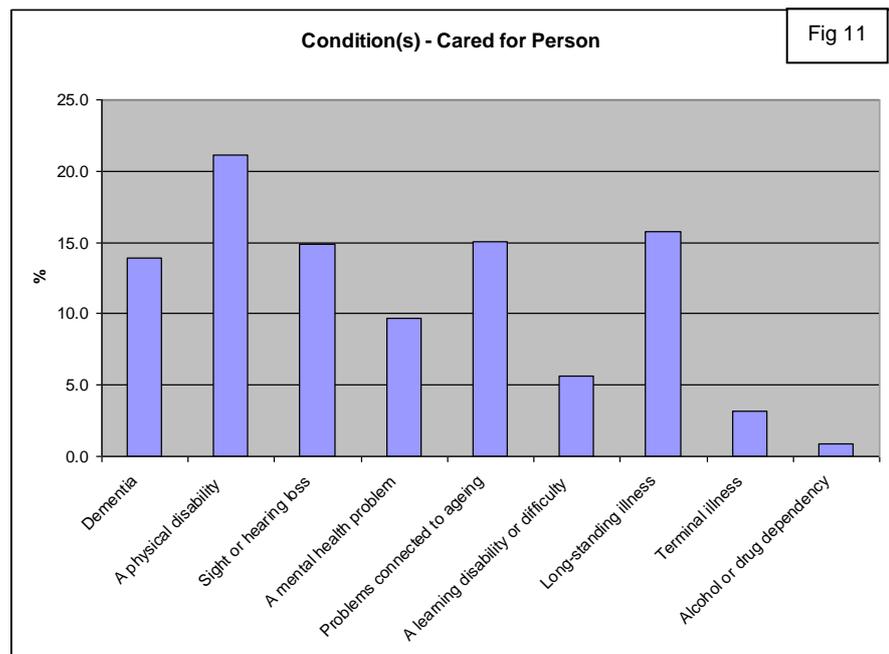


Fig 10 demonstrates that over 70% of people being cared for were 65 or over. The remaining 30% were evenly spread across the younger age ranges – with, on average, 5% in each.

Respondents were asked to indicate what condition or illness affected the person they cared for. It was possible to select multiple answers to this question. 435 carers answered the question and 27% of these selected two answer options with 26% selecting three. 16% indicated four or more were applicable.

Fig 11 shows the most common response was physical disability (21%) with dementia, sensory loss, problem connected to aging and long standing illness coming next all in the region of 14% or 15%. Around 10% of people reported caring for a person with a mental health issue.

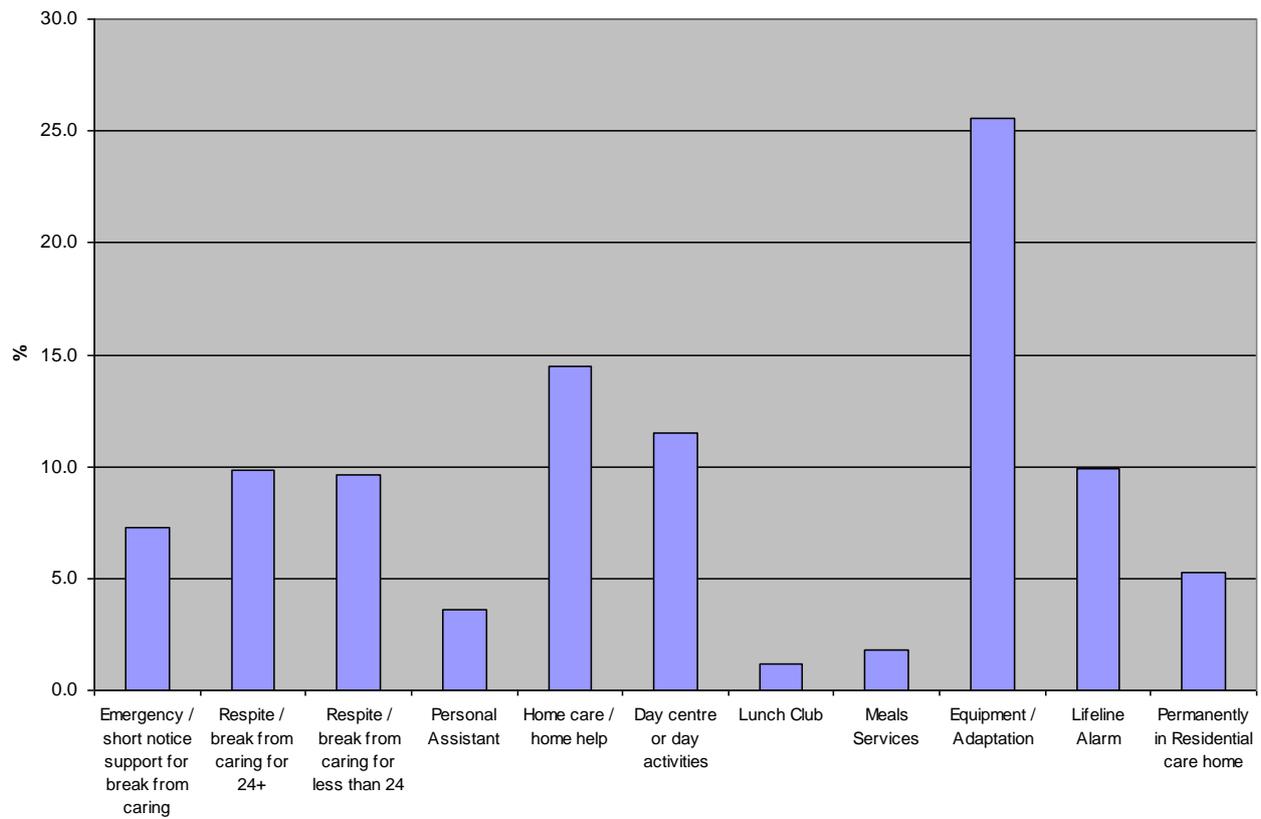


There were also questions about the support or services the cared for person had accessed, Fig 12 over page shows that equipment or adaptations were the most common with 25% of responses. Home care and day activities accounted for a further 14.5% and 11.5% respectively. Respite (under and over 24 hours) and lifeline alarms accounted for around 10% each and emergency support around 7%.

357 people answered the question and it was possible to select more than one response in relation to services or support accessed, 71% indicated they had accessed two or more and 46% had accessed three or more.

Fig 12

Support or Services Accessed - Cared for Person



QUALITY OF LIFE (QoL)

The survey includes a set of questions relating to six domains of quality of life. The domains and the questions have been developed over a number of years and are similar to those used in the ASCS with people who use services. The answers allow carers to rate different aspects of their quality of life from the 'best possible' state to the 'worst possible' state. During the data analysis process a score is allocated to each of the six answers allowing an overall figure to be calculated for the County. In this instance the overall quality of life index for carers in Cumbria is 8.2 – the maximum possible is 12 and the minimum is 0. It will be possible to compare this in relation to similar Local Authorities once national data is available later in 2013. As the number of questions and possible answer options differ for carers it is not possible to compare this score with that for the ASCS.

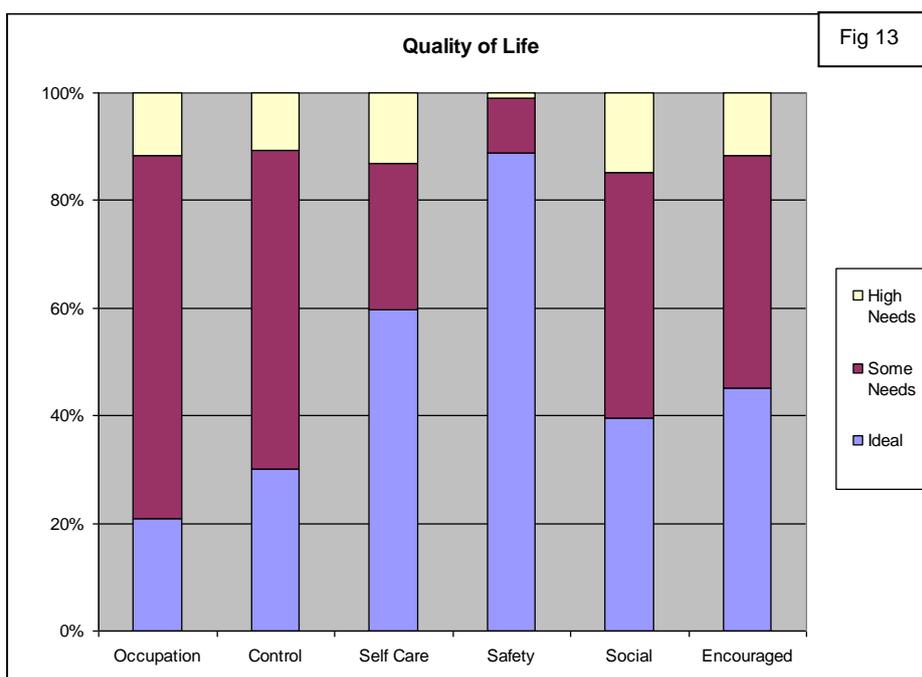


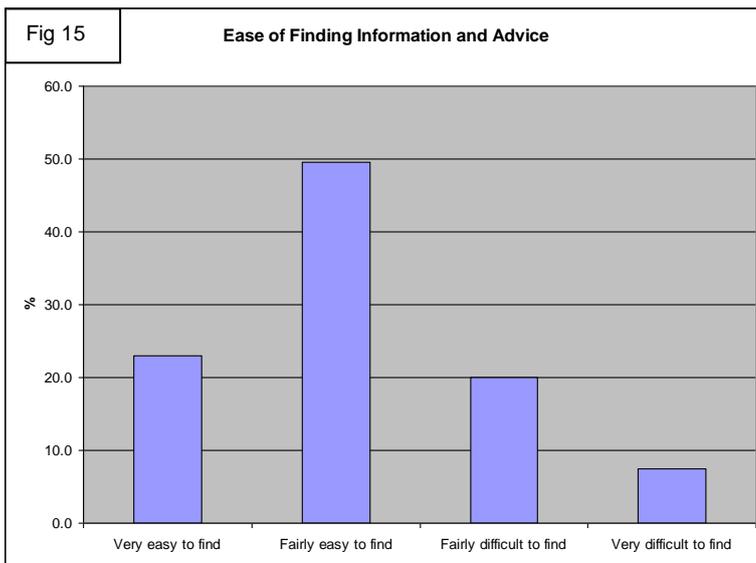
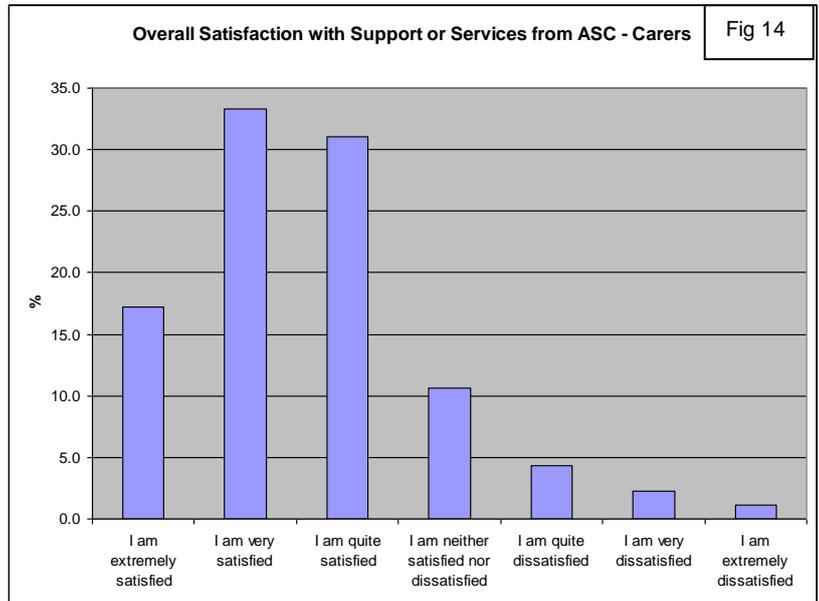
Fig 13 above shows responses across the domains broken down by the level of need indicated by their answers. Safety is the domain with the most respondents reporting the 'ideal' state with 89% having no worries about their personal safety. The Occupation, Control domains have the lowest percentages of carers reporting the 'ideal' state with 21% and 30% respectively the social contact and feeling encouraged / supported coming next with 39% and 45%. These four domains also have over 45% (and up to 67%) of carers reporting some needs and between 10.5% and 15% all respondents reporting 'high' needs.

A similar set of questions were asked of carers in 2009 and the responses to this do not differ greatly from those received this time and shown above.

SATISFACTION AND FINDING INFORMATION

Fig 14 shows that around 51% of carers report being either 'extremely' or 'very' satisfied with the support or services they have received from ASC. 31% are in the 'quite' satisfied category. About 8% of carers are reporting some degree of dissatisfaction.

This question was asked in the 2009 survey of Carers mentioned previously. There is a drop of about 5% in those reporting being either 'extremely' or 'very' satisfied, although this may not be statistically significant. 27% were 'quite' satisfied and 6% were dissatisfied to an extent.



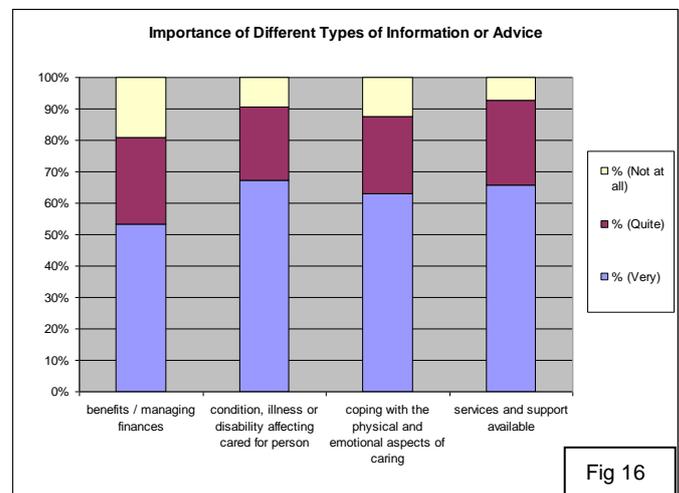
In Fig 15 you can see that of those carers who had tried to find information or advice about support, services or benefits around 73% reported it was either 'very' or 'fairly' easy to find. However this means that around 27% had some degree of difficulty.

More encouragingly once they had located information 93% found it either 'very' or 'quite' helpful.

Additional questions included to support a wider consultation with carers, asked about what methods they would use when accessing information and the overwhelming response was that people

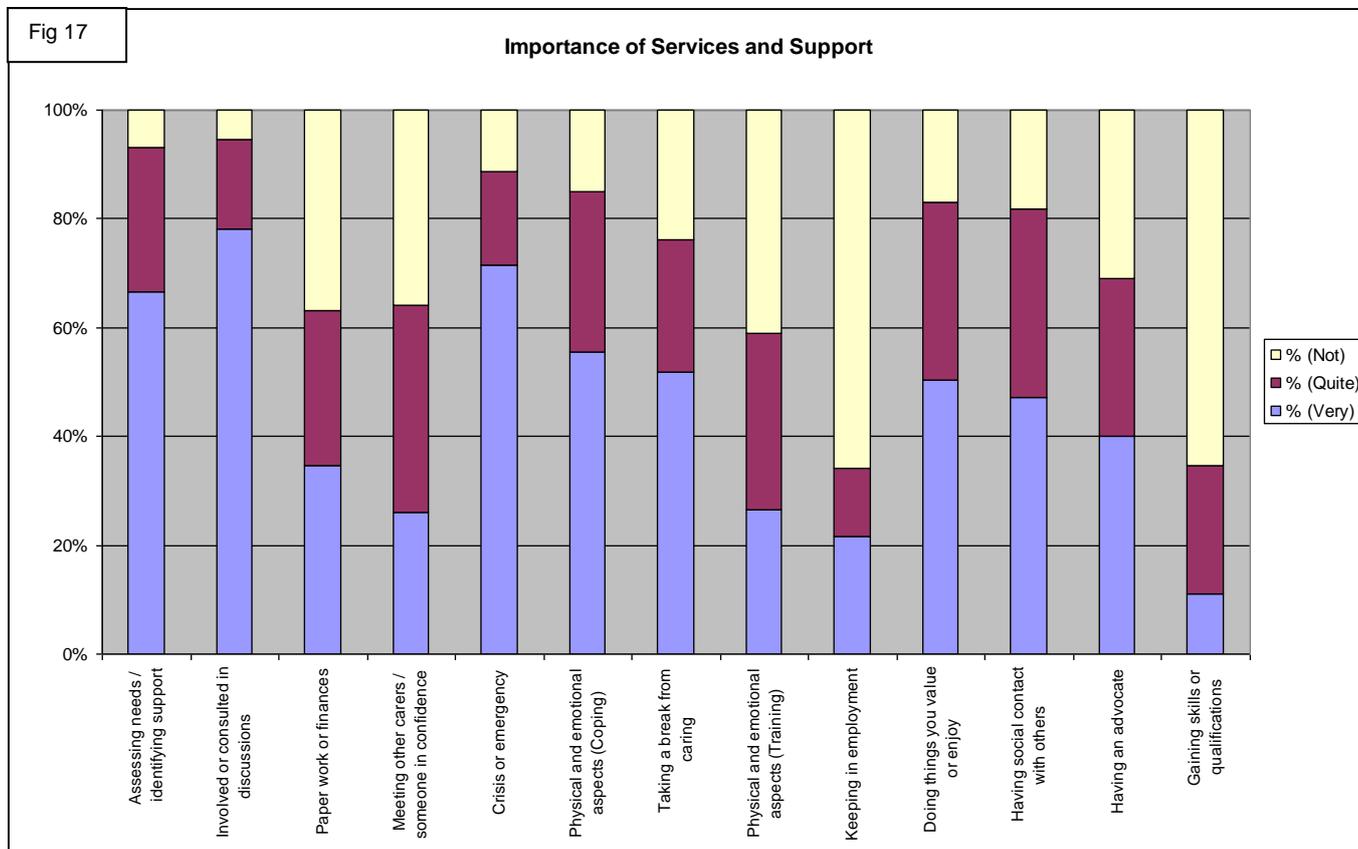
preferred to do this either face to face (96%) or via telephone (87%) with a social worker or other professional. Printed leaflets and factsheets were also popular with 77% of respondents indicating they would use this method. Online methods were very unpopular with 63% saying they wouldn't use websites and 93% saying they would not use social media to access information or advice.

Carers said that information and advice about a condition, illness or disability affecting the person they care for was most important followed closely by support and services available to them – Fig 16. Coping with the physical and emotional aspects of caring and finding out about benefits or managing finances were also rated as very important by more than half of those who responded.



IMPORTANCE OF SUPPORT AND SERVICES – CARERS

One of the other additional questions, added in support of the wider consultation, asked about the importance places on a range of support and services. Fig 17 below shows the responses to this question.



The top three areas felt to be important by most carers were:

- Being involved or consulted in discussions in relation to support or services for the person they care for
- Support or service to help them in an emergency or crisis
- Having their needs as a carer assessed and appropriate support or services identified

The three areas felt to be least important were:

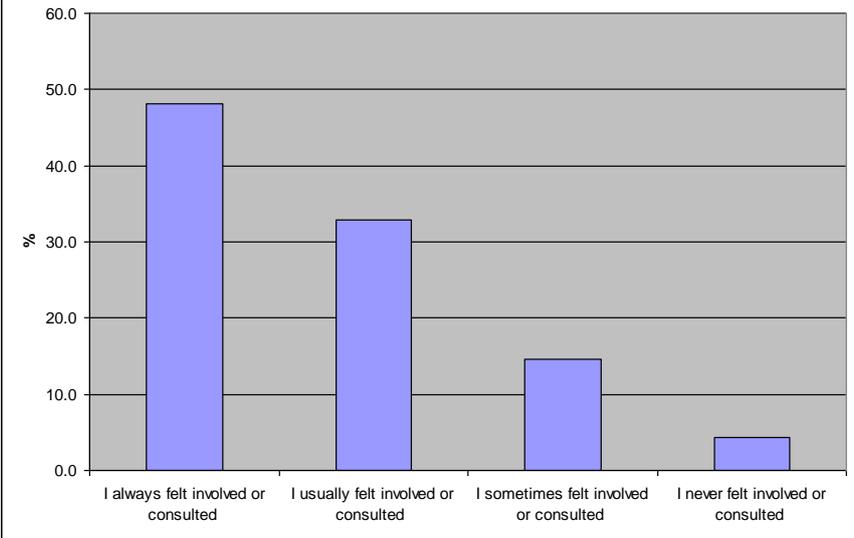
- Help to stay in employment
- Gaining new skills or qualifications
- Training on the emotional or physical aspects of caring

Given the age profile of carers surveyed, and the length of time that many have been caring, those less important areas might be expected.

Fig 18 below indicates that just over 80% of carers said they 'always' or 'usually' felt involved or consulted in discussions relating to the person the care for. However, this does mean that around 20% don't.

How Involved or Consulted Carers Feel
(In discussions relating to the support or services of person they care for)

Fig 18



ADULT SOCIAL CARE OUTCOMES FRAMEWORK (ASCOF)

The responses to the Carers Survey feed the following ASCOF measures.

ASCOF Measure	Result
1D - Carer Reported Quality of Life	8.1
3B – Overall satisfaction of carers with social services	50.6%
3C – The proportion of carers who report that they have been included or consulted in discussions about the person they care for	81%
3D - The proportion people who use services and carers who find it easy to find information about services (carers element only)	72.5%

NB: Outcome 3D is joined to the equivalent question from the Adult Social Care Survey to produce the final outcome - therefore the score indicated above is NOT the final outcome and is only the Carers element of this indicator.

THEMES FROM COMMENTS

Throughout the survey there was opportunity for carers to provide comments on what is important to them and how they feel they could be supported better. The following paragraphs are a summary of the common themes emerging from these comments.

Most frequently people commented about the communication of information. This was in relation to:

- the awareness of staff and organisations (adult social care and health in the main) in what support is available for carers
- not being given information which they later found out by other means
- inconsistency of information, being told one thing by one person / organisation and then something else by another
- difficulty in finding key information

“The quality of information received has depended on which social worker I have asked”

“When my father came to live with me following his release from hospital the social worker gave me no information....after a few weeks we were given another social worker who was very helpful”

“Most services I use I have only found out about by friends. Social workers or ASC do not pass on any of this information.”

“The advice is there but can be conflicting”

“Different people said different things and no one really seemed to work together.”

“Information should be more available in places like Doctors, surgeries chemists etc.”

Generally comments suggest that carers would appreciate a central information point where they can get key information on what support is available, when and where from and understand eligibility for this.

“Initially it was hard to get good information. It would have been good to have had just one central point of contact and some written information. Not just one subject, but all different aspects of looking after someone”

“A central information point would be great.”

“Info and advice about all the different agencies and services is difficult to access and there seems to be so many and no one seems to have an ‘overall’ view.”

“When the initial crisis happened it was difficult to know who to ask for advice and how to seek out this information. Trying to find telephone numbers was unclear and even getting names of agencies was not easy. It was mostly trial and error before being pointed in the right direction.”

There were a number of comments relating to lack of contact, poor follow up and information being delivered too late.

“More contact and information from our social worker. We never hear from her or see her.”

“It would be helpful if messages were passed on instead of repeatedly having to ring back.”

“We had a good social worker but she now works in another department. We feel quite neglected now”.

“The right noises made on the phone but no follow up.”

“Advice was helpful but follow up was dire.”

“No assessment done to provide free care this should have been done follow ups are very lacking.”

“Carers should be given more information on respite care and sitting services. Unfortunately I did not get this information early enough to prevent me becoming stressed and depressed, I had no idea this help was available until I rang social services and said I could no longer cope”.

Many carers expressed in their comments that it is very important that professionals supporting them understand their situation and the difficulties they face whilst caring.

“lack of services and understanding of the problems that can happen”

“Me and X are exhausted, not sure how much longer we can carry on, can’t seem to get the social worker to understand. Don’t know what they are actually waiting for or how bad mum needs to be before they agree with us.”

“I think that when you are caring for a relative that is usually someone who is close to you – you don’t think about how to do it or what services you need- you just get on and do your best. It takes health care and professionals to recognise when you are struggling and need help.”

Respite was the service most mentioned on comments and carers were reporting issues around availability, difficulty in organising and timing (i.e. emergency / booking in advance)

“Having written confirmation particularly relating to respite....longer notice so I can make arrangements for myself and not leave it to the last minute.”

“Good respite care houses are in very short supply.”

“I would like to see a care home specifically for respite care. Respite shouldn't depend on crisis care. You also need to change carer's concept of respite. They should feel they and their dependants can enjoy a holiday. Lots of old people are concerned about going into an old people's home even for respite care so perhaps it's time to change the name and the place they go to.”

Other common themes were focused around:

- Having cover so that carers can attend support groups and networks or just have some time to themselves for a few hours
- Communication between organisations and 'being passed around' – too many agencies and organisations being involved
- Overly complicated procedures, information and forms – especially in terms of eligibility, costs and who pays for what
- Speed of information and advice provision

Appendix 1 – Background to the Survey

Commissioned by the Department of Health (DH), the survey and guidance on how to carry it out is developed by the Health and Social Care Information Centre (HSCIC). Local authority representatives are also involved in the development process.

The HSCIC guidance states that the aim of the Caring for Others (Carers) Survey is to “provide assured, benchmarked local data on outcomes to support local services to think about ways of improving outcomes in a very challenging financial climate. The survey is constructed so that an individual outcome can be disaggregated into constituent groups. So, as well as providing an overall quality of life index, the survey will provide intelligence on whether specific groups experience better outcomes, whether services are meeting all outcome needs.” (Department of Health, 2012)

It features heavily in the Adult Social Care Outcomes Framework (ASCOF) and will be used to populate four of the outcome measures:

- 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.

It is also significant nationally as a driver for policy feeding “monitoring of the impact of the national carers strategy.” (Department of Health, 2012)

Local Authorities are able to include additional questions in the Carers Survey but must have the questions and their location within the survey approved by the HSCIC. Cumbria included 3 additional questions to gather information to support commissioning of services for carers and to supplement a wider consultation exercise. The reports relating to these questions and the consultation generally can be accessed at http://www.opinionsuite.com/cumbria/cumbria-county-council/adult-and-cultural-services/http-www-opinionsuite-com-cumbria-cumbria-county/consult_view .

The 2011-12 Carers Survey was sent to a random sample of carers who had an assessment or review of their caring needs in the 12 months prior to September 2012. This included carers of people from all client groups in community. The sampling method used ensures the results can be said to be representative of the views of carers who have had an assessment or review – this data was provided by the Carers Organisation in each district and also from Making Space.

We sent out 900 surveys and received 437 completed returns giving an overall return rate of 48.5%. This number of responses means a margin of error is only +/- 4.1%. 70% of responses were received in response to the initial mail out. A reminder, sent out three weeks later, prompted the remaining 30%.

Further information on the background to this key piece of national research, including a copy of the survey and guidance, are available from knowledge.management@cumbria.gov.uk

This is the first time that this national Carers Survey has been mandatory and featured in the ASCOF. However, it was carried out on a voluntary basis in 2009. Not all of the questions have remained the same but where possible comparisons have been drawn.