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Developing a Carers' Experience Performance Indicator

Juliette Malley, Diane Fox and Ann Netten

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PERSONAL SOCIAL SERVICES RESEARCH UNIT

University of Kent

University of Kent
Cornwallis Building
Canterbury
Kent
CT2 7NF
Tel: 01227 823963/823862
PSSRU@kent.ac.uk

London School of Economics

London School of Economics
LSE Health & Social Care
Houghton Street
London
WC2A 2AE
Tel: 020 7955 6238
PSSRU@lse.ac.uk

University of Manchester

University of Manchester
Dover Street Building
Oxford Road
Manchester
M13 9PL
Tel: 0161 275 5250
PSSRU@manchester.ac.uk

www.PSSRU.ac.uk

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1 Executive summary

The work presented here was commissioned under the previous government, with a view to developing a performance indicator (PI) for carers that could be used to populate the National Indicator Set (NIS) for the new spending period starting in 2011. To reflect the then Labour government's policy to realign the performance framework around the objective of improving outcomes for all, a PI that better reflected carers' experiences and outcomes was required. Surveys are an ideal mechanism for generating representative and generalizable data on the experiences and outcomes of carers. The aim of the work reported here was therefore to put forward a set of proposals for potential PIs from a survey of carers and present evidence concerning the relative merits of the proposals. Although the new government is set to reform the performance framework designed by Labour, it seems likely that a measure focused on the experiences and outcomes of carers will be of interest since these themes fit with the principles and ethos for the new outcomes framework set out by the Coalition government (Department of Health, 2010).

A potential source of carers' experiences and outcomes is the Personal Social Services Survey of Adult Carers in England 2009-10 (formerly known as the Carers Experience Survey) (Fox et al., 2010). This survey was designed during 2009 to capture information about the pledges made in the Labour government's Carers' Strategy (Department of Health, 2008). The survey was heavily based upon the 2008 Kent Carers Survey (Holder et al., 2009) with some amendments to reflect the priorities in the Carers' Strategy. The development of the two surveys involved fieldwork with 75 carers. The questionnaire is printed in Appendix A.

The Personal Social Services Survey of Adult Carers was carried out by Councils with Adult Social Services Responsibilities (CASSRs) under the guidance of the NHS Information Centre for Health and Social Care (IC) for the first time in November 2009 on a voluntary basis. Ninety CASSRs took part. The sample included carers who had received an assessment or review (either jointly with a service user or separately) in the last twelve months and carers named on the file of a service users who had received an assessment or review in the last 12 months, although not all CASSRs were able to identify carers through both of these routes leading to some variability in the composition of the sample between CASSRs. In our analysis of the potential PIs we have been careful to highlight how the variability in the composition of the sample may affect the score each CASSR achieves on a given PI.

1.1 Possible indicators

The desirable qualities for PIs depend largely on how the PIs are to be used and by whom. In the literature five desirable qualities are outlined: acceptability to stakeholders, feasibility of its use, validity, reliability and sensitivity. It is the relative balance between these qualities that is decided by how the PI is to be used and by whom. In this report we examine the validity, reliability and sensitivity of potential options for future PIs. We also discuss the acceptability and feasibility of options, on the basis of our understanding about how these PIs could be used. Of course, how these PIs are to be used is still a matter for debate and will only become clear as the Coalition publishes its strategy for carers and a social care white paper. In presenting the options for PIs we therefore limit our discussion to presenting the results of our analyses into validity, reliability and sensitivity and where we have felt it is necessary we highlight some of the important considerations surrounding feasibility and acceptability of the options. We do not make recommendations around the choice of PI since this is a matter for policymakers and stakeholders to debate in the light of the findings of this report and emerging policy considerations.

An advisory group was convened to identify the aspects of carers' experience that should be covered by a PI and initial proposals were circulated for comments to a wider group of stakeholders via the advisory group members' networks. As a result of the recommendations of the advisory group, further analysis was carried out on two potential types of PI. The first covered questions (or items) relating to access to and experience of services. The second covered items on quality of life and aims to encompass the Carers' Strategy pledge that carers should be able to have a life of their own. A series of questions asking about access to basic health services and carers' experiences of health services were not developed as potential PIs because they were considered outside of the control of CASSRs. However, depending on how policymakers wish to resolve the issue of attribution (discussed below) we may want to consider developing PIs in the future which have shared accountability across health and social care.

The service-related items were found to be unsuitable for development as a multi-item measure. A strength of the survey, as designed, was that it was suitable for a very diverse group of carers with different experiences. However, the heterogeneity of the group meant that a high proportion of carers selected the 'not applicable' option for service-related items. However, the two questions which had the fewest 'not applicable' responses, question 7 and question 9 (see Appendix A), were taken forward to be considered for PIs. In summary, the two options for service-related indicators were:

- **Question 7**, which asks carers about their overall satisfaction with the support or services received for themselves or the person they care for from Social Services. On the basis of analysis the proposed PI is the proportion of carers reporting that they were 'extremely' or 'very' satisfied out of all those responding (with a valid response) to the question (see Appendix D for scoring algorithms).
- **Question 9,** which asks whether services provided to the cared-for person have made the carer's life easier. Again on the basis of analysis the proposed PI is the proportion of carers reporting that services provided to the cared-for person made their life 'easier' out of all those responding (with a valid response) to the question (see Appendix D).

By contrast, the quality of life (QOL) questions were answered well by all respondents. Psychometric analysis demonstrated that the seven questions (or items) measuring different aspects of quality of life, questions 18 to 24 (Appendix A), are suitable for scaling. The option we considered for a quality of life indicator was:

- A summation of responses to questions 18 to 24 to form a single score of Quality of Life, which we refer to as **Carer QOL**. (see Appendix D for scoring)

1.2 Analysing the qualities of the indicators

The two service-related items and the carer QOL scale were analysed to explore their reliability, validity and sensitivity. The following methods were applied:

- *Validity:* The measures were correlated against a survey question asking the carer to report their overall quality of life on a seven-point scale. Given the aims of the Labour government's Carers' Strategy we felt that the measure that had the highest correlation with this question fitted best with national priorities and had therefore the best validity.
- *Reliability:* This was examined using two different methods. The first method draws on generalizability theory. The analysis splits the observed variation in the scores into that attributable to the CASSR and that attributable to the individual, generating what is known as a variance partition coefficient (VPC). The VPC is simply the proportion of variation due to the CASSR. From the VPC it is possible to calculate the number of respondents required to achieve an adequate level of reliability. The second method draws on the criterion used by the IC, which is that the confidence interval around the PI should not be greater than +/-4% of the length of the scale. As with the generalizability method, this method can be used to calculate the number of respondents required to meet this criterion.
- *Sensitivity:* The sensitivity of the PI can be determined by exploring whether the measure captures meaningful changes. 'Meaningful' is difficult in this context as there is no yardstick. We therefore simply explore whether there are any differences between CASSRs on each of the PIs as an indication of their sensitivity and usefulness as indicators. The rationale being that if there is no variation the indicator is not useful.

1.3 The qualities of the indicators

Analysis for reliability, validity and sensitivity of the three proposed PIs revealed that each of the measures had different qualities:

- In terms of *sensitivity,* we found that all of the potential PIs varied across CASSRs implying that there is variation across CASSRs on all of these measures.
- The multi-item carer QOL measure is the most *valid* measure of quality of life. It had the highest correlation with the general quality of life measure (over 0.6). Question 9 had the weakest correlation (0.21) and question 7 was in between (0.34). We therefore conclude that the carer QOL measure has the best fit with national priorities, at least as specified in the previous government's Carers' Strategy.
- The *reliability* analysis was more ambiguous as the two different methods gave rise to different conclusions. For example, we found that for the carer QOL PI the IC criterion for accuracy was achieved at relatively low numbers of respondents compared with the other two PIs. However, the very low VPC for this PI (1.6%), lower than all the other PIs, showed that very little of the observed variation is actually attributable to the CASSR. Following generalizability theory, this means that a *large* number of respondents are required to achieve an adequate level of reliability for this PI. By contrast, we found that the satisfaction PI required many more respondents to meet

the IC criterion of accuracy compared to the carer QOL measure (and question 9), but it had a higher VPC, albeit only 2.75%, indicating that more of the variation in responses is attributable to the CASSR. This meant that the satisfaction PI requires *fewer* respondents than the carer QOL PI to achieve an adequate level of reliability under generalizability theory methods. The PI based on question 9 was in between these two PIs, requiring fewer respondents to meet the IC criterion of accuracy compared to the satisfaction PI, but more than the carer QOL PI. However, it had a similar VPC (1.69%) to the carer QOL PI, so the number of respondents required to achieve an adequate level of reliability is larger than the number required for the satisfaction PI.

The apparent paradox in these findings around reliability can be explained by the different approaches. The criterion used by the IC is not concerned with the source of the variation in the estimates. The analysis to determine sample size seeks to find the number of respondents required such that the noise (whatever its source) to signal ratio is as low as the accuracy criterion requires. The approach based on generalizability theory, by contrast, attempts to partition the variation in estimates between the variation due to individual variation and the variation due to the CASSR. The analysis to determine sample size then seeks to find the number of respondents required to reduce the noise (variation not due to the CASSR) to signal ratio to an adequate level. Arguably when we are interested in using the data to assess the CASSR, it is the latter approach to reliability that is of most interest. However, policymakers may choose not to use the measures to assess CASSRs in which case the IC criterion is acceptable.

For each of the PIs using either method of ascertaining reliability, some of the CASSRs failed to meet the required level of reliability. Using the IC criterion only one CASSR, a very small CASSR in terms of total population, failed to meet the criterion on the carer QOL PI, but 15 CASSRs failed to meet the criterion for the satisfaction PI. By contrast, using the generalizability theory method, 13 CASSRs failed to meet an adequate level of reliability for the carer QOL measure, but only 5 failed to meet an adequate level with the satisfaction PI. Again question 9 was somewhere in between these two extremes.

Based on the comparison of qualities between PIs, it would seem that the PI based on question 9 is the least good option since variation on this indicator is less attributable to CASSR than the satisfaction PI and it is the least valid measure, in terms of its ability to capture quality of life. The acceptability to stakeholders of the remaining options (question 7 and carer QOL) is open for debate. The priorities of stakeholders and the importance they place on the attribution of the measure to the action of services or the local authority's policies more generally are likely to influence their preferences.

Arguments in favour of the satisfaction PI are that it is simple to understand. It is also phrased to be specific to social services. However, analysis has shown that still only a very small amount of the variation is actually attributable to the CASSR, although we have suggested this could be underestimated because of the heterogeneity of service use by members of the sample. A concern with this question is, however, that attribution depends on carers recognising that the services they and the cared-for person receive are funded by social services. The impact of receiving support from third sector organisations may not be captured from this question but broadening the wording to include help from other agencies may diminish its properties as a PI. In the world of personalisation and with potential developments around the 'Big Society' agenda there is the danger that such a measure will fail to capture the effect of such indirect forms of support from social services on people's lives with consequent biases in a PI based on this measure.

The carer QOL measure is a more complicated measure, but this could make it more difficult to game. It is also the best measure of quality of life. A significant problem with this measure is that many factors other than social care services may influence a carer's quality of life. This makes interpreting variations within and between CASSRs difficult without multivariate analysis.

Finally, it should also be noted that the choice of indicator has consequences. Our analysis comparing the ranking of CASSRs under the three different PIs showed that although the rankings were broadly similar there were a number of differences in ordering of CASSRs depending on the PI used.

1.4 Attribution to the effect of services and the CASSR

The most important question to be addressed when deciding between question 7 and carer QOL is what function do we want the PI to perform and is the PI performing this function? This is related to the acceptability of the PI. One aspect of this decision is around the extent to which it is thought important to be able to attribute the value of the PI to the action of services or the CASSR. This is particularly an issue where the measure aims to capture outcomes and the decision depends on the interpretation of the term outcome. Outcomes are usually used to mean the results of a particular intervention and therefore would imply the need for attributing the score on an indicator to the effect of services. However, policymakers may wish to use a broader interpretation which does not aim to attribute outcomes to particular services. The aim is simply to understand what types of outcomes carers have. This latter interpretation does seem more in keeping with the way the term is used in policy documents.

Even if it is felt that the aim is to understand what outcomes carers have, the issue of attribution is still important. This is for two reasons: First, all of the PIs analysed here had very low VPCs; consequently the majority of the observed variation (over 95% for all the PIs) is due to variations in individual characteristics. Exploratory work suggests that some of the individual variation in the PI scores is explained by the method through which the carer was included in the sample (through assessment or association with a cared-for person), and that these differences may in turn be explained by differences in the characteristics of the cared-for person. Since the CASSRs may vary widely in the characteristics of the cared-for person and carers in their sample, it is important to understand to what extent such variations influence the PI scores to aid interpretation of observed differences between CASSRs. It is also the case that the carers in the sample receive a wide variety of different services, so we are likely to be underestimating the effect of services (and therefore the CASSR) with the methods we have used. It is important to be able to estimate the effect of such services on the lives of carers to understand whether and to what extent they are effective. Detailed multivariate analysis is required to explain variations in the PIs both within and between CASSRs and adjustments could then be made to control for those factors that are beyond the control of the CASSR.

However, this would require careful work and discussion to determine what factors should be measured and what counts as 'beyond the control of the CASSR'.

Second, understanding the effect of services is complicated by the fact that services to the carer benefit both the carer and the cared-for person. For example a day care service may be provided to give the carer a break from caring and so allow them to have a life of their own, go to work and so on; but it also has benefits for the cared-for person, perhaps providing a forum within which to meet and make new friends, engage in activities and learn new things, as well as have their basic needs attended to. Equally a service provided to the cared-for person, such as a home care service, has obvious benefits for the cared-for person but can have benefits (and dis-benefits) for the carer. For example when the home care service is late or unreliable it may negatively affect the well-being of the carer who may worry that the person they care for is not being supported properly; conversely when it is provided reliably the carer may be comforted knowing that the person they care for is being supported well. When we are thinking about outcomes as the goal of measurement, ideally we would want to reflect the benefits realised from one service or care package to the whole care network (carer(s) and cared-for person). Indeed in the era of personalisation such a goal seems more important as budgets will be used for the benefit of both the service user and carer; to focus on only one beneficiary of the service risks generating a biased picture of service effectiveness.

1.5 Conclusions: immediate and longer-term decisions

The two options – carer QOL and satisfaction – are the most statistically viable options for PIs in the short term. A decision needs to be taken as to the acceptability of using indicators as a measure of performance where the majority of the observed variation is not directly attributable to the CASSR. Presentation of such a measure will be important. It will also be important when presenting the data to make it clear that where a CASSR appears to score poorly this is not necessarily an indictment of their policies towards carers.

In the medium term much useful insight could be gained from multivariate analysis exploring the factors that explain variations between and within CASSRs. This analysis would help to understand why CASSRs have different scores on the PIs and how differences between CASSRs should and could be interpreted.

In the longer term there are a number of possible directions for this survey. One direction is related to the attribution issue we have raised. If the aim is to create a PI that is truly attributable to the action of services, it would be better to focus on the impact on the carer, of the budget or care package provided to the service user and carer as a unit. Such an approach would require considerable theoretical and analytic work to combine the necessary elements. However, a measure constructed in this manner would ensure that the value of services to carers as well as to service users is captured, which may result in better allocation of resources.

A measure focused on the carer-service user unit has consequences for the sampling procedure for the survey, since the population of carers of interest would be described as those carers who receive a personal budget or are caring for someone who receives a personal budget. It would not include those carers and cared-for people who have no contact with Social Services, which would mean that certain carers would not be surveyed. Since this would limit the scope of the survey, such a focus may be politically undesirable. However, the National Survey of Carers in Households (The Information Centre, 2010a) is another survey of carers that reached a much broader group of carers than those sampled in this survey. If the aim is to survey all types of carers this survey may be a more appropriate vehicle for capturing the experiences and outcomes of all carers and monitoring national trends.

1.6 Postscript: The Coalition government and future directions

The analyses conducted in this report were commissioned under the previous Labour government. We have tried to think about the relevance of this work for the present Coalition government, but at present the direction of policy concerning carers and social care is unclear. Forthcoming policy papers will undoubtedly clarify the future responsibilities of CASSRs with regard to public health, social care and carers and the 'refresh' of the Carers' Strategy planned for November 2010 will define the Coalition government's priorities for the next four years. In trying to answer the questions we raised in this report about the acceptability of each of the proposed PIs, we have drawn on the previous government's Carers' Strategy. It may be that when the Coalition's strategy for carers is published some of this discussion will need to be revised in light of new priorities.

As this project was nearing completion, a consultation document regarding the future NHS outcomes framework was published (Department of Health, 2010). This framework suggests that the key focus of measurement should be outcomes, which fits well with the arguments we have made in this paper in favour of a measure focusing on quality of life and the concerns we have raised over attribution of the effect of services. The outcomes framework advocates an overarching broad outcome indicator with sub-level indicators linked more closely to services. Future work may wish to explore how the options in this paper could be moulded to fit within such a framework should a similar type of framework emerge for social care. Given the announcement that public health duties will be transferred to local authorities, it may also want to examine the potential for other questions, such as those on health services, to be included in such a framework.

2 Introduction

The work presented here was commissioned under the previous government, with a view to developing a performance indicator (PI) for carers that could be used to populate the National Indicator Set (NIS) for the new spending period starting in 2011. For some time, the Department of Health (DH) has been working with the Association of Directors of Adult Social Services (ADASS) and other stakeholders to examine how the current NIS can be 'refreshed'. One aspect of this work has focused on developing a new carers' PI, which aims to better reflect carers' experiences and outcomes, in line with Labour's policy to realign the performance framework around the objective of improving outcomes for all (Office of the Deputy Prime Minister, 2005). The source of data for this work has been the new survey of carer's experiences and outcomes carried out for the first time in 2010. Although the new government is keen to reform the performance framework, it seems likely that a PI focused on the experiences and outcomes of carers will be of interest since it fits with the principles and ethos for the new outcomes framework set out by the Coalition (Department of Health, 2010).

3 Aims and structure of the report

The aim of this work is twofold. First to develop PIs that could be used to assess outcomes for and the experiences of carers, and second to provide empirical evidence for the reliability, validity and sensitivity of the potential PIs to help policy-makers and relevant stakeholders decide between the proposed PIs. We start by providing some background and context to the study. First we outline the policy context driving the monitoring of performance related to carers and suggest a number of ways performance could potentially be measured using data collected from the Personal Social Services Survey of Adult Carers in England 2009-10. We also outline the development and scope of the national Personal Social Services Survey of Adult Carers in England 2009-10 and its predecessor the 2008 Kent Carers Survey.

In the following section, we discuss the data and methods used to develop the PIs and assess their validity, reliability and sensitivity. The analyses presented here are all based on the data collected from the Personal Social Services Survey of Adult Carers in England 2009-10 by a selection of local authorities. This section of the report and the results section are highly technical. Readers who are not interested in the technical detail can skip over these sections to the discussion where we summarise the methods used and our findings. We conclude by discussing the relative merits of each of the PIs based on the assessment criteria of validity, reliability and sensitivity, and also consider how they could be judged against the criteria of acceptability and feasibility.

4 Background

Since 2001, all councils with adult social services responsibilities (CASSRs) have been required to conduct surveys of users' experiences of social services (UES). These are national surveys carried out by CASSRs and are regarded as an important part of the overall performance framework for social care, providing councils with information about how they might improve services locally and central government and regulators with information to monitor and compare the performance of councils. CASSRs are required to submit their raw data to the Information Centre for Health and Social Care (IC), and user surveys are now an established part of CASSRs' annual data returns to central government.

Although there has been interest in conducting a survey of carer's experiences within the social services user survey group (an advisory and agenda-setting group for the user survey programme), the user survey programme has until this time focused on the experiences of service users rather than their carers. The publication of the Labour government's Carers Strategy in 2008, however, proved a sufficient impetus to develop a carers' survey (Department of Health, 2008) As a result the first centrally mandated national carers' survey in England was conducted by 90 CASSRs on a voluntary basis between November 2009 and February 2010.

The UESs have been used as a source of data for PIs and it was clear that one potential use of the carers' survey data could be to populate PIs in the performance framework. A criticism of the carer's PI, NI 135, collected for the NIS for the period 2008 to 2010, is that it focuses on the activities of local authorities and offers limited information about carers' experiences or outcomes. In view of this criticism, the DH was keen to develop a PI for carers that better reflects carers' experiences and outcomes, in line with the then Labour government's policy to realign the performance framework around the objective of improving outcomes for all (Office of the Deputy Prime Minister, 2005). This objective is echoed in the recent Coalition government proposals for a new outcomes framework (Department of Health, 2010). A PI based on the carers' survey would therefore fit much better with the current direction for performance measurement.

4.1 Development of the carer's experience survey questionnaire

The Personal Social Services Survey of Adult Carers in England 2009-10 (Fox et al., 2010) (see Appendix A) was based upon the 2008 Kent Carers' Experience Survey (CES) which was commissioned by the Department of Health and Kent County Council (KCC) (Holder et al., 2009). Both surveys were developed by researchers at the Personal Social Services Research Unit (PSSRU). To develop the Kent CES researchers ran a series of focus groups with 20 carers to identify the aspects of service quality, and outcomes that carers felt were most relevant to their lives and general well-being. The data collected served as a basis on which to develop questions reflecting the priorities of carers. The questions were then tested for understanding with a further 25 carers using the technique of cognitive interviewing (Willis, 2005). These interviews helped to refine the question wording and ensure that the questions were expressed in language that made sense to carers and resonated with them.

The Personal Social Services Survey of Adult Carers in England 2009-10 built upon the KCC questionnaire with additional questions to reflect the pledges made in the Labour government's 2008 Carers Strategy, which was published after the Kent survey had been developed (Department of Health, 2008). Specific questions about breaks from caring were added and questions to capture carers' experience of healthcare settings and support received from employers were introduced. A further 30 cognitive interviews with carers were carried out to test the new questions for understanding, and to ensure that the questions developed were relevant to carers living outside the Kent area. The IC carried out a pilot of the national survey with a small sample of CASSRs in February 2009, which was successful (The Information Centre, 2009). On this basis of this pilot, a voluntary national survey was recommended.

4.2 Measuring performance

The Personal Social Services Survey of Adult Carers in England 2009-10 questionnaire covers a number of different aspects of carers' experiences of services and life more generally. This focus, together with the size of the dataset provides an opportunity to explore several different options for potential carers' experience PIs based upon robust empirical evidence. Any of the survey questions could be chosen as a PI, but some may be more acceptable to stakeholders than others. To help identify which aspects of carers' experiences should be reflected in a future PI, an advisory group consisting of stakeholders from the following organisations was convened: The Standing Commission on Carers, CASSRs, third sector organisations (Carers UK and Princess Royal Trust for Carers), Care Quality Commission, Department of Health, NHS Information Centre and Personal Social Services Research Unit (PSSRU). In addition, the group invited comments on initial proposals from a wider group of stakeholders via their networks. The advisory group agreed that two potential carer experience PIs should be developed. One to reflect a key policy aim stated in the Carers' Strategy: whether carers are able to have a life of their own and therefore to focus on the quality of life of carers. The second should reflect local priorities and focus on access to and quality of services.

In selecting a final PI, a key question is how will it be used in the future and by whom? There are a variety of potential users of the data and a number of ways in which these same stakeholders could make use of it. For example, government departments and regulators may use the information to monitor performance nationally and make comparisons across different localities to identify 'beacons' or 'coasting' areas. In the past the government has chosen some PIs as targets and has attached financial rewards to achievement of the target. The general public, service users and carers could also make use of the statistics to assess the effectiveness of their local services, and depending on whether the data are available at the level of the individual service, to inform their purchasing choices between providers. CASSRs and third sector organisations might use the results to gauge the success of local initiatives for carers and CASSRs may also use the data to inform their commissioning decisions.

PIs can clearly serve a variety of functions and the way data are to be used and by whom has significant consequences for the characteristics of a PI. The desirable qualities of a PI are set out in Figure 1. Many of these qualities are in conflict with each other and choosing between them may depend on which function the PI is designed to serve. For example simplicity is often in conflict with the principle that the PI should not be able to be gamed since more simple measures are usually easier to game. Clearly where financial incentives are attached to targets, or organisations are rated by their performance on the PI, it is important that the PI cannot be easily gamed. However, this goal would be less important if data were solely to be used for information since the stakes associated with poorer relative or absolute performance would be less high and there would be less incentive to game the PI. The relative balance of these qualities is a matter for debate, but informed debate clearly depends on clarity over which of the uses and users are most important and recognition of the need to compromise.

Figure 1: Desirable qualities of a PI

Acceptability: the extent to which the indicator is acceptable and relevant to those being assessed. For those undertaking the assessment, several elements are necessary for a PI to be considered acceptable. The elements include; relevance to current and future policy aims, whether the PI is easy to understand, is well-defined and easy to calculate. It can also include aspects linked to uses, such as whether it can provide data that are comparable over time and across different locations; and whether it can be attributed to the action of CASSRs, the NHS or other providers who are accountable for the outcome. Another area of concern is around ensuring that the PI cannot be gamed and does not induce perverse incentives.

Feasibility: the extent to which valid, reliable and consistent data is available for collection and reporting in a timely manner, so the data are useful.

Reliability: the indicator should have minimal measurement error, or at least be accurate enough for its purpose. In the case of survey-based PIs, where each service user is a rater of CASSR performance, inter-rater reliability should be high; that is responses from raters should be similar. Where responses are variable, it is important that a good level of reliability can be achieved by increasing the number of raters.

Sensitivity: the indicator should have the capacity to detect changes in the unit of measurement, in this case variations in outcomes across CASSRs (and potentially providers) and variations in outcomes within CASSRs over time.

Validity: the extent to which the indicator accurately measures what it purports to measure. Key issues here are whether the indicator is underpinned by evidence and/or consensus, the extent to which the indicator has the ability to accurately predict outcomes, and whether the basis for scoring and combining responses is defensible.

Adapted from a document produced by Nalyni Shanmugathasan, DH and Campbell, S.M., J. Braspenning, et al (1993). Improving the quality of health care: Research methods used in developing and applying quality indicators in primary care. BMJ 326 (7393): 816-819.

The first two of the desirable qualities – acceptability and feasibility – are primarily a matter for decision-makers and stakeholders to debate. Empirical data can be used to inform these debates, but this can only be collected after implementation. For example evidence related to the process of collecting the data for the PI, can be used to inform feasibility, and on-going evidence related to the behaviour of stakeholders in reaction to the PI, can be used to inform concerns about gaming. Attribution of the PI to the action of the organisation can also be informed by detailed analysis and data collection. In contrast, the latter three features – reliability, sensitivity and validity – can be assessed empirically (at least to some extent) prior to implementation and are therefore the focus of the analytical part of this report.

5 Methods

5.1 Questionnaire and data collection

The Personal Social Services Survey of Adult Carers in England 2009-10 was conducted between November 2009 and February 2010 (The Information Centre, 2010b). The sample was drawn from the following groups for the national survey:

1. Carers who have received (either separately or jointly with the service user) an assessment or review in the last 12 months
2. Carers named on the file of a service user who has received an assessment or review in the last 12 months (carers known by association)[1].

It is important to acknowledge that the approach to sampling produces results for a subset of carers who are in contact with statutory, third sector or private social care services themselves or indirectly via the person the care for. Participation by CASSRs was voluntary and 90 out of 152 (59%) took part. However, these results should not be generalised to England because the CASSRs that did not volunteer to participate may have a different population of carers to those that did.

The Personal Social Services Survey of Adult Carers in England 2009-10 is administered by CASSRs. To ensure, as far as possible, homogeneity in the conduct of the survey across CASSRs, the IC provided CASSRs with survey guidance, questionnaires (including large print and translated versions), letters inviting carers to take part in the survey, telephone and face-to-face scripts and a data return to forward to the IC for analysis.

The final questionnaire designed by PSSRU (see Appendix A) comprised 58 questions, covering the following broad topic areas:

- Characteristics of the carer
- Characteristics of the person being cared for
- Use of social care services by the carer and cared for person
- Satisfaction with services
- Views about service quality
- Views about the impact of services and their quality of life (outcomes)

Of these 58 questions, 39 were mandatory. The remaining 19 questions were optional and CASSRs could select or de-select them to reflect their interests.

One feature of the questionnaire was that a large number of questions had ‘not applicable’ response options. An early finding from the survey development work was that carers are a very diverse group, with many different experiences and circumstances. Some of the diversity in this group relates to the characteristics of the person they care for. For instance the emotional consequences and tasks associated with caring for a spouse with dementia are very

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[1] Only 41 (46%) of participating CASSRs were able to include this group of carers as some CASSRs did not hold enough detailed information to identify carers known by association.

different to those required to care for an adult child with multiple sclerosis or mental illness. Diversity also arises from the degree and type of contact carers have with services. One option would have been to develop different surveys for carers of different clients or to focus the survey on carers receiving services. However, the advisory group were clear that the survey should be relevant to all adult carers (aged 18 and over) supporting someone aged 18 and over including carers of people who have:

- dementia
- problems connected to ageing
- learning disability or difficulty
- physical disability
- sensory impairment
- mental illness,
- difficulties with drugs or alcohol
- a terminal illness
- a longstanding illness.

Such diversity necessitates a questionnaire that can accommodate the variability in carers' circumstances and experiences. To achieve this we introduced 'not applicable' options to questions that may only be relevant to certain carers. This was particularly an issue for those questions focusing on experiences of services.

5.2 Analysis

Descriptive statistics are presented on the characteristics of the sample. To address the concern raised in the advisory group that the population of carers responding to this survey may be quite different to the carers in the general population, where possible we have compared the characteristics of this sample to national data on the population of carers. Because not all CASSRs were able to sample carers known by association, we also explore whether there are differences in the characteristics of carers who received an assessment compared to those identified via the case file of a service user.

We were guided in our choice of questions to focus on for PI development by the views of the advisory group. It was the opinion of this group that we should focus on developing PIs covering the following topic areas: carer's quality of life and access to and quality of services. Twenty-three questions covered the topic areas identified by stakeholders as important in measuring carers' experiences and the performance of services. Of the questions identified, seven relate to quality of life (questions 18 to 24) and sixteen relate to access to services and service quality (questions 7, 9, 10, 14, 16, 30-37 and 39-41). A large number of items were considered for potential PIs within these two broad areas, as the aim was for the PI to be composed of a number of different items, forming a composite multi-item measure.

Complexities in the dataset, however, meant that the analysis could not be conducted on the entire dataset. Of the questions selected for further analysis a total of nine questions were optional and were omitted from the questionnaire by some CASSRs. However, five CASSRs also excluded some of the mandatory questions. This means that where the analysis includes an omitted or voluntary question all the responses from those CASSRs that omitted the question will be excluded. Similarly, where items have a high rate of ‘not applicable’ responses, all those responding ‘not applicable’ to any of the questions considered for the multi-item measure will be excluded from the analysis.

There are however a number of reasons why questions with high rates of ‘not applicable’ responses should not be considered suitable for national PIs. Any PI based on questions with high rates of ‘not applicable’ responses would exclude a large proportion of carers. To use this question as a PI would be a very inefficient use of the data, and would also raise questions about the value of surveying those carers whose views are excluded from the PI. In addition the aim of the survey has always been to be as inclusive as possible so it would be contrary to the spirit of the exercise to choose a PI based on this survey that is not inclusive. This is not to say that the questions with not applicable responses have no place in this survey; it is only a comment on their suitability for national indicators. Prior to developing PIs from the data we therefore explore the pattern of non-response to the questions on service quality and access, which are proposed as potential PIs and have ‘not applicable’ response options, to ensure that we focus our efforts on developing PIs from questions that are relevant to the majority of carers completing the questionnaire.

5.3 Developing multi-item PIs

Within the framework of classical test theory, factor models are commonly employed to develop multi-item scales from a pool of items since the aim of the model is to explain the common variance of the items through a smaller number of latent variables, known as factors (De Vellis, 2003). The structural relationship between the items is investigated first through examination of inter-item correlations. Polychoric correlations are used because of the ordinal nature of the measurement scale for each item (Olsson, 1979a). Polychoric correlations are calculated in STATA version 11 using the user-written polychoric programme. Exploratory factor analysis is carried out in STATA version 11 on the polychoric correlation matrix, as research has shown that Pearson correlations can lead to incorrect conclusions where the items are ordinal (Olsson, 1979b; Holgado–Tello et al., 2010). We use the maximum likelihood method for factor extraction primarily because it allows for statistical evaluation of the factor solution (Fabrigar et al., 1999). Strong loadings of the items on the latent variable and low values for the unique variance of the items indicate that the latent variable explains the items well and the items can be summed together as a scale.

To reflect the fact that the probability of endorsement of a response option varies across the quality of life (QOL) items in a graduated way, for this multi-item measure we also used a less familiar technique known as Mokken scaling or non-parametric item response theory (IRT), which is a more appropriate model than the factor model for developing scales when items are hierarchical (Moorer et al., 2001; Sijtsma and Molenaar, 2002; Sijtsma et al., 2008). If items are hierarchical then it is possible to determine a person’s response to any of the items in the set based on their response to one item, as endorsement of one item response option necessarily entails endorsement of other item response options that are less difficult, i.e. there is a transitive relationship between the item response options. IRT models the hierarchical nature of items probabilistically; in an IRT model the probability that a person positively responds to a certain item response option is a function of both the position of the person along the latent continuum and the position of the item response option along the latent continuum. We would expect some of the items, such as those representing QOL, to show this hierarchical pattern of response because the QOL attributes are not equivalent in the sense that some states are less desirable than others. The states that are less desirable should be endorsed less frequently than those that are more desirable (c.f. Moorer et al., 2001).

Mokken scaling is a non-parametric version of the more familiar Rasch model and makes fewer restrictions about the function relating the probability of response to the location parameters for items and persons. Mokken scaling only requires that the function increases with the latent trait value (monotone homogeneity). Items may obey the requirement of monotone homogeneity yet not be useful scale items. Loevinger's coefficient of homogeneity (H), which is the ratio of observed Guttman errors (errors in the aforementioned transitivity relationship) to total errors under the null hypothesis that items are totally unrelated, is used to assess scalability. It can be constructed for an item, item pairs and the set of items (scale). Higher values of H for the scale indicate a more reliable ordering of items and persons, with values of $H \geq 0.3$ indicating a weak scale, values ≥ 0.4 a medium scale and values ≥ 0.5 a strong scale (Mokken, 1971; Sijtsma and Molenaar, 2002). As a rule of thumb, items with H values < 0.3 are considered to be unscalable since they do not provide a reliable ordering of persons (Sijtsma and Molenaar, 2002).

Like factor analysis, Mokken scaling can be used to investigate the dimensionality of the QOL items and identify those that scale strongly and less strongly together. We use a variant of the Mokken procedure proposed by Hemker et al (1995), applied by Moorer et al (2001) and available in the MSP (version 5) software (Molenaar and Sijtsma, 2000). Hemker at al note that a multi-dimensional item bank will often appear to form one scale at low values of *c*, where *c* is equal to H for the scale and is the acceptance criteria for the scale. As *c* is increased to values up to 0.6, if the scale is multi-dimensional it will often break up into several homogeneous subscales, while unidimensional scales will remain intact. Since we expect the QOL items to form a unidimensional scale we would therefore expect the scale to break up into individual items as *c* is raised and not to form several scales.

5.4 Developing the single-item PIs

If too many people report that a proposed item for the multi-item PI is not applicable then it is not possible to include the item in the multi-item scale as it will make the PI less inclusive. It is possible that many of questions proposed for the multi-item scale have high rates of 'not applicable' responses, which is indeed what we found for the access and quality of services items. In such instances it is not possible to develop a multi-item scale. We therefore considered instead whether any of the proposed items had rates of 'not applicable' response low enough to warrant investigating whether they could be used as single-item PIs.

To develop a PI based a single item we first explore the distribution of the item, paying attention to the skewness statistic to determine whether the mean score on the item across carers within a CASSR can be used as a PI. Where the items are skewed the mean is not a meaningful measure of the distribution, so we propose converting the measure to a proportion. For example, a PI could be defined as the proportion of those who responded to the question answering the first response option out of all those who responded to the question (with a valid response). The choice of cut-point used to form the proportion should be based on the mid-point of the distribution.

5.5 Assessing validity

Validity assesses the extent to which the instrument measures what it is intended to represent. In Messick's words, it is "*an integrated evaluative judgement of the degree to which empirical evidence and theoretical rationales support the adequacy and appropriateness of interpretations and actions based on test scores or other modes of assessment*" (Messick, 1990: 1). Here the measure is intended as a performance indicator; it should be able to provide information for a variety of stakeholders (as outlined above) to help them make decisions about commissioning services and to assess service quality. The advisory group identified access to and experience of services and quality of life as the foci for PIs. Validating the PI is therefore a matter of identifying the extent to which the instrument captures its intended focus. We examine this by looking at the correlation between the PI and other items in the questionnaire that appear to be measuring similar constructs. The key question used in this analysis is general quality of life, question 17, which we would expect to be related to carers' experiences of services and a multi-item quality of life measure.

5.6 Assessing reliability

Measurement is always subject to error, arising from random error associated with, for example, misunderstandings and systematic error, for example, associated with the measurement instrument, which may not be a perfect measure of the concept. Measures of reliability aim to quantify how sensitive measurement is to error. Reliability is related to the standard error of measurement (SEM), which is commonly used to construct confidence intervals around estimates, through the formula:

$$SEM = \sigma_X \sqrt{(1-r)} \quad ,$$

Where *r* is the reliability and σ_X is the standard deviation of the test (X).

Cronbach's alpha is commonly used to assess the reliability of multi-item measures. It is a measure of the internal consistency of the items and as such provides an indication of how reliably the instrument or test captures a concept, for example the concept of QOL, for each individual. Since each item is assumed to measure the concept with some degree of error, the more items in the test the more information there is for each individual and the more accurate the measurement for each individual. Therefore Cronbach's alpha increases as the number of items in the test increases.

Whilst Cronbach's alpha provides a good indication of how reliably the multi-item measure measures an individual carer's QOL, for example, it does not indicate the reliability of the measure as a PI. This is because when the multi-item measure is used as a PI for a CASSR, each carer effectively becomes a rater of the performance of the CASSR, and each carer rates the performance of the CASSR with error. Drawing on generalizability theory, in this situation systematic error not only arises from the instrument but also from systematic variation in the ratings of carers within one CASSR; the true score can be thought of as the between-CASSR variation in the PI score (Shavelson and Wenbb, 1991; Cronbach et al., 1997; Brennan, 2000). Reliability of the PI is therefore given by the following formula:

$$r = \frac{VAR_B}{VAR_B + \frac{VAR_W}{n}},$$

Where VAR_B is the between-CASSR variance, VAR_W is the within-CASSR variance, and n is the number of respondents to the test. Reliability is therefore a function of the number of raters and like Cronbach's alpha reliability will increase as the number of respondents increases.

To estimate reliability for each PI we estimate a variance-components model via restricted maximum likelihood[2] in STATA version 11 to decompose the variability in the performance score into between- and within-CASSR variance.

In the past the IC has used the criterion that the 95 per cent confidence interval for the mean should have a width no greater than eight per cent of the scale (or plus or minus four per cent around the mean) to determine the required attained sample size for each CASSR. The formula for estimating sample size, n, can be written as:

$$n = \frac{z_{\alpha/2}^2 \sigma^2}{d^2},$$

where d is half the width of the required confidence interval, z is the value of the normal deviate for a two-sided 95% confidence interval (i.e. the value at p=0.025, which is approximately 1.96) and σ^2 is the population variance. For binary data, the population variance is given by p(1-p), where p is the probability of success (in this case success is rather awkward terminology since success is defined as the probability of unmet need). We use this formula to estimate the required sample size according to the IC criterion for the accuracy of the PI estimate.

In addition, the IC generally applies the finite population correction (FPC) when calculating the reliability of estimates. The FPC is an adjustment that is applied to the standard error, when calculating the confidence interval. It takes account of the size of the sample in relation to the population. Where populations are small and the size of the sample is relatively large this adjustment is more important. The adjustment is given by:

$$FPC = \sqrt{\frac{N-n}{N-1}} \ ,$$

where N is the size of the population and n is the size of the sample. Applying this correction to calculate the confidence interval has the effect of narrowing the confidence interval by the

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[2] A variance-components model is used instead of analysis of variance since it is more appropriate where designs are not balanced, as is the case here Rasbash, J. and Goldstein, H. (1994) Efficient Analysis of Mixed Hierarchical and Cross-Classified Random Structures Using a Multilevel Model, *Journal of Educational and Behavioral Statistics*, 19, 4, 337-350.. Restricted maximum likelihood estimation rather than maximum likelihood estimation is used since it is more accurate when the aim is to provide estimates of the variance components Hox, J. and Maas, C. (2006) Multilevel Models for Multimethod Measurements, in M. Eid and E. Diener (eds) *Handbook of Multimethod Measurement in Psychology,* American Psychological Association, Washington, DC.

factor calculated as the FPC. From the equation it can be seen that the greater the difference between the sample and the population, the larger the factor and the smaller the adjustment. We can apply the FPC to the data to calculate how many CASSRs failed to meet the IC accuracy criterion on each PI.

5.7 Assessing sensitivity

The sensitivity of an instrument can be assessed by examining whether the instrument is able to detect meaningful changes in the unit of measurement. In this instance sensitivity is measured in terms of whether the PI is able to detect meaningful changes in the performance of CASSRs over time and meaningful differences in the performance of CASSRs at one point in time. Detecting *meaningful* changes and differences is the key issue at stake and it is therefore important to define what we mean by meaningful. For health measures it is common to find meaningful being equated with therapeutically significant. However, there is no obvious parallel for carers and anyway we are interested in detecting meaningful differences among CASSRs not individual carers. Instead here we focus on whether there are any differences across CASSRs on the PIs using tests based on analysis of variance and comment on the significance of these findings, by examining standard errors.

6 Results

Questionnaires were sent via post to a total of 87,801 carers via 90 local authorities in England. These 90 councils have a similar profile in terms of type and region to the total 152 CASSRs in England. Responses were received from 35,165 carers producing a response rate of 40 per cent. Average response rates for previous UESs of service users are higher varying between 50 and 60 per cent. However, it is unsurprising that the response rate for carers is lower considering how busy their lives can be.

The participating carers were identified from CASSR records in two ways. Those carers who had undergone an assessment or review in the last 12 months (either jointly with the services user or separately) accounted for 82 per cent of the responses. Of those carers that had received an assessment or review 78 per cent had subsequently received information or services. The remaining 18 per cent of carers were identified from the record of a service user who had undergone and assessment or review in the last 12 months. This smaller group are referred to as carers by association.

There were some differences in the characteristics of those responding to the survey when compared to the total sample. Respondents were more likely than non-respondents to:

- Have had a separate assessment or review
- Have received information or services after an assessment or review
- Be aged between 55 and 84
- Be white
- Be caring for someone with dementia

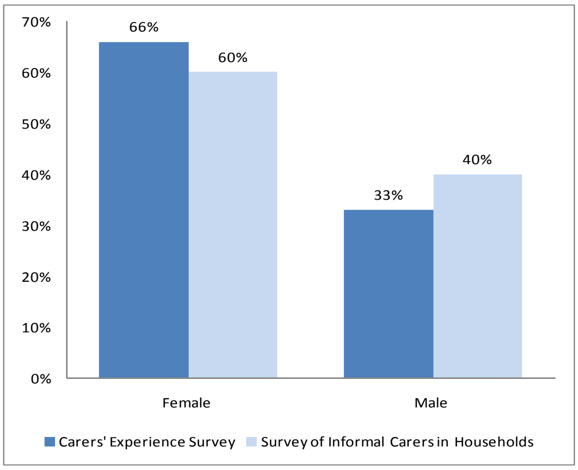
The finding that those carers who had received their own assessment and information or services subsequently were more likely to respond to the questionnaire is interesting. It is possible that carers who had not received an assessment, information or services may have assumed that the survey was not relevant to them since it was sent to them by the council. It would be interesting to explore some of these relationships in more detail.

The majority of the responses were received from completed postal questionnaires. Only 1% (n=386) of respondents completed the survey over the telephone and a total of 35 carers requested a face-to-face interview. A very small number of carers requested a translated version of questionnaire (n=28).

6.1 Characteristics of carers

Two-thirds of the respondents were female (66 per cent). Figure 2 compares this to the provisional findings of the Survey of Informal Carers in Households – 2009/2010 England (The Information Centre, 2010a).

Figure 2: Comparison Survey of Carers in Households - percentages of respondent's gender



The breakdown of gender across the two surveys is similar although there were slightly more female respondents in the Personal Social Services Survey of Adult Carers in England 2009-10 (referred to in this chart as the Carers Experience Survey). The variation in the proportion of female carers may be explained by the dissimilar age profiles of the two surveys. A higher proportion of carers aged 65 and over responded to the Personal Social Services Survey of Adult Carers in England 2009-10 (49 per cent) when compared to the Survey of Informal Carers in Households (24 per cent). The higher proportion of carers aged 65 and over is unsurprising as the sample was drawn from a subset of carers of people known to Social Services, which is likely to include a large proportion of older people. As women on average live longer than men, they are more likely to be represented in the older age groups. The ethnic profile across the two surveys was similar with 91 per cent of respondents identifying they were from a white ethnic background[3].

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[3] The 2009/2010 Carer Experience Survey contains missing data for 6% of respondents as CASSR records were unable to provide data on ethnic background.

6.2 Characteristics of service users (cared-for person)

Of the people receiving support and help from the responding carers, the majority were women (66 per cent) and fewer were men (34 per cent). As we identify above, the majority of the service users being cared for were over 65 (71 per cent) (see Figure 3).

Figure 3: Cared-for person's age

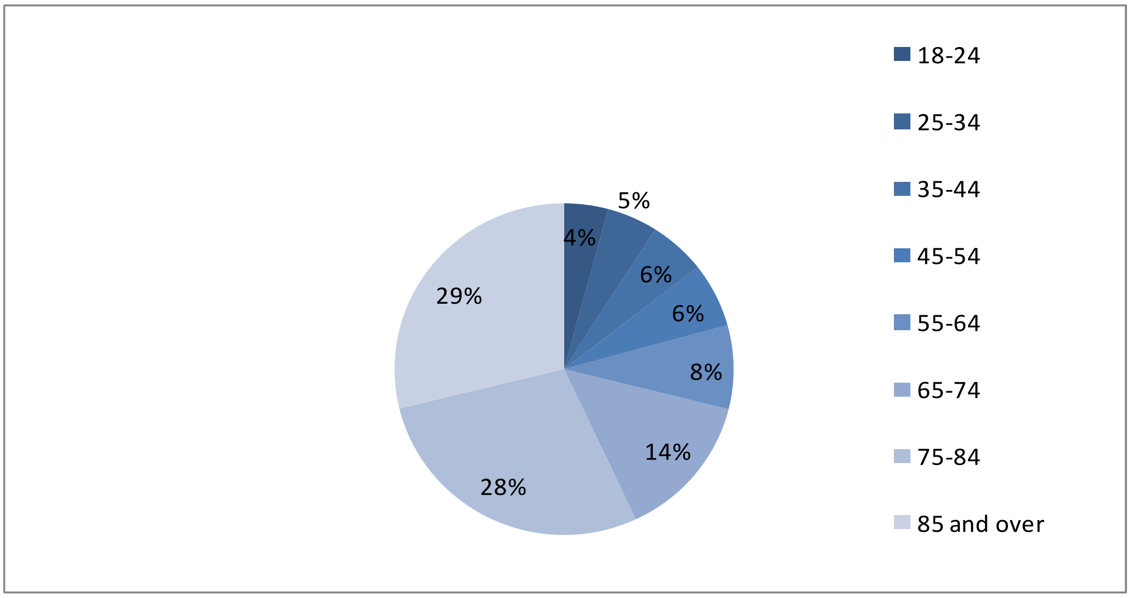
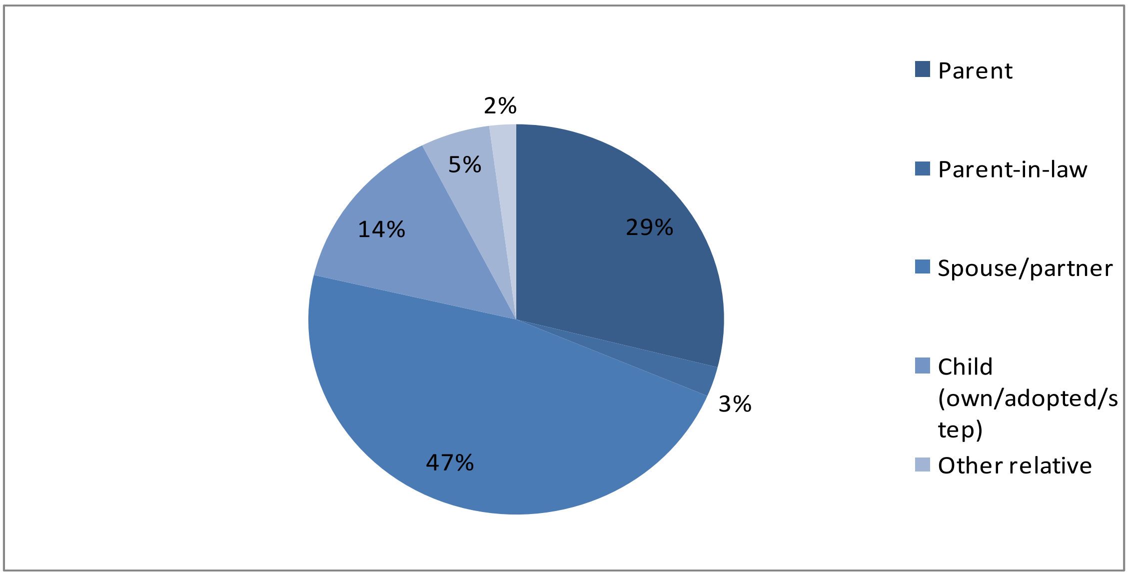


Figure 4 illustrates that most carers in the sample were supporting a spouse or partner (47 per cent) with the next largest group caring for a parent or parent-in-law (31 per cent).

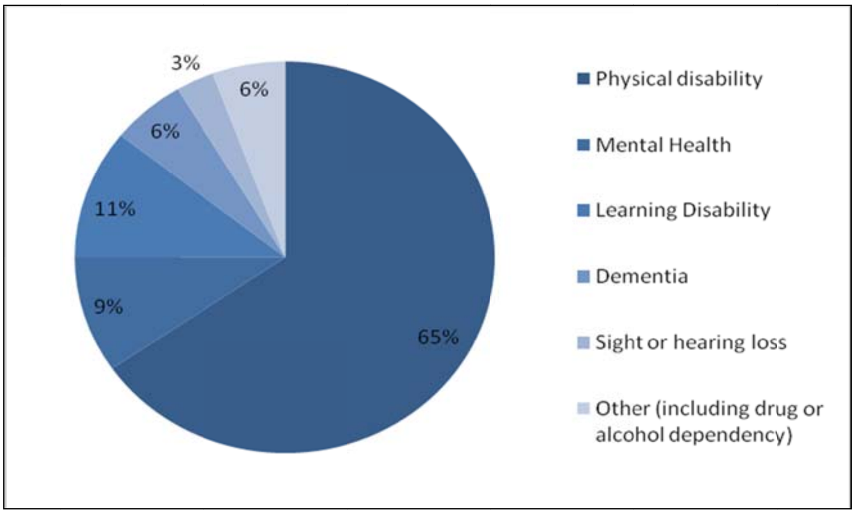
Figure 4: Relationship of cared for person to carer



7% of carers reported caring for more than one person.

The needs of the person being cared-for are shown in Figure 5. The high proportion of people with physical disabilities could be accounted for by the way CASSRs attribute service users' primary need when they have multiple needs.

Figure 5: Needs of the cared-for person



Differences in carers' characteristics across sample groups

Because only some CASSRs were able to sample carers known by association we conducted some exploratory work to see if there were any variations in the characteristics of carers across these groups. We found that there were considerable differences in the characteristics between the two groups and offer a few illustrative examples below. The associations reported indicate relationships between variables but do not imply a causal link. We found receiving a separate assessment was associated with carers supporting a male adult child whereas receiving a joint assessment was associated with caring for a female parent. Caring for 50 or more hours per week is associated with receiving a separate assessment. This finding may be unsurprising in the context of the *Carers Equal Opportunities Act 2004* and its application by CASSRs and practitioners. A higher proportion of carers looking after someone who has mental health problems, learning disabilities or drug/alcohol problems received a separate assessment. The intensity of caring for people with these particular needs may account for the higher proportion of their carers receiving a separate assessment. Alternatively, practitioners may undertake more separate assessments with these carers to preserve confidentiality and promote good relationships between the carer and the cared-for person.

There is an association between those respondents caring for people with physical disabilities or sight/hearing loss and receiving a joint assessment. A higher proportion of this group were caring for between 0-34 hours per week. A higher proportion of carers who had not received an assessment were caring for someone with physical disabilities compared to other needs and were more likely to be spending 0-19 hours per week caring.

6.3 Responses to the potential performance items

The distribution of responses to each of the questions selected as potential performance items are presented in Appendix B. Significance tests (chi-squared) indicating differences in responses between carers sampled after receiving a joint or separate assessment and those carers identified by association with a service user, are also shown.

The significance tests show that there are highly significant differences (p=<0.001) in responses between the three sample groups (separate assessment, joint assessment and carers by association) for the majority of the potential performance items which reflect differences in experiences of services and quality of life. Items relating to helpfulness of information (q32) and the frequency of contact with a care manager (q36) are significant but to a lesser degree (p=0.002 and P=0.025 respectively). However, there are no significant differences in carers' responses to the item relating to the flexibility of services (q39) or the item which asks about being treated with courtesy and respect by care workers (q41).

A higher proportion of carers who had received a separate assessment felt the services the person they care for received made no difference in making their lives easier and were more likely to report needing 'some' or 'a lot more' help. Being very dissatisfied with breaks of more than 24 hours and having needs in all the quality of life domains was associated with receiving a separate assessment. Carers receiving a joint assessment were more likely to report finding it easy to access services for themselves and the person they care for compared to those receiving a separate assessment or those carers who have not been assessed (carers by association). Access to services and satisfaction differs between the sample groups and exploratory analysis indicates that this appears to be linked to differences in the needs of the cared for person. It could be the case that carers' experience of services and quality of life are influenced by the support and services provided to the cared for person. However, further analysis of the dataset is required to 'separate out' each of these elements.

6.4 Pattern of valid and non-valid item responses to PI items

The number of valid responses varies widely amongst the potential service-related performance items. Part of the variability in valid response rates to items can be accounted for by the omission of some or all of the nine optional service-related questions by CASSRs. However, a large part of the variation is also explained by high rates of 'not applicable' responses, ranging from 11% to 58%, to many of the access to and quality of services items (see Appendix C). One possibility we considered was whether the 'not applicable' response was associated with particular types of carers, and could be related to the sampling group (carers receiving a joint or separate assessment and carers identified by association). Since only some CASSRs could sample carers by association there could be an argument for dropping this group from the sample if it was felt that many of the questions were not relevant for this group. Appendix C summarises the pattern of valid and non-valid responses to each of the items considered for the PIs and also reports significance tests of association (chi-squared) in the pattern of valid and non-valid responses across the sampling groups.

There are highly significant differences on all items between the three sample groups in the type of response given i.e. valid, not applicable or item non response. Examination of the cross-tabulations reveals that carers by association were more likely to either not respond or answer ‘not applicable’ to questions about particular services, such as breaks (q14 & q16) and information (q31 &32). The difficulty of carers by association to respond to specific service questions is unsurprising, as they are less likely to be directly receiving services for themselves. A higher proportion of carers receiving a separate assessment did not respond or answered ‘not applicable’ to questions which encompass aspects of quality of services received by the cared-for person, particularly those relating to domiciliary and day care services (q40 & q41). Generally, carers receiving a joint assessment were more able to respond to the majority of the questions but there were a few exceptions. A larger proportion of those jointly assessed answered ‘not applicable’ or did not respond to question 33, which asks how easy or difficult it has been to arrange services for the cared for person in the last twelve months. Since there are complex patterns in respondents’ selection of the ‘not applicable’ option, for example, respondents do not universally select ‘not applicable’ for all the questions in a particular section of the questionnaire and the ‘not applicable’ option is not consistently confined to certain sampling groups, it is hard to make a case for restricting a multi-item PI based on the access to and quality of services questions to certain types of carers.

In the light of these findings, we suggest that service-related items are unsuitable for multi-item measure development, due to the high proportion of carers selecting ‘not applicable’ and the unpredictable variation in their responses. A multi-item performance indicator based on these items would offer information about only a limited number and range of carers’ experiences. There are, however, two service-related items that have much lower rates of ‘not applicable’ responses. These are the items on overall satisfaction with Social Services (q7) and whether support/services have made things easier (q9), which have rates of ‘not applicable’ responses of 11% and 14% respectively. For this reason we have taken these two questions forward for consideration as single-item performance measures.

6.5 Development of the multi-item carer QOL PI

The seven items relating to quality of life were applicable to all carers and were therefore suitable for further testing to establish the feasibility of creating a multi-item measure (referred to in the remainder of this report as Carer QOL). Table 1 shows the inter-item polychoric correlations for each of the carer QOL items. The correlations are mostly moderate to large, between 0.3 and 0.7 (Cohen, 1988). Some item pairs have very large correlations over 0.7, including occupation with the items control over daily life and time and space, and control over daily life with the items time and space and social participation, but none of these correlations exceed 0.8. The strength of the correlations between these item pairs could indicate that there is some conceptual overlap between these items. Safety has the lowest correlations with the other items, but the correlations are mostly moderate. Only its correlation with occupation is low at less than 0.3. The implication from this analysis is that the items are sufficiently strongly correlated to be considered for scaling.

Table 1: Matrix of polychoric correlations for Carer QOL items

	Occupation	time and space	control	personal care	safety	social participation	encouragement and support
Occupation	1.0000						
Time and space	0.7732	1.0000					
Control	0.7055	0.7902	1.0000				
Personal care	0.5304	0.5883	0.6251	1.0000			
Safety	0.2877	0.3097	0.3311	0.4332	1.0000		
Social participation	0.6513	0.6811	0.7004	0.6266	0.4027	1.0000	
Encouragement and support	0.5237	0.5592	0.5623	0.5181	0.3297	0.6051	1.0000

Factor analysis

Tests for the suitability of the factor analysis procedure were all good. The Kaiser-Meyer-Olkin (KMO) test of sampling adequacy for this dataset was 0.88, which is considered “meritorious”. Bartlett’s test for sphericity rejected the null hypothesis that the variables are not inter-correlated ($X^2(21)=50099.13$, $p=<0.001$). Maximum likelihood (ML) factoring extraction was performed through STATA factormat on the polychoric correlation matrix of the seven Carer QOL items[4]. One factor was extracted with an Eigenvalue 3.98. The likelihood ratio test of independence against the saturated model is significant ($X^2(21)=8.3X10^4$, $p=<0.001$) indicating that the factor analysis is meaningful and the items are inter-correlated.

The one-factor model is shown in Table 2. All the variables load onto the factor with a loading greater than 0.4. The factor explains the majority of the variance of most items; only the safety has a unique variance greater than 0.6, which indicates that the factor does not explain this variable very well. Cronbach’s alpha for this scale is 0.83, which is considered to be very good. Interestingly alpha is increased if the safety item is dropped from the scale to 0.85, reflecting the fact that it does not correlate as strongly with the other items. However, the qualitative development work for the questionnaire suggested that safety is an important aspect of QOL for carers and we feel it is important to retain this item to ensure content validity and the face validity of the scale with carers. The strong loadings of all the items and

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[4] The maximum likelihood factoring extraction method assumes that the items are multivariate normal, an assumption which is not met with these data: Mardia’s test for skewness = 8.165, X^2 (84) =27009.672, $p < 0.001$; Mardia’s test for kurtosis = 77.685, X^2 (1) = 8490.718, $p < 0.001$; Henze-Zirkler = 654.009, X^2 (1) = $4.04x10^5$, $p < 0.001$; Doornik-Hansen X^2 (14)= 57450.022, $p < 0.001$. We therefore repeated the analysis using principal axis factoring which is recommended when the assumption of multivariate normality is violated, but the same solution was found Fabrigar, L.R., Wegener, D.T., MacCallum, R.C. and Strahan, E.J. (1999) Evaluating the Use of Exploratory Factor Analysis in Psychological Research, *Psychological Methods*, 4, 3, 272-299..

the positive results from Bartlett's test of sphericity and the KMO suggest that the items are similar enough to be summed together into a carer QOL scale.

Table 2: Pattern matrix for the one-factor solution

Variable	Factor	Uniqueness
Occupation	0.8204	0.3269
Time and space	0.8829	0.2204
Control	0.8741	0.2360
Personal care	0.7081	0.4987
Safety	0.4103	**0.8316**
Social participation	0.8092	0.3453
Encouragement and support	0.6663	0.5561

Items with unique variance > 0.6 shown in bold

If CASSRs' social care and carer policies and the services they provide have an impact on carers' QOL, we would expect carers experiencing the same set of policies and services to have more similar QOL (all other things being equal) than carers experiencing a different set of policies and services. It is likely that carers within the same CASSR will have more similar QOL than carers in different CASSRs, giving the dataset a clustered structure. Clustering of responses, in this case by CASSR, can have an effect on the factor solution and it is generally recommended that where data is clustered steps are taken to adjust for the clustering by using a multilevel factor analytic approach (Steele and Goldstein, 2006). It is possible to gauge whether the multilevel factor analysis will substantially affect the results by exploring using a variance-components model[5] the proportion of variance that is attributable to the CASSR for each of the items (Muthén, 1994; Grilli and Rampichini, 2003). This analysis revealed that very little of the variance for each item is attributable to systematic variation at the CASSR level, with the variance partition coefficient (VPC) varying from 0.8% for time and space to 4.6% for safety as shown in Table 3. This means that only 0.8% of the variance in the time and space item is attributable to the CASSR; for the safety item 4.6% of its variance is attributable to the CASSR. It is therefore unlikely that a multilevel factor analysis would substantially alter the results and we have not pursued this any further.

Table 3: Variance Partition Coefficient for each QOL item

	VPC for CASSR
occupation	1.1%
time and space	0.8%
control	1.1%
personal care	2.1%
safety	4.6%
social participation	1.6%
encouragement and support	1.3%

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[5] We ran a cumulative logistic model for ordinal responses using the user-defined gllamm procedure in STATA Rabe-Hesketh, S., Skrondal, A. and Pickles, A. (2002) Reliable estimation of generalized linear mixed models using adaptive quadrature, *Stata Journal*, 2, 1, 1-21..

Mokken scaling analysis

The results of the procedure to investigate the dimensionality of the carer QOL items are shown in Table 4 using lowerbounds from 0.3 to 0.8 with steps of 0.1[6]. At 0.3 all items form one scale, but as the lowerbound is increased items drop out of the scale. Safety drops out first as the lowerbound is increased to 0.4; most of the other items drop out at around 0.6 and 0.7. Importantly, none of the items form secondary scales, indicating that the items form a uni-dimensional scale rather than a set of multi-dimensional scales. This corresponds with the findings from the factor analysis where one clear factor was extracted.

Table 4: Scales determined using Mokken item selection procedure (N=19,843)

c	Scale 1	Scale 2	Excluded
0.3	1, 2, 3, 4, 5, 6, 7		
0.4	2, 3, 4, 5, 6, 7		1
0.5	2, 3, 4, 5, 6, 7		1
0.6	4, 5, 6, 7		1, 2, 3
0.7	5, 6		1, 2, 3, 4, 7
0.8			1, 2, 3, 4, 5, 6, 7

Analysis of the fit of the MH model to the carer QOL items shows that there are no violations of the model. Loevinger's homogeneity (H) coefficient, which is a proportional reduction in error statistic, forms the basis of the assessment of scalability. It is a summary measure of the goodness of fit of the Mokken model to the observed data and varies between zero and one, with a value of one meaning perfect fit and a value of zero indicating no improvement over the null model. The H coefficient for the scale is 0.54, which indicates that the items form a strong scale and the respondents can be ordered by means of the set of items.

The scalability parameters and statistics are summarised in Table 5. The item H-coefficient gives an indication of the power of the items to discriminate between persons. The H for the all the items, except safety, is much greater than 0.3, which is taken to indicate that the items discriminate well between individuals. The safety item discriminates adequately between people to be considered for the scale since its item H is greater than 0.3.

Table 5: Scalability parameters and item characteristics (N=19,843)

			Percentage responding		
Item	Mean	H	High	Medium	Low
occupation	1.89	0.58	23.1	64.3	12.6
time and space	1.89	0.61	26.8	57.6	15.6
control	1.80	0.62	30.8	58.9	10.3
personal care	1.52	0.53	61.4	25.5	13.1
safety	1.17	0.31	84.3	14.2	1.5
social participation	1.69	0.58	43.6	43.5	12.9
encouragement and support	1.66	0.49	46.9	39.8	13.2

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[6] All cases with missing data for at least one of the carer QOL items are excluded from the analysis, leaving a sample of size 19843.

Scale	11.62	0.54			

We concluded from this analysis that the seven items could be combined to form a multi-item measure. The measure is formed following psychometric principles, and the scoring method is set out in Appendix D. The scale takes values from zero to 14. The mean value for this sample is 9.4 (SD=3.13, median=9, n=19,843).

6.6 Development of the single-item PIs

Question 7, "satisfaction with support and services from Social Services for carer and cared for person" and question 9 "the effect of support and services on how easy or difficult things are for the carer" are both suggested as potential single-item PIs. Table 6 shows the distributional characteristics for these measures, including a measure of skewness carried out in STATA v11 using the sktest function. The measures are both significantly skewed so the mean is not a valid measure of the distribution. We therefore suggest that a single-item PI should be based on a proportion.

Table 6: Distribution statistics for questions 7 and 9

	N	Mean	SD	Min	Max	Skew	Kurtosis
Q7	29,863	2.6	1.30	1	7	1.19***	4.71***
Q9	19,607	1.2	0.45	1	3	2.35***	7.89***

Table 7 shows the distribution of responses to the two questions. Roughly 50 per cent of the sample responds to question 7 that they are either extremely or very satisfied, and we recommend using this as a cut-point for the PI. Cross-tabulations with question 17, the general quality of life support this decision as there seems to be a difference in the quality of life of people who respond that they are fairly rather than extremely or very satisfied (analysis not shown here). The distribution for question 9 has much less variance than for question 7 as the vast majority, over 80 per cent of respondents, choose the option that support and services have made their lives 'easier'. We recommend that easier is used the cut-point for this PI. The PI for both of these questions is therefore based on a binary recoding of the responses to the questions, as shown in Appendix D.

Table 7: Frequency distribution for questions 7 and 9

	Frequency	Percent	Cumulative Percent
Question 7			
I am extremely satisfied	5,237	17.5	17.5
I am very satisfied	10,810	36.2	53.7
I am fairly satisfied	8,637	28.9	82.7
I am neither satisfied nor dissatisfied	2,689	9.0	91.7
I am fairly dissatisfied	1,222	4.1	95.8
I am very dissatisfied	664	2.2	98.0
I am extremely dissatisfied	604	2.0	100.0
Total	29,863	100.0	
Question 9			
easier	16,378	83.5	83.5
no difference	2,777	14.2	97.7

harder	452	2.3	100.0
Total	19,607	100.0	

6.7 Validity of performance measures

The three potential PIs are the multi-item measure of carer QOL, a measure of satisfaction with services and support for the carer and the cared for person (question 7), and a measure of the effect of support and services on how easy or difficult the carer's life is (question 9). We would expect all of these measures to have a relationship with the general quality of life measure, question 17, but for the relationship between the carer QOL measure and the general QOL item to be the strongest.

The carer QOL measure is strongly correlated with the general QOL item ($r=-0.64$, $p<0.001$, $n=19659$)[7]. The correlation is negative because 1 represents poor QOL on the carer QOL measure but the best QOL on the general QOL item. As expected the correlation between questions 7 and 9 and the general QOL item are lower than for the carer QOL measure (for question 7: $r=0.34$, $p<0.001$, $n=28803$; for question 9: $r=0.21$, $p<0.001$, $n=19210$)[8]. This finding lends support to the validity of the carer QOL measure as a measure of carer's QOL.

6.8 Reliability of performance measures

The decomposition of the variance into its between- and within-CASSR components is summarised in the variance partition coefficient (VPC) which is an estimate of the proportion of the variance attributable to the CASSR. The VPC for each of the PIs is shown in Table 8[9]. The VPC is very small for all of the PIs but largest for Q7, which asks about satisfaction with support and services for the carer and cared for person received from social services. This means that the majority of the variance in the PI scores is accounted for by rater variance, which is also confounded with random error[10].

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[7] This analysis was conducted using a Pearson correlation coefficient, but was repeated using a polyserial correlation coefficient to reflect the categorisation of the general QOL item. Rho calculated via the polyserial correlation was -0.68 (standard error 0.004), which is not very different from the Pearson correlation coefficient.

[8] This analysis was conducted using a Pearson correlation coefficient, but was repeated using a polychoric correlation coefficient to reflect the categorisation of the general QOL item and questions 7 and 9. Rho calculated via the polychoric correlation for question 7 is 0.36 (standard error 0.006) and for question 9 is 0.30 (standard error 0.001), which are not very different from the Pearson correlation coefficient.

[9] The carer QOL model was estimated using an identity link, but the models for question 7 and 9 were estimated using a logit link to reflect the binary nature of the variables.

[10] In fact for the carer QOL measure, the rater error is also conflated with the item error and the item-individual interaction error, because the score is composed of a number of items. It is possible to separate out these sources of error by extending the variance-components model. However, this requires significant computer power and we have not had the time to explore this here.

Table 8: Variance partition coefficient for each PI

	VPC
Carer QOL	1.60%
People responding ‘extremely’ or ‘very satisfied’ to question 7 about satisfaction with support and services from Social Services for carer and cared for person	2.75%
People responding ‘easier’ to question 9 about the effect of support and services on how easy or difficult things are for the carer	1.69%

Figure 6 shows how the reliability of each of the PIs increases with the number of carers. The chart can be used to provide an indication of how large the valid sample needs to be to achieve a reliable estimate for each PI. 80 per cent is generally considered to be an adequate level of reliability for a measure. The number of respondents required to reach this level of reliability is lowest for Q7 at around 150 respondents and highest for the carer QOL measure at around 250 respondents. The number of respondents required for Q9 is very similar to that for the carer QOL measure at around 230 respondents.

Figure 6: Reliability of PIs as a function of the sample size

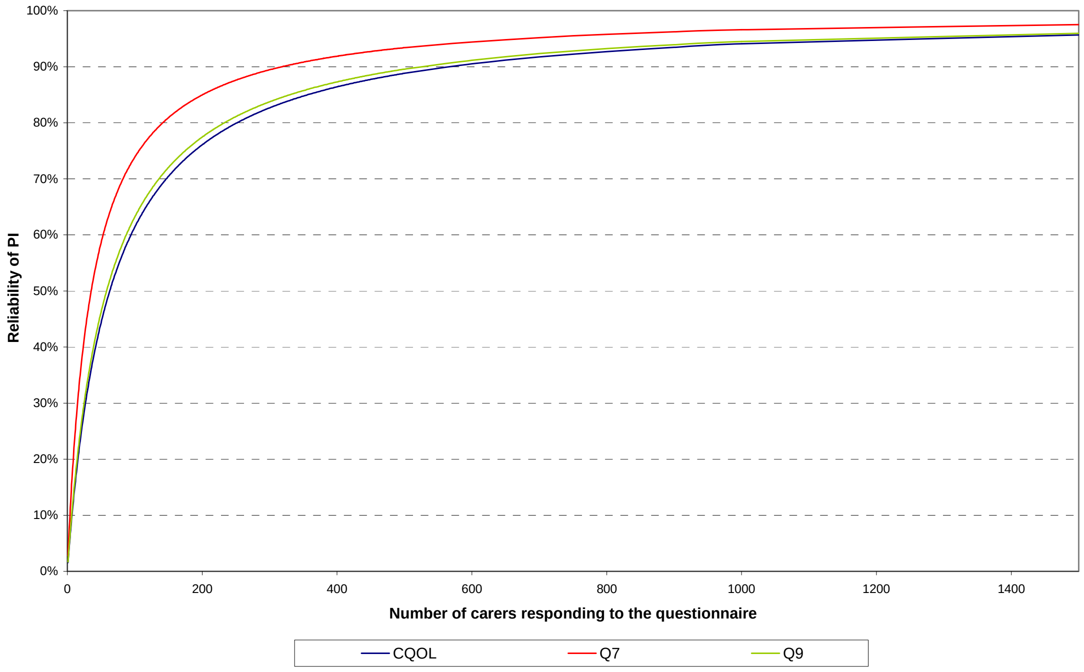


Table 9 shows the required attained sample size using the criterion that the 95 per cent confidence interval for the mean within each CASSR should have a width no greater than eight per cent of the scale (or plus or minus four per cent of the scale). According to this formula, the largest sample size is required for question 7 and the smallest for the carer QOL measure – the opposite of that found above. The difference is because the reliability calculation above is based on the proportion of the variation that is explained by the CASSR. This method for estimating reliability does not take account of the source of variation.

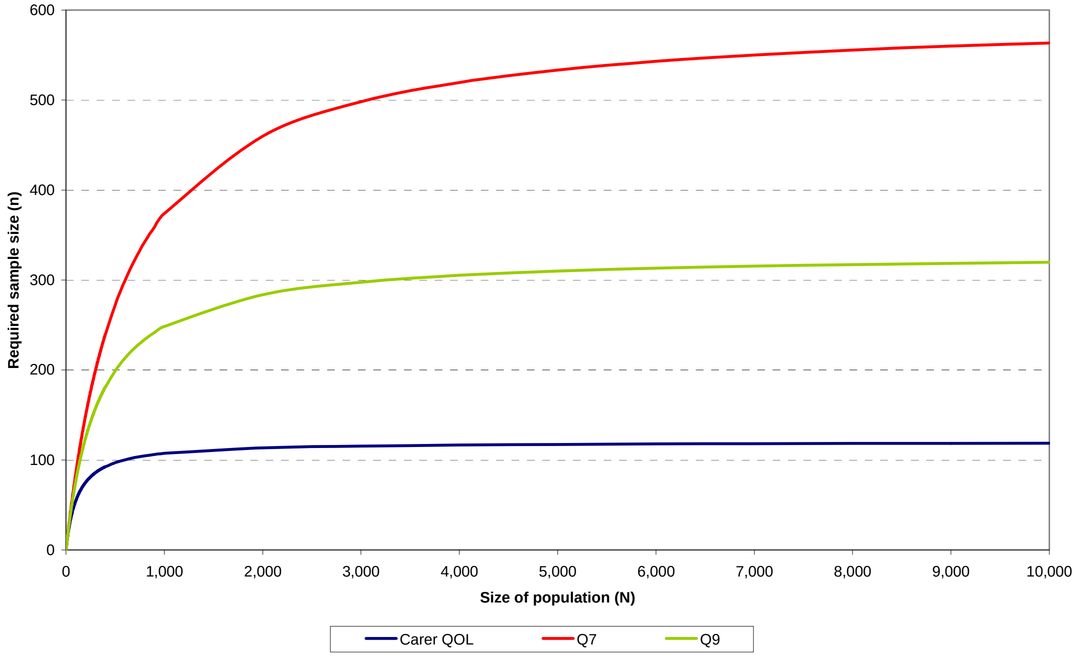
Table 9 Required sample size using IC criterion of +/- 4% accuracy

	Mean	Variance	Margin of error	Required sample size*
Carer QOL	9.38	9.81	0.56	120
Question 7	0.54	0.25	0.04	597
Question 9	0.84	0.14	0.04	330

*required n is calculated with FPC adjustment

The IC uses the FPC adjustment to calculate confidence intervals. We show in Figure 7 below the effect of making the FPC adjustment on the required sample size for different population sizes for each of the PIs. It can be seen that as the population size increases, the required sample size approaches the required sample size set out in Table 9 above. Based on data collected from CASSRs, the smallest population size recorded was 30 and the largest was 9,386. The average population size was 1,978 and median was 1,346. On this basis the majority of CASSRs would require close to the maximum required sample size for the carer QOL PI and question 9, but a much smaller sample size for question 7.

Figure 7: Required sample size as a function of FPC using IC criterion of an accuracy of +/-4%



It is also possible to calculate how many CASSRs failed to meet the two different reliability criteria for each of the PIs, i.e. the IC criterion and the 80 per cent reliability criterion based on generalizability theory and estimation of the VPC. Table 10 shows the number of CASSRs failing to meet the criteria for each PI. Very few CASSRs failed to meet the IC criterion for the carer QOL PI and the PI based on question 9. However, for question 7, which had more variability in scores, the IC criterion was not by 15 CASSRs. Of these CASSRs not meeting the criterion, nine did not include carers known by association in the sample and six did include carers known by association in the sample. The reverse pattern is observed for the method based on generalizability theory: 13 CASSRs fail to meet the standard for the carer QOL PI; 12 failed to meet the standard for question 9; and only five failed to meet the standard for question 7.

Table 10: Number of CASSRs with confidence intervals greater than IC criterion of +/- 4% and failing to meet 80% reliability standard based on calculation of reliability using VPC method

PI	Number of CASSRs failing to meet IC criterion*	Number of CASSRs failing to meet 80% reliability standard based on VPC
Carer QOL	1	13
Question 7	15	5
Question 9	2	12

*One CASSR did not provide population size, but it is a large county CASSR and its sample was very large, so it is unlikely that the confidence interval would be significantly affected by the FPC

6.9 Sensitivity of performance measures

A one-way between subjects ANOVA was conducted to compare the effect of living in different CASSRs on carer QOL scores. There are significant differences between CASSR in carer QOL scores (F [56, 19786]=6.38, p=<0.001 level). The variation in carer QOL scores is illustrated in Figure 8 which shows the mean carer QOL scores for each CASSR with 95% confidence intervals[11].

The circles represent the mean scores for each CASSR. The error bars around the mean for each CASSR represent the 95% confidence interval for the mean. The solid vertical black line represents the grand mean for the whole sample. Similar graphs are also presented for the single-item PIs, questions 7 and 9 (Figure 9 and Figure **10** respectively). As for carer QOL we also find significant differences between CASSRs on the PI formed from question 7 (rho=0.037, X2=388.39, p=<0.001) and from question 9 (rho=0.017, X2=76.85, p=<0.001).

The confidence interval provides an indication of the uncertainty associated with the estimate of the mean for each CASSR. Importantly, and contrary to popular opinion, differences are not observed between CASSRs where the errors bars do not overlap. The error bar required to represent this is much more difficult to construct. However, the correct error bar to achieve five per cent significance when making a single comparison can be approximated by an error bar of width 1.39 times the standard error of the mean (Goldstein and Healy, 1995). Adjustments are required when multiple comparisons are being made. Graphs based on this approximation are shown for all of the three PIs considered in Appendix E.

Comparing Figure 8 to Figure 10, there does seem to be some variation in the ordering of CASSRs across the three PIs. It is, however, quite difficult to judge how much the ordering

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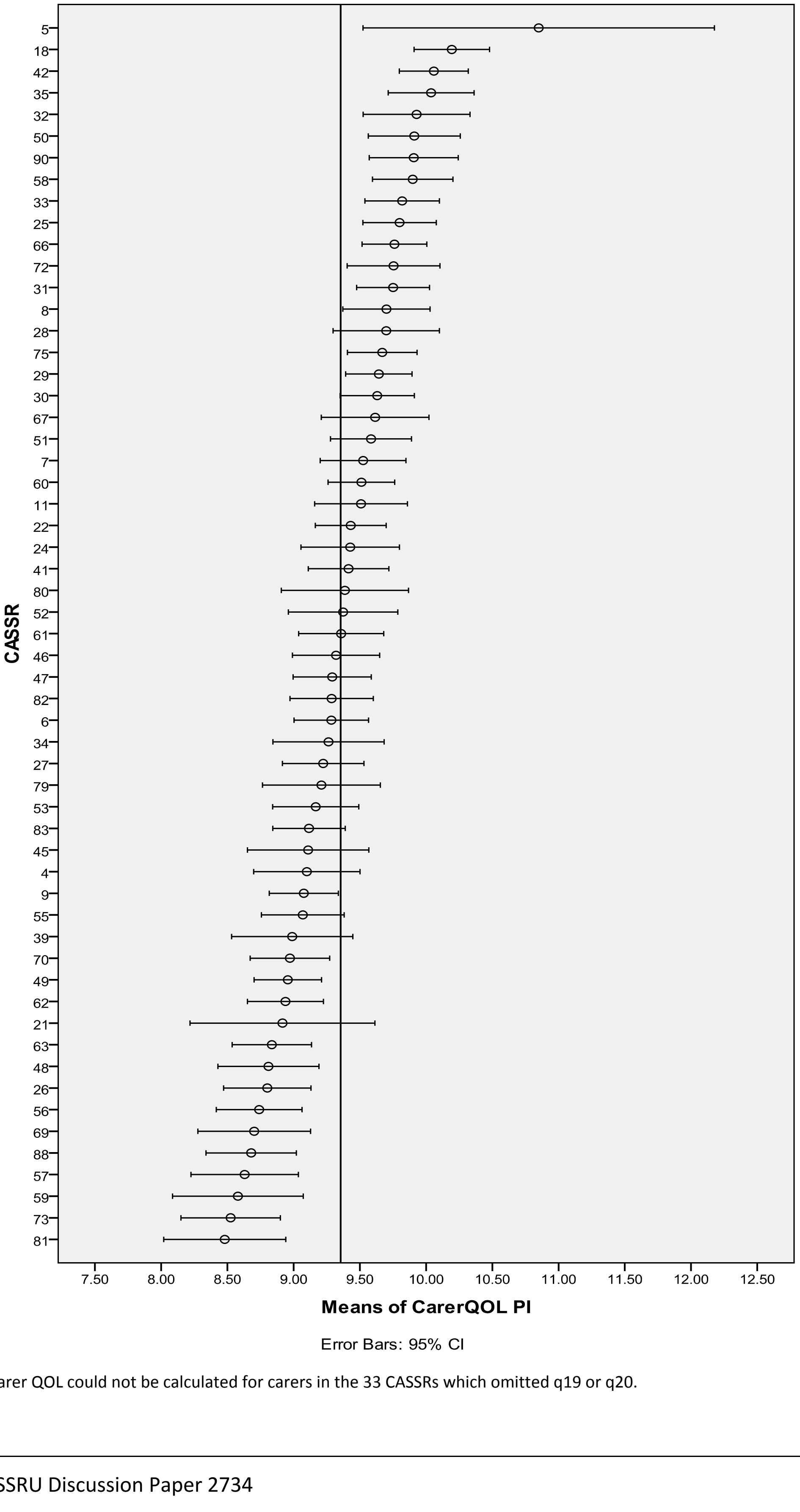
[11] The confidence intervals are calculated from standard errors not adjusted using the finite population correction.

changes as 33 CASSRs are not included in Figure 8 as they did not include one of the questions needed to constitute the carer QOL measure and 27 CASSRs are not included in Figure 10 as they did not include question 9 in the questionnaire. We have therefore compared the ordering of CASSRs across the PIs (on those CASSRs that are common to each PI pairing) by running a Spearman's Rank Correlation Coefficient test. The results of this test are shown in Table 11. The correlations are strong but that fact that all correlations are below 0.7 indicates that the ordering of CASSRs does change according to the choice of PI. The most difference in ordering is observed between question 9 and the carer QOL PI where the correlation does not quite reach 0.5.

Table 11: Correlation in ordering of CASSRs for each PI

PI	Carer QOL	Question 7	Question 9
Carer QOL			
Question 7	0.64		
Question 9	0.49	0.66	

Figure 8: Means of Carer QOL PI with 95% confidence intervals



Carer QOL could not be calculated for carers in the 33 CASSRs which omitted q19 or q20.

Figure 9: Means of PI based on question 7 with 95% confidence intervals

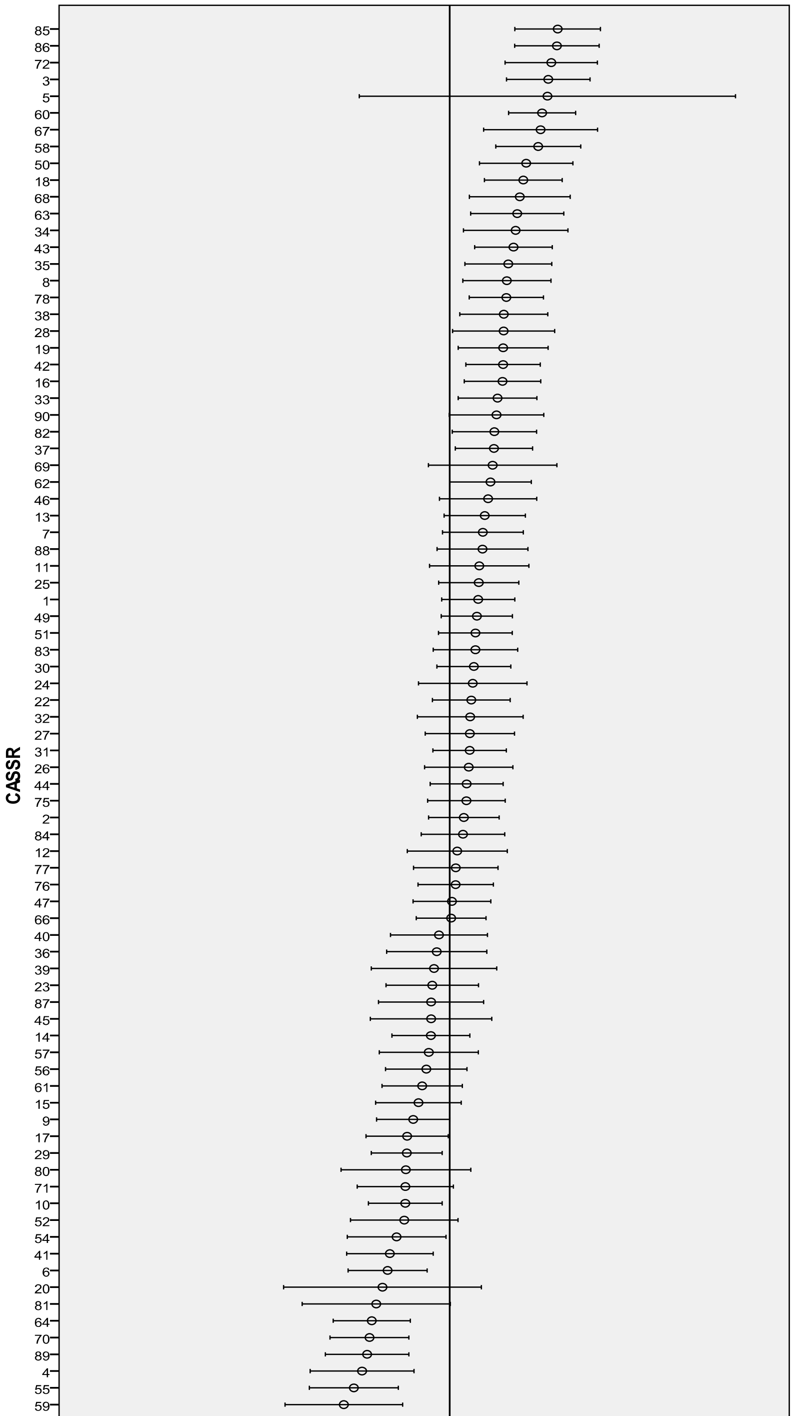
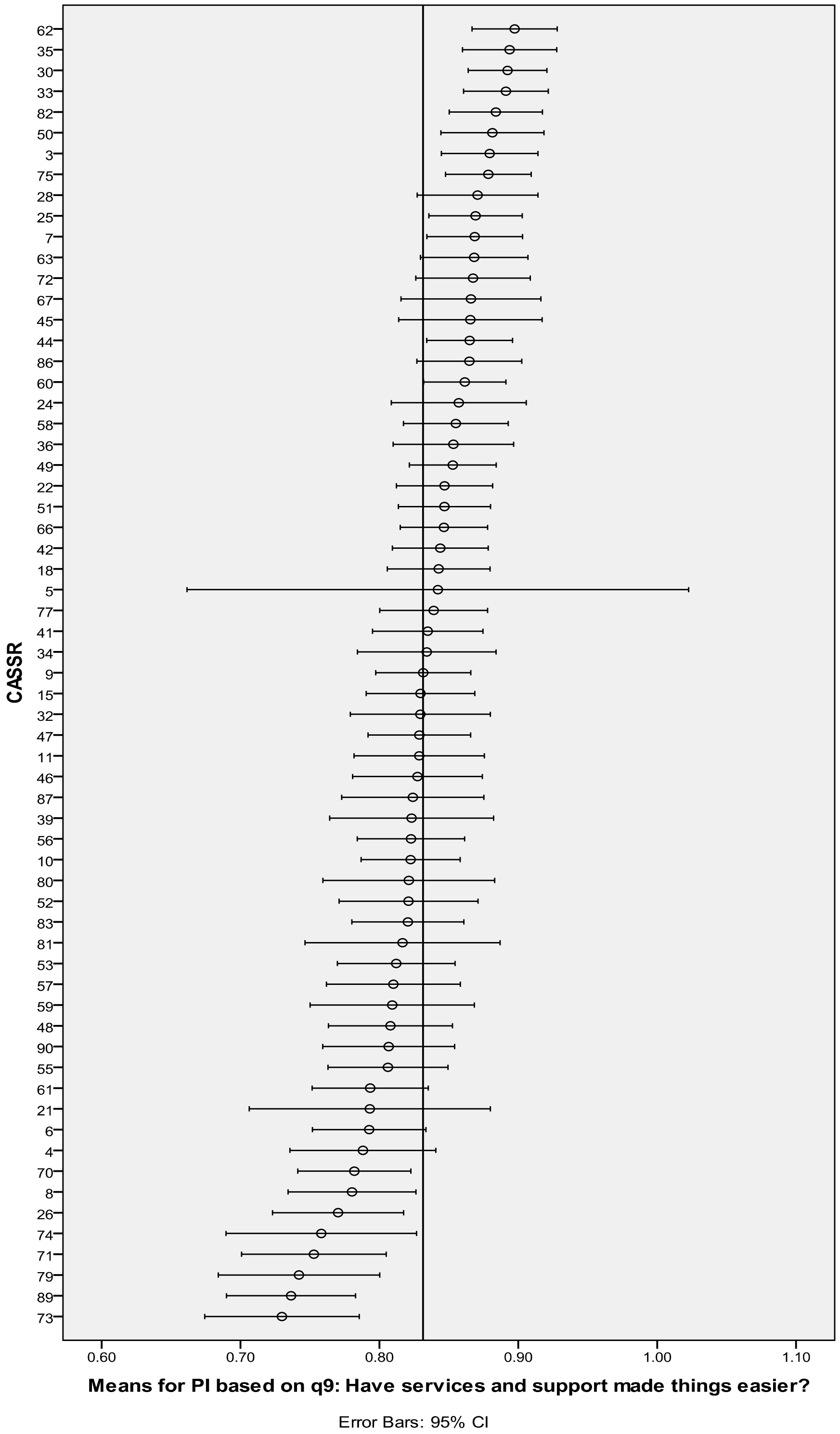


Figure 10: Means of PI based on question 9 with 95% confidence intervals



Excludes 27 CASSRs that omitted question 9

6.10 The effect of sampling on PI scores

CASSRs identified carers through three different mechanisms: those who had received a joint assessment with the service user, those who had received an assessment that was separate to the service user's assessment; and those who had not received a formal assessment, but were known through association with the service user because presence of a carer had been recorded on the service user's record. We have already identified in the exploratory analysis that we found differences between carer sample groups in the responses to many of the questions used in these PIs. It is therefore important to explore whether there are also significant differences between these groups on the PIs as it may be that some of the variation observed between CASSRs may in fact be due to differences in the make-up of the sample.

In total 45 CASSRs were not able to identify carers known by association with a service user. We also found that seven CASSRs were not able to identify any carers jointly assessed with service users and of these only one was able to identify carers known by association. In addition we found that four CASSRs were not able to identify any carers assessed separately to service users, but all of these were able to identify carers by the other two routes. It is not clear how similar the recording of carers known by association is across those CASSRs that were able to identify this group of carers, meaning that even within this group there could be variations in the composition of the sample depending on how thorough records of carers are kept within service user files.

To explore the effect that carer sampling group may have on the value of PIs, we have reported the value for PIs for each CASSR by whether the carer was identified by assessment or by association.

Table 12 to Table 14 in Appendix F show the number of respondents, means and 95% confidence intervals for each of the PIs by carer sampling group[12]. Table 12 shows the mean scores for assessed carers is generally lower than the mean scores for carers by association on the carer QOL PI. Considering that assessed carers are likely to be caring more hours per week, this may be unsurprising. Table 13 and Table 14 show a more mixed picture for questions 7 and 9 respectively. The mean scores for question 7 were higher for carers by association in around half of the CASSRs[13] but were higher for assessed carers in the other half of CASSRs. In a minority of CASSRs, the scores were the same for both sample groups. For question 9, higher mean scores for carers by association were reported by a third of CASSRs, whereas in the remaining two thirds of CASSRs, assessed carers reported either equal or higher mean scores than those reported by carers by association. However, the differences observed between sampling groups are unlikely to be solely related to the presence or absence of assessment. As we have already identified the characteristics of the carer and cared-for person also vary by sampling group, which may mediate the observed effect. There are also a number of other factors that may influence the values of PIs that operate at the level of the CASSR, such as the presence of services for carers and the eligibility criteria for services for

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[12] We did not use the FPC to calculate the confidence intervals in this table, because the size of the population of carers known by assessment and by association were unknown.

[13] Based on those reporting figures for both sampling groups.

users applied in the CASSR, that may be unrelated to the sampling group of the carer, but may anyway be correlated with sampling group. For this latter reason, the picture drawn from observing variations in the PIs across these groups may therefore be misleading.

To understand the effect of sampling group on the PIs, a one-way between-subjects ANOVA was conducted. There are significant differences between carer sample group in carer QOL scores (F [3, 18432]=43.92, p=<0.001)[14]. A roughly equivalent test was performed for the two single-item PIs, which takes account of their binary nature[15]. This test shows that there were also significant differences between carer sample groups on the PI formed from question 7 ($X^2(2)=38.73$, p=<0.001) and from question 9 ($X^2(2)=27.75$, p=<0.001). All of these tests were repeating collapsing the two assessment categories into one assessment category. Differences between those in the assessed and known by association categories were found for each PI. Although this analysis does show that whether the carer had an assessment and the type of assessment held has an effect on each of the PIs examined here, it does not prove that having an assessment leads to better quality services or outcomes since other factors such as age of the carer (found in many studies to be positively correlated with satisfaction) may mediate this effect. Detailed multivariate analysis is required to separate out these effects.

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[14] Bartlett's tests for homogeneity of variances between the groups was not significant ($X^2(2)=3.57$, p=0.168) indicating that the results of the ANOVA are valid.

[15] We use a logit regression framework to examine whether the mean score varies by carer sample group, testing for differences across groups using a Wald test.

7 Discussion

The criteria for sampling carers for the Personal Social Services Survey of Adult Carers in England 2009-10 was as broad as possible in order to capture the views of as many carers as possible. It aimed to include the carers of all types of adult social care service users including carers not living with the cared-for person as well as co-resident carers. The level of support and services received by this sample of carers ranged widely, from those receiving no support at all to those receiving regular services. It is difficult to develop a survey to gather the experiences of such a diverse group, as many of the important questions about experiences will not be relevant to every one of the carers. For example, it is important and useful for CASSRs to understand how effective and satisfied carers are with services provided to give them a break from caring, but this question will not be relevant to the large numbers of carers not receiving any services to give them a break from caring. Reflecting this diversity in the population we found that a high proportion of carers selected the ‘not applicable’ responses to certain service-related questions. This limited the potential to use these questions as PIs: if PIs are based on questions that are ‘not applicable’ to a number of respondents, a portion of the respondents to the survey will be excluded from the measure. This would be an inefficient use of data and would be undesirable for a national PI reflecting the experiences of *all* carers. Our focus therefore for the PI development was on questions that had low rates of ‘not applicable’ responses.

The items that the majority of carers could complete were overall satisfaction with Social Services (q7), the effectiveness of services provided for the cared for person in making the carer’s life easier (q9) and aspects of quality of life (q18-24). In addition most carers did respond to items asking them about their experiences of NHS services (q42-46) but these items were not developed further as the advisory group questioned the extent to which the performance of NHS services is within the control of social care commissioners and whether it would be considered an acceptable PI for CASSRs. However, following the recent announcement of the Coalition government to pass over responsibility for public health to local authorities (Department of Health, 2010), stakeholders may now take a different view. We will return to this point at the end of this discussion.

The PIs taken forward for further analysis do vary in terms of their validity, reliability. We found that all of the potential PIs varied across CASSRs implying that there is variation across CASSRs on these measures. The multi-item carer QOL measure is the best measure of quality of life, so has the best fit with national priorities as specified in the previous government’s carers’ strategy. However, as the reliability analysis showed, although the IC criterion for accuracy was achieved at relatively low numbers of respondents compared to the other two PIs, very little of the observed variation is actually attributable to the CASSR. Following generalizability theory, this means that a large number of respondents are required to achieve an adequate level of reliability. By contrast, the satisfaction PI requires many more respondents to meet the IC criterion of accuracy compared to the carer QOL measure, but more of this variation in responses is attributable to the CASSR. This means that the satisfaction PI requires fewer respondents than the carer QOL PI to achieve an adequate level of reliability. The PI based on question 9 like the satisfaction PI correlated less well with the measure of quality of life. It required fewer respondents to meet the IC criterion of accuracy compared to the satisfaction PI, but more than the carer QOL PI. But like the carer QOL PI, very little of the variation in the PI scores was attributable to the CASSR, so the number of respondents required to achieve an adequate level of reliability is high and similar to the number required for the carer QOL PI.

This apparent paradox between these findings around reliability can be explained by the different approaches. The criterion used by the IC is agnostic to the source of the variation in the estimates. The analysis to determine sample size seeks to find the number of respondents required such that the noise (whatever its source) to signal ratio is as low as the accuracy criterion requires. The approach based on generalizability theory, by contrast, attempts to partition the variation in estimates between the variation due to individual variation and the variation due to the CASSR. The analysis to determine sample size then seeks to find the number of respondents required to reduce the noise (variation not due to the CASSR) to signal ratio to an adequate level. Arguably when we are interested in using the data to assess the CASSR, it is the latter approach to reliability that is of most interest.

Based on the comparison of qualities between PIs, it would seem that the PI based on q9 is the least good option since it is about as reliable as the carer QOL PI but it is less valid than the carer QOL PI, in terms of its ability to capture quality of life. The acceptability to stakeholders of the remaining options (q7 and carer QOL) is open for debate. The priorities of stakeholders and the importance they place on the attribution of the measure to the action of services or the local authority’s policies more generally are likely to influence their preferences. A further issue that may influence decisions is the sensitivity of the measures to changes over time. It has not been possible to assess this aspect with this dataset as we only have data for one point in time. In the future, as more data points become available this will be an important area for research.

The most important question to be addressed when deciding between the remaining PIs is what function do we want the PI to perform and is the PI performing this function? In the current political climate, with such an interest in measuring outcomes, an important function is arguably the ability of the PI to successfully reflect the impact of both central and local government policy on carers’ lives. This question of attribution is not straightforward to address particularly in the postal survey context. As it stands very little of the variability in each of the measures is attributable to the CASSR – less than five per cent for both of the measures. It is therefore useful to set out the pros and cons for both the satisfaction and carer QOL PIs and the extent to which scores on the PI are attributable to national and local policies.

7.1 Satisfaction PI

The single-item PI based on q7 which measures overall satisfaction with Social Services has good reliability at relatively small attained samples (around 150 people), which is beneficial for CASSRs that have poor response rates or few carers. It is also sensitive to differences across CASSRs, but is less valid compared to carer QOL as a measure of quality of life so fits less well with the aims of the carers’ strategy. Single-item measures have the advantage of being easy to understand and calculate and similar measures have been used in the past, so CASSRs will be familiar with them. However, simple measures are easier to game and concerns about this have been raised in relation to the use of a similar measure in previous UESs.

The object of Question 7 is Social Services and as such, it could be argued that any variations in scores on the PI can reasonably be attributed to the influence of Social Services. Indeed, as the reliability analysis showed a larger proportion of the variance was attributable to the CASSR compared to the carer QOL measure. However, we actually found that very little of the variation at only 2.75% was attributable to the CASSR. This may be because both the terms 'satisfaction' and 'Social Services' can be interpreted in many ways and it is difficult to be know what carers are thinking about when they are giving their responses (Goldstein and Healy, 1995). This seems a likely explanation: cognitive testing during the questionnaire development (Holder et al., 2009) revealed that not all carers realised Social Services commission support and services provided by other agencies, so there is a danger that services commissioned by Social Services that are not 'badged' Social Services will be excluded from assessments of satisfaction. The personalisation agenda will further fragment provision as will any developments associated with the 'Big Society'. Thus although it may seem from the wording of the question that variations in this PI are in some sense attributable to Social Services, the evidence we have collected suggests that the overwhelming majority of the observed variation is explained by individual variation. In addition, to the extent that the variation is attributable to the CASSR, any improvements in support that arise from indirect channelling of funding or support by Social Services into other organisations are unlikely to be reflected in the PI. There is the potential that CASSRs that embrace the 'Big Society' and personalisation agendas will appear to do less well than those that try to provide services directly through Social Services.

7.2 Carer QOL PI

The multi-item Carer QOL measure is the best measure of quality of life out of the three proposed PIs and is likely to be capturing the previous government's carers' strategy aim of the extent to which carers have a life of their own. From a statistical point of view, the measure has good psychometric properties, which justifies the approach taken here whereby responses to each of the items are summed together to form a scale taking values from zero to fourteen. Statistically, the scale is improved by dropping the safety item and it could also be argued that the high correlation between the time and space item and other items, such as control over daily life, means that there is some conceptual overlap and time and space could be dropped from the scale. However, we recommend retaining all the items to preserve face and content validity and ensure the scale captures a rounded picture of quality of life.

The reliability analysis found that more respondents are needed for the carer QOL PI than the satisfaction PI to achieve a good level of reliability --roughly 100 more. This was problematic for some CASSRs with poor response rates and small numbers of carers (although it was also a problem for the satisfaction PI). The carer QOL PI is more 'noisy' than the satisfaction PI because less variation is attributable to the CASSR. We found that only 1.6% of the variation in scores was attributable to the CASSR. This is a very low amount, and means that over 98% of the variation in the carer QOL scores is attributable to individual-level variation. It may be that the small additional amount of variation (around 1%) attributable to the satisfaction PI compared to the carer QOL arises because the satisfaction question asks specifically about Social Services.

7.3 The problem of attribution

The fact that only a very small amount of variation in both the carer QOL and satisfaction PI is attributable to the CASSR could be considered a problem for a PI designed to capture some feature of the performance of the CASSR. Exploratory work suggests that some of the individual variation in the PI scores may be explained by differences in the characteristics of the cared-for person and there may be wide variations in these characteristics between CASSRs. It therefore seems important to understand what is driving some of the individual-level variation, as part of the reason for not observing a large CASSR-effect statistically may in fact be due to the diversity of the sample and types of services received. Multivariate analysis to determine the factors which explain individual-level variation would help and adjustments could then be made to control for those factors that are beyond the control of the CASSR. However, this would require careful work and discussion to determine what factors should be measured and what counts as 'beyond the control of the CASSR'. This problem of attribution cannot be resolved easily and is an issue for both of the proposed PIs. In the meantime, policymakers need to consider the acceptability of using a measure to assess CASSR performance where a very small amount of the variation is due to the CASSR.

Acceptability could hinge on the interpretation of outcomes – whether the interest is in outcomes from services or outcomes for carers more generally – and how the data are to be used. For example, where data are used to judge the performance of CASSRs to generate a 'ranking' or 'targets' attribution is important. But where data are to be for 'intelligence' purposes attribution is less important as the data are there to generate questions for further analysis. In any case it needs to be clear that the scores attained by CASSRs are not necessarily a reflection of their performance.

A further aspect to the attribution problem is related to the dyadic nature of caring. The benefit from a service to a carer or to a cared-for person is partly realised by the carer and partly realised by the cared-for person. For example a day care service may be provided to give the carer a break from caring and so allow them to have a life of their own, go to work and so on; but it also has benefits for the cared-for person, perhaps providing a forum within which to meet and make new friends, engage in activities and learn new things, as well as have their basic needs attended to. Equally a service provided to the cared-for person, such as a home care service, has obvious benefits for the cared-for person but can have benefits (and dis-benefits) for the carer. For example when the home care service is late or unreliable it may negatively affect the well-being of the carer who may worry that the person they love is not being looked after properly; conversely when it is provided reliably the carer may be comforted knowing that the person they love is looked after well. When we are thinking about outcomes as the goal of measurement, ideally we would want to reflect the benefits realised from one service or care package to the whole care network (carer(s) and cared-for person). Indeed in the era of personalisation such a goal seems more important as budgets will be used for the benefit of both the service user and carer; to focus on only one beneficiary of the service risks generating a biased picture of service effectiveness.

8 Conclusions: Immediate and future options

The two options presented above are the most statistically viable options for PIs in the short term and a decision needs to be taken as to the acceptability of using as a PI a measure where the majority of the observed variation is not directly attributable to the CASSR. Presentation of such a measure will be important and it may be wise to think of the carer QOL measure, for example, as a measure of the quality of life of carers in a particular area, making it clear that where a CASSRs appears to score poorly this is not necessarily an indictment of their policies towards carers. Consideration should be given to the label PI, which implies that the measure in some way is an indication of the performance of the organisation being assessed. As we have mentioned in the medium term multivariate analysis exploring the factors that explain variations between and within CASSRs may be of use in trying to understand how scores should and could be interpreted.

In the longer-term if the aim is to create a PI that is attributable to the action of services, it may be of value to focus on the impact on the carer, of the budget or care package provided to the service user and carer as a unit. It would still be necessary to undertake modelling to ensure that the impact of services is adjusted to allow for factors beyond the control of CASSRs, but the contribution of services would be factored into the modelling through the size of the personal budget. Such an approach would require considerable theoretical and analytic work to combine the necessary elements. However, a measure constructed in this manner would ensure that the value of services to carers as well as to service users is captured, ensuring that any resource allocation decisions made on the basis of data collected are not biased because they only consider the effect of services on the service user.

Such a measure has consequences for the sampling procedure for the survey, since the population of carers of interest would be described as those carers who receive a personal budget or are caring for someone who receives a personal budget. It would not include those carers and cared-for people who have no contact with Social Services. The primary use of such a PI would be for CASSRs to help them with the allocation of resources, but it would also be of value in monitoring the productivity of services at a national level. However, such a measure does not fit with the broader aims of the carers' survey to ensure that all carers are enjoying a good life. It may therefore be of interest to run a national survey alongside the CASSR-led surveys at intervals of several years to measure general trends in the quality of life of carers in England. Questions on quality of life, for example, could be added to the National Survey of Carers in Households which surveyed all carers, irrespective of their contact with Social Services. This type of survey may provide a much better reflection of the national picture concerning carers and would be a good way of monitoring the effect of national policies by examining national trends.

8.1 Postscript: The coalition government and future directions

The analyses conducted in this report were commissioned under the previous Labour government. We have tried to think about the relevance of this work for the present coalition government, but at present the direction of policy concerning carers and social care is unclear. Forthcoming White Papers will undoubtedly clarify the future responsibilities of CASSRs with regard to public health, social care and carers and the 'refresh' of the Carers' Strategy planned for November 2010 will define the coalition government's priorities for the next four years. In trying to answer the questions we raised in this report about the acceptability, validity and so on of each of the proposed PIs, we have drawn on the previous government's Carers' Strategy. It may be that when the coalition's strategy for carers is published some of this discussion will need to be revised in light of new priorities.

As this project was nearing completion, a consultation document regarding the future NHS outcomes framework was published (Department of Health, 2010). This framework suggests that the key focus of measurement should be outcomes, which fits well with the arguments we have made in this paper in favour of a measure focusing on quality of life and the concerns we have raised over attribution of the effect of services. The outcomes framework advocates an overarching broad outcome indicator with sub-level PIs linked more closely to services. Future work may wish to explore how the options in this paper could be moulded to fit within such a framework should a similar type of framework emerge for social care. Given the announcement that public health duties will be transferred to local authorities, it may also want to examine the potential for other questions, such as those on health services, to be used as sub-level PIs.

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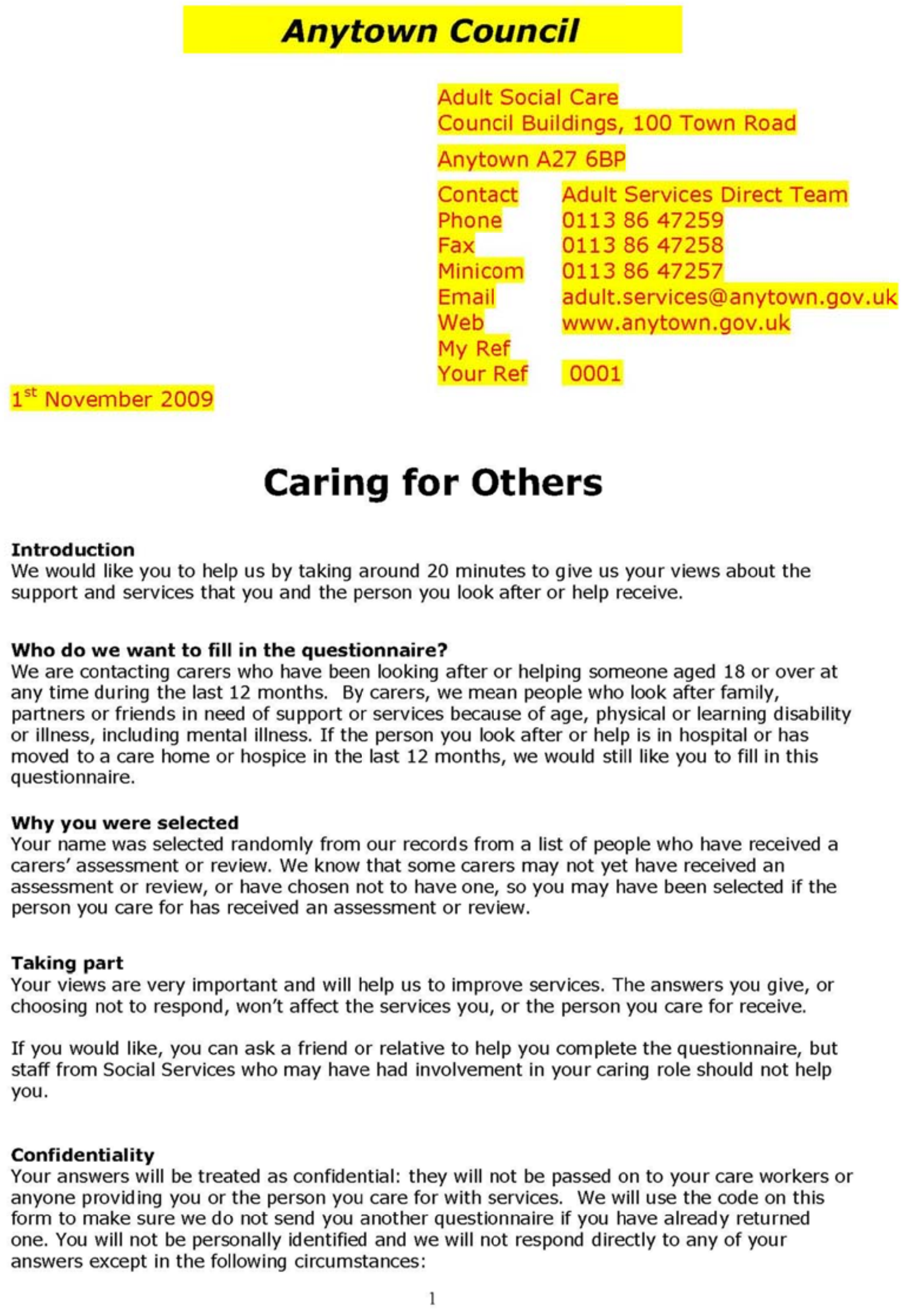
10 Appendix A – Personal Social Services Survey of Adult Carers in England 2009-10 questionnaire



Anytown Council

Adult Social Care
Council Buildings, 100 Town Road
Anytown A27 6BP

Contact	Adult Services Direct Team
Phone	0113 86 47259
Fax	0113 86 47258
Minicom	0113 86 47257
Email	adult.services@anytown.gov.uk
Web	www.anytown.gov.uk
My Ref	
Your Ref	0001

1st November 2009

Caring for Others

Introduction
We would like you to help us by taking around 20 minutes to give us your views about the support and services that you and the person you look after or help receive.

Who do we want to fill in the questionnaire?
We are contacting carers who have been looking after or helping someone aged 18 or over at any time during the last 12 months. By carers, we mean people who look after family, partners or friends in need of support or services because of age, physical or learning disability or illness, including mental illness. If the person you look after or help is in hospital or has moved to a care home or hospice in the last 12 months, we would still like you to fill in this questionnaire.

Why you were selected
Your name was selected randomly from our records from a list of people who have received a carers' assessment or review. We know that some carers may not yet have received an assessment or review, or have chosen not to have one, so you may have been selected if the person you care for has received an assessment or review.

Taking part
Your views are very important and will help us to improve services. The answers you give, or choosing not to respond, won't affect the services you, or the person you care for receive.

If you would like, you can ask a friend or relative to help you complete the questionnaire, but staff from Social Services who may have had involvement in your caring role should not help you.

Confidentiality
Your answers will be treated as confidential: they will not be passed on to your care workers or anyone providing you or the person you care for with services. We will use the code on this form to make sure we do not send you another questionnaire if you have already returned one. You will not be personally identified and we will not respond directly to any of your answers except in the following circumstances:

We will use the code on this form to identify who you are only if you select the option saying that you are extremely worried about your personal safety on question **number 22**. In that circumstance, we will use the code to identify you so that someone (but not your care worker) can contact you to talk about it.

Councils may change this if they would contact more than those who say they are extremely worried

If you indicate on this form that you would like to take part in future research on question **number 57**, we will use the code to identify who you are so that we can contact you.

The above statement should be omitted by councils omitting question 57. Please note that the above question numbers will change, depending on which optional questions are selected by councils and any local questions added.

What will be done with the results of the survey
The results of the survey will be used by the Care Quality Commission, the Department of Health and your local authority to see how happy people are with the support and services they receive, to see whether improvements need to be made to local care services, and for further research or analysis.

If you would like to receive a copy of the results of this survey please tick the last box at the end of the questionnaire.

What to do if you have queries or would like to know how to obtain information on the results
If you, or your friend or relative have questions you would like to ask about the survey, please ring [insert telephone number] on Monday to Friday between 10.00 am and 12.00 pm or between 2.00 pm and 4.00 pm.

Any queries you may have about the services you receive should be directed to staff responsible for that service, as the staff supporting this Carers survey may not be specialist advisors.

Reminder Letters
If you do not return this questionnaire then you may be sent reminder letters. If you do not wish to receive reminders then please send back the blank questionnaire in the envelope provided.

Sending back the completed questionnaire
Once you have completed the questionnaire please return it in the envelope provided by **[insert date]**. You don't need to put a stamp on the envelope.

Thank you for helping us by completing this questionnaire.

Councils wishing to provide a channel for carers to get in touch about further information, advice or services could insert contact details here

2

If you look after a family member, partner or friend in need of support or services because of their age, physical or learning disability or illness, including mental illness, we would like you to complete this questionnaire.

Section 1: About the person you care for
The questions in this section ask about the person you care for, by which we mean the person you look after or help, and your experience of support and services.

1. How many people aged 18 or over do you care for? ☐

If you care for more than one person, please answer **only** in relation to the person you spend the most time helping. If you spend an equal amount of time caring for two or more people, please answer in relation to the person who lives with you. If you live with two or more people that you spend an equal amount of time caring for, please choose **one** person to answer about.

2. Who is the person you care for?

Please tick [✓] one box

Parent ☐
Parent-in-law ☐
Spouse/partner ☐
Child (own/adopted/step) ☐
Other relative ☐
Other non-relative/friend/neighbour ☐

3. How old is this person?______________years

(If you don't know the exact age please give an approximate one)

4. Are they male or female?

Please tick [✓] one box

Male ☐
Female ☐

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

Please tick [✓] all that apply

- Dementia ☐
- A physical disability ☐
- Sight or hearing loss ☐
- A mental health problem ☐
- Problems connected to ageing ☐
- A learning disability or difficulty ☐
- Long-standing illness ☐
- Terminal illness ☐
- Alcohol or drug dependency ☐

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

Please tick [✓] one box

- With me ☐
- Somewhere else ☐

7. Overall, how satisfied are you with the support or services you and the person you care for have received from Social Services in the last 12 months?

Please tick [✓] one box

- We haven't received any support or services from Social Services in the last 12 months ☐
- I am extremely satisfied ☐
- I am very satisfied ☐
- I am fairly satisfied ☐
- I am neither satisfied nor dissatisfied ☐
- I am fairly dissatisfied ☐
- I am very dissatisfied ☐
- I am extremely dissatisfied ☐

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

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

	Yes	**No**	**Don't know**
Care home	☐	☐	☐
Personal assistant	☐	☐	☐
Home care/home help	☐	☐	☐
Day centre or day activities	☐	☐	☐
Lunch club	☐	☐	☐
Meals on wheels	☐	☐	☐
Equipment or adaptation to their home (such as a wheelchair, handrails or an alarm system)	☐	☐	☐
Supported employment	☐	☐	☐
Special College	☐	☐	☐

Question answers in red above are optional examples and can be removed if your council does not provide these services. Similarly, additional options can be added if you wish but not returned to the NHS Information Centre on the data return

9. Thinking about the support or services the person you care for has received (provided by a voluntary organisation, a private agency or Social Services) in the last 12 months, which of the following statements best describes your present situation? OPTIONAL QUESTION

Please tick [✓] one box

The person I care for has received no support or services in the last 12 months ☐

The support or services have made things easier for me ☐

The support or services have made no difference to me ☐

The support or services have made things harder for me ☐

10. At the present time, do you and the person you care for have the right amount of support or services, in terms of the hours or days you need? OPTIONAL QUESTION

Please tick [✓] one box

At the present time, we do not receive any support or services ☐

No, we have more hours or days than we need ☐

The amount is about right ☐

No, we need a few more hours or days ☐

No, we need a lot more hours or days ☐

Section 2: About your needs and experiences of support

The questions in this section ask about the support and services that **you** use as a carer. They may be arranged by you or by Social Services. They may be provided by a voluntary organisation, a private agency or Social Services.

11. Which of the following types of organisation do you get the <u>most</u> support or services from......? OPTIONAL QUESTION

Please tick [✓] one box

Voluntary organisations ☐

Private agencies ☐

Social Services ☐

Don't know ☐

12. Have you used any of the support or services listed below, to help you as a carer over the last 12 months?

They may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

	Yes	**No**	**Don't know**
Information and advice	☐	☐	☐
Support from carers groups or someone to talk to in confidence	☐	☐	☐
Training for carers	☐	☐	☐
Advocacy for carers (Advocates speak on your behalf or assist you to express your views)	☐	☐	☐
Emergency care back-up scheme	☐	☐	☐
Help with household tasks or gardening	☐	☐	☐
Practical help to complete forms	☐	☐	☐

Question answers in red above are optional examples and can be removed if your council does not provide these services. Similarly, additional options can be added if you wish but not returned to the NHS Information Centre on the data return

13. In the last 12 months, have you used any support or services to help you take a break from caring, lasting more than 24 hours?

Please do <u>not</u> include unpaid help from family and friends.

Please tick [✓] one box

Yes ☐

No, because there were no support or services available to me ☐

No, because the support or services available were not suitable ☐

No, for other reasons ☐

Don't know ☐

14. Overall, how satisfied were you with the support or services that helped you to take a break from caring, lasting more than 24 hours?

Please tick [✓] one box

I haven't used any support or services to have a break lasting more than 24 hours ☐

I was extremely satisfied ☐

I was very satisfied ☐

I was fairly satisfied ☐

I was neither satisfied nor dissatisfied ☐

I was fairly dissatisfied ☐

I was very dissatisfied ☐

I was extremely dissatisfied ☐

15. In the last 12 months, have you regularly used any support or services to help you have a rest from caring for between 1 hour and 24 hours?

Please do not include unpaid help from family and friends.

Please tick [✓] one box

Yes ☐

No, because there were no support or services available to us ☐

No, because the support or services available were not suitable ☐

No, for other reasons ☐

Don't know ☐

16. Overall, how satisfied were you with the support or services that regularly helped you to have a rest from caring for between 1 hour and 24 hours?

Please tick [✓] one box

I haven't used any support or services to have a rest for between 1 and 24 hours ☐

I was extremely satisfied ☐
I was very satisfied ☐
I was fairly satisfied ☐
I was neither satisfied nor dissatisfied ☐
I was fairly dissatisfied ☐
I was very dissatisfied ☐
I was extremely dissatisfied ☐

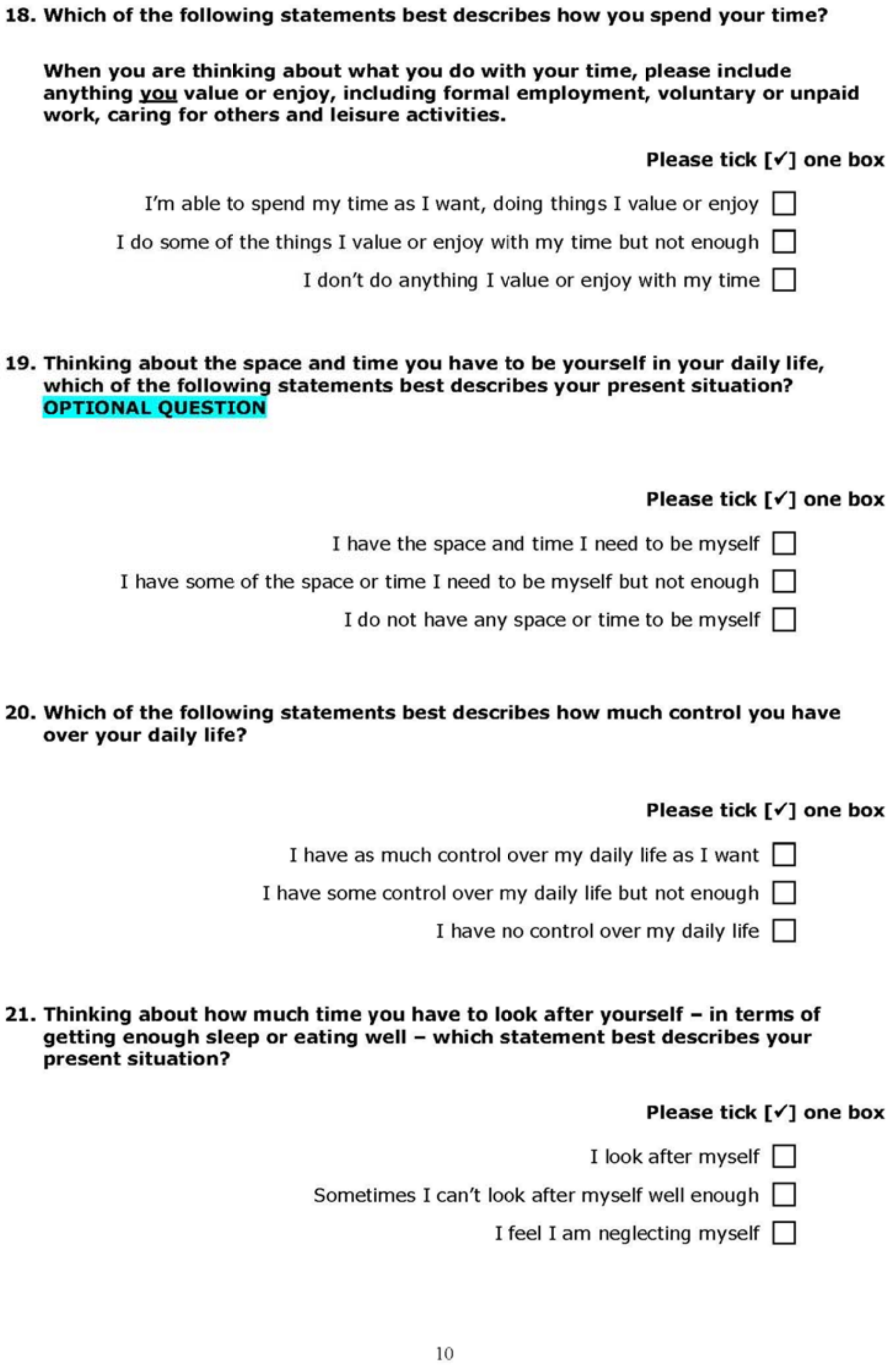
Section 3: The impact of caring and your quality of life

Some of the questions in this section look at the impact of caring on particular aspects of your life, while others ask about the quality of different parts of your life more generally.

17. Thinking about the good and the bad things that make up your quality of life, how would you rate the quality of your life as a whole?

Please tick [✓] one box

So good, it could not be better ☐
Very good ☐
Good ☐
Alright ☐
Bad ☐
Very bad ☐
So bad, it could not be worse ☐



18. Which of the following statements best describes how you spend your time?

When you are thinking about what you do with your time, please include anything <u>you</u> value or enjoy, including formal employment, voluntary or unpaid work, caring for others and leisure activities.

Please tick [✓] one box

I'm able to spend my time as I want, doing things I value or enjoy ☐
I do some of the things I value or enjoy with my time but not enough ☐
I don't do anything I value or enjoy with my time ☐

19. Thinking about the space and time you have to be yourself in your daily life, which of the following statements best describes your present situation?
OPTIONAL QUESTION

Please tick [✓] one box

I have the space and time I need to be myself ☐
I have some of the space or time I need to be myself but not enough ☐
I do not have any space or time to be myself ☐

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

Please tick [✓] one box

I have as much control over my daily life as I want ☐
I have some control over my daily life but not enough ☐
I have no control over my daily life ☐

21. Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation?

Please tick [✓] one box

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

22. Thinking about your personal safety, which of the statements best describes your present situation?

By 'personal safety' we mean feeling safe from fear of abuse, being attacked or other physical harm.

Please tick [✓] one box

I have no worries about my personal safety ☐

I have some worries about my personal safety ☐

I am extremely worried about my personal safety ☐

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

Please tick [✓] one box

I have as much social contact as I want with people I like ☐

I have some social contact with people but not enough ☐

I have little social contact with people and feel socially isolated ☐

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

Please tick [✓] one box

I feel I have encouragement and support ☐

I feel I have some encouragement and support but not enough ☐

I feel I have no encouragement and support ☐

25. Thinking about the skills needed for caring, which statement best describes your present situation?

Please tick [✓] one box

I do not need any training at present ☐

I would like some training ☐

I need some training ☐

26. Thinking about how easy it is for you to get basic services to meet your needs – such as going to see a GP, visiting a dentist or going to the library – which of the following statements best describes your present situation?

Please tick [✓] one box

I can get the basic services I need ☐

I can't always get the basic services I need ☐

I can't always get the basic services I need, and I think there is a risk to my health ☐

27. How is your health in general?

Please tick [✓] one box

Very good ☐

Good ☐

Fair ☐

Bad ☐

Very bad ☐

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

Please tick [✓] all that apply

Feeling tired ☐

Feeling depressed ☐

Loss of appetite ☐

Disturbed sleep ☐

General feeling of stress ☐

Physical strain (e.g. back) ☐

Short tempered/irritable ☐

Had to see own GP ☐

Developed my own health condition ☐

Made an existing condition worse ☐

Other ☐

No, none of these ☐

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

Please tick [✓] one box

No, not at all ☐

Yes, to some extent ☐

Yes, a lot ☐

Section 4: Information and advice quality

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

30. Please tick the box which comes closest to describing how quickly Social Services have responded to your queries or questions in the last 12 months.

Please tick [✓] one box

I have not contacted Social Services with a query or question in the last 12 months ☐

Someone always got back to me ☐

Sometimes they got back to me, but sometimes I had to contact them again ☐

I had to contact them more than twice, but eventually someone got back to me ☐

They didn't get back to me ☐

31. In the last 12 months, have you found it easy or difficult to <u>find</u> information and advice about support, services or benefits? Please include information and advice from different sources, such as voluntary organisations and private agencies as well as Social Services.

Please tick [✓] one box

I have not tried to find information or advice in the last 12 months ☐

Very easy to find ☐

Fairly easy to find ☐

Fairly difficult to find ☐

Very difficult to find ☐

32. In the last 12 months, how helpful has the information and advice you have received been? Please include information and advice from different organisations, such as voluntary organisations and private agencies as well as Social Services.

Please tick [✓] one box

I have not received any information or advice in the last 12 months ☐

Very helpful ☐

Quite helpful ☐

Quite unhelpful ☐

Very unhelpful ☐

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

The next questions are about organising the support and services for you and the person you care for.

33. Has it been easy or difficult to get the support or services the person you care for needs in the past 12 months? The services may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services. OPTIONAL QUESTION

Please tick [✓] one box

There was no need to get any support or services in the last 12 months ☐

Very easy ☐

Quite easy ☐

Quite difficult ☐

Very difficult ☐

34. Have you found it easy or difficult to get the support or services you need as a carer in the last 12 months? The services may be provided by different organisations, such as a voluntary organisation, a private agency or Social Services.

Please tick [✓] one box

I did not need any support or services in the last 12 months ☐

Very easy ☐

Quite easy ☐

Quite difficult ☐

Very difficult ☐

35. In the last 12 months, have you or the person you care for had to wait to get any support or services? OPTIONAL QUESTION

Please tick [✓] one box

We haven't asked for any support or services in the last 12 months ☐

No, we haven't had to wait ☐

Yes, but the wait was not a problem ☐

Yes, and the wait should be a bit shorter ☐

Yes, and the wait should be a lot shorter ☐

36. How do you feel about the level of contact you had with the care manager or social worker that works with the person you care for? OPTIONAL QUESTION

Please tick [✓] one box

The person I care for does not have a care manager or social worker ☐

The level of contact should be reduced ☐

The level of contact is about right ☐

The level of contact should be increased a little ☐

The level of contact should be increased a lot ☐

37. In the last 12 months, do you feel you have been involved or consulted as much as you wanted to be, in discussions about the support or services provided to the person you care for?

Please tick [✓] one box

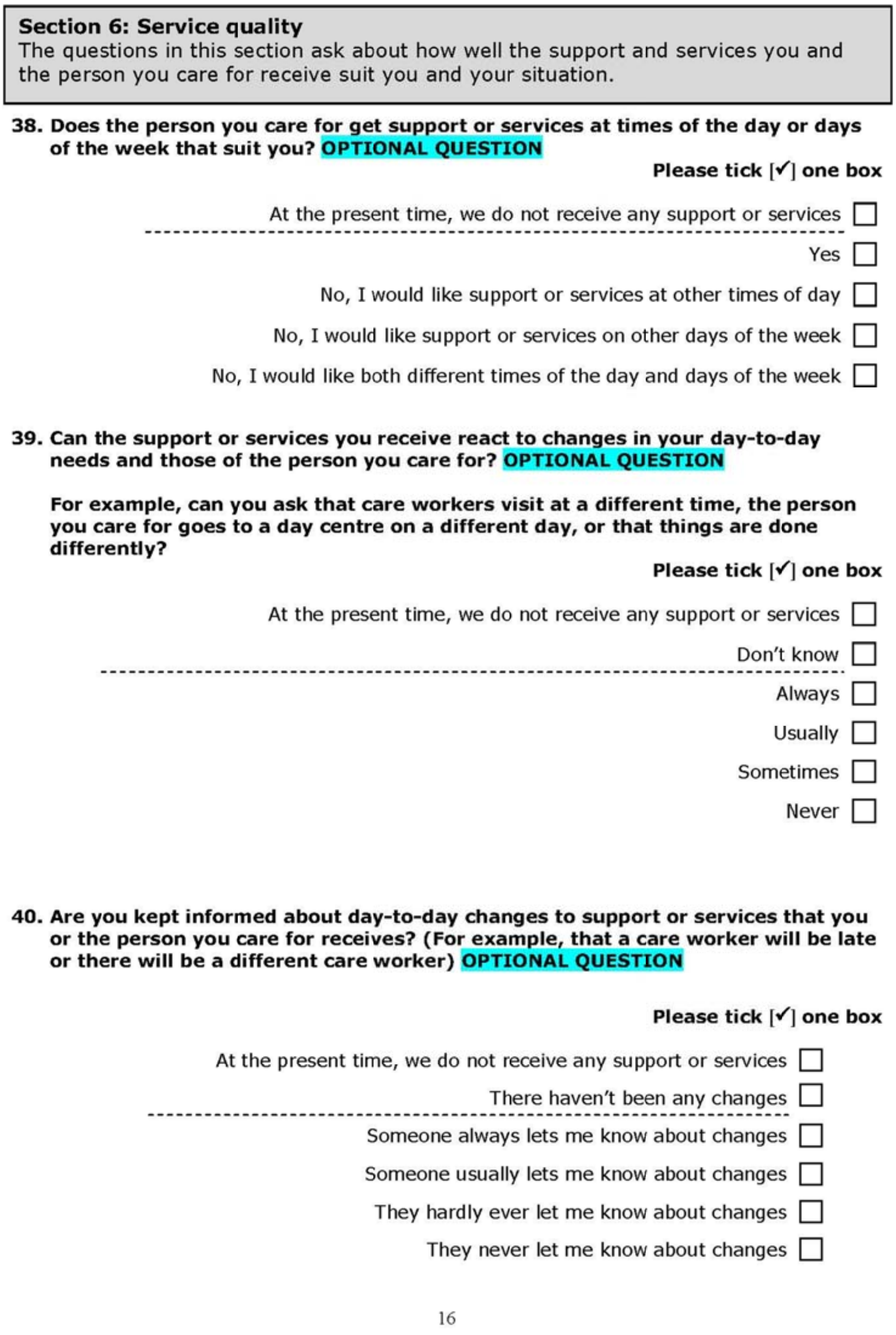
There have been no discussions that I am aware of, in the last 12 months ☐

I always felt involved or consulted ☐

I usually felt involved or consulted ☐

I sometimes felt involved or consulted ☐

I never felt involved or consulted ☐



Section 6: Service quality

The questions in this section ask about how well the support and services you and the person you care for receive suit you and your situation.

38. Does the person you care for get support or services at times of the day or days of the week that suit you? OPTIONAL QUESTION

Please tick [✓] one box

At the present time, we do not receive any support or services ☐

Yes ☐

No, I would like support or services at other times of day ☐

No, I would like support or services on other days of the week ☐

No, I would like both different times of the day and days of the week ☐

39. Can the support or services you receive react to changes in your day-to-day needs and those of the person you care for? OPTIONAL QUESTION

For example, can you ask that care workers visit at a different time, the person you care for goes to a day centre on a different day, or that things are done differently?

Please tick [✓] one box

At the present time, we do not receive any support or services ☐

Don't know ☐

Always ☐

Usually ☐

Sometimes ☐

Never ☐

40. Are you kept informed about day-to-day changes to support or services that you or the person you care for receives? (For example, that a care worker will be late or there will be a different care worker) OPTIONAL QUESTION

Please tick [✓] one box

At the present time, we do not receive any support or services ☐

There haven't been any changes ☐

Someone always lets me know about changes ☐

Someone usually lets me know about changes ☐

They hardly ever let me know about changes ☐

They never let me know about changes ☐

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41. Do care workers or personal assistants treat you with courtesy and respect?
OPTIONAL QUESTION

Please tick [✓] one box

At the present time, we do not receive any support or services ☐

Always ☐
Usually ☐
Sometimes ☐
Never ☐

Section 7: Experience of health services as a carer

42. Do you feel you have been treated with respect as a carer, when you have been in contact with health professionals at a NHS hospital about the person you care for, over the last 12 months?

Please tick [✓] one box

I have not been in contact with health professionals at a NHS hospital about the person I care for in the last 12 months ☐

Always ☐
Usually ☐
Sometimes ☐
Never ☐

43. Do you feel you were involved as much as you wanted to be in discussions about the care and treatment of the person you care for, when you have been in contact with health professionals at a NHS hospital in the last 12 months?

Please tick [✓] one box

I have not been in contact with health professionals at a NHS hospital about the person I care for in the last 12 months ☐

Always ☐

Usually ☐

Sometimes ☐

Never ☐

44. Do you feel you have been treated with respect as a carer, when you have been in contact with health professionals from a GP surgery/health centre about the person you care for, over the last 12 months?

Please tick [✓] one box

I have not been in contact with health professionals at a GP surgery/health centre about the person I care for in the last 12 months ☐

Always ☐

Usually ☐

Sometimes ☐

Never ☐

45. Do you feel you were involved as much as you wanted to be in discussions about the care and treatment of the person you care for, when in contact with health professionals from a GP surgery/health centre in the last 12 months?

Please tick [✓] one box

I have not been in contact with health professionals at a GP surgery/health centre about the person I care for in the last 12 months ☐

Always ☐

Usually ☐

Sometimes ☐

Never ☐

46. Overall, do you feel GPs support you in your role as a carer?

Please tick [✓] one box

The GPs I see don't know that I am a carer ☐

Always ☐

Usually ☐

Sometimes ☐

Never ☐

Section 8: About yourself

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

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

Please tick [✓] all that apply

Retired ☐

Employed full-time ☐

Employed part-time (working 30 hours or less) ☐

Self-employed full-time ☐

Self-employed part-time ☐

Not in paid work ☐

Doing voluntary work ☐

Other ☐

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

Please tick [✓] one box

I am in paid employment and I feel supported by my employer ☐

I am in paid employment but I don't feel supported by my employer ☐

I do not need any support from my employer to combine work and caring ☐

I am not in paid employment because of my caring responsibilities ☐

I am not in paid employment for other reasons ☐

I am self-employed or retired ☐

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

Please tick [✓] one box

- Less than 6 months ☐
- Over 6 months but less than a year ☐
- Over 1 year but less than 3 years ☐
- Over 3 years but less than 5 years ☐
- Over 5 years but less than 10 years ☐
- Over 10 years but less than 15 years ☐
- Over 15 years but less than 20 years ☐
- 20 years or more ☐

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

Please tick [✓] one box

- 0-9 hours per week ☐
- 10-19 hours per week ☐
- 20-34 hours per week ☐
- 35-49 hours per week ☐
- 50-99 hours per week ☐
- 100 or more hours per week ☐
- Varies – Under 20 hours per week ☐
- Varies – 20 hours or more per week ☐
- Other ☐

If other please specify:

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

Please tick [✓] all that apply

Personal care? ☐
(Things like dressing, bathing, washing, shaving, cutting nails, feeding, using the toilet)

Physical help? ☐
(Such as helping with walking, getting up and down stairs, getting into and out of bed)

Helping with dealing with care services and benefits? ☐
(Things like making appointments and phone calls, filling in forms)

Helping with paperwork or financial matters? ☐
(Such as writing letters, sending cards, filling in forms, dealing with bills, banking)

Other practical help? ☐
(Things like preparing meals, doing his/her shopping, laundry, housework, gardening, decorating, household repairs, taking to doctor's or hospital)

Keeping him/her company? ☐
(Things like visiting, sitting with, reading to, talking to, playing cards or games)

Taking him/her out? ☐
(Such as taking out for a walk or drive, taking to see friends or relatives)

Giving medicines? ☐
(Things like making sure he/she takes pills, giving injections, changing dressings)

Keeping an eye on him/her to see he/she is all right? ☐

Giving emotional support? ☐

Other help? ☐

52. Do you have any of the following?

Please tick [✓] all that apply

A physical impairment or disability ☐
Sight or hearing loss ☐
A mental health problem or illness ☐
A learning disability or difficulty ☐
A long-standing illness ☐
Other ☐
None of the above ☐

53. How old are you? _________________ **years**

Councils may choose to omit the above question if it can be supplied accurately from their current records.

54. Are you male or female?

Please tick [✓] one box

Male ☐

Female ☐

Councils may choose to omit the above question if it can be supplied accurately from their current records.

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

Please tick [✓] one box

White ☐
(British, Irish, Traveller of Irish Heritage, Gypsy/Roma, any other White background)

Mixed ☐
(White and Black Caribbean, White and Black African, White and Asian, any other Mixed background)

Asian or Asian British ☐
(Indian, Pakistani, Bangladeshi, any other Asian background)

Black or Black British ☐
(Caribbean, African, any other Black background)

Chinese ☐

Any other ethnic group ☐

Councils may choose to omit the above question and supply data from their own records if they are confident of the quality and coverage of the information about the carer's assessment of their ethnic origin in their current records. Councils including this question may break down the categories further if they wish to do so.

56. Did someone help you to complete this questionnaire?

Please tick [✓] one box

Yes ☐

No ☐

Councils may seek further information on the category of person who helped here if they wish – but these should only be categories of person (e.g. relative) and not names. Any expanded categories need to be aggregated back to just an overall 'yes' category before entering the results onto the data return.

57. If further research were to take place, would you be happy for us to contact you?
OPTIONAL QUESTION

Please tick [✓] one box

Yes ☐
No ☐

58. Please use the space provided below to describe any other experiences you would like to tell us about or to write any other comments you would like to make?
OPTIONAL QUESTION

Please tick (✓) this box if you would like to receive a copy of the report of this survey ☐

Thank you for helping us by filling in this questionnaire.
Please post it back to us in the envelope provided.
You do not need to put a stamp on the envelope.

For your views to count please return this form by [insert date]

11 Appendix B – Variations in valid responses to potential performance items by sample group

	Carers by association		Carers with a joint assessment		Carers with a separate assessment		Total		Pearson Chi-Square	(df)	Significance
	%	n	%	n	%	n	%	n			
Q7: Overall satisfaction with Social Services											
I am extremely satisfied	2.7	738	8.5	2334	6.2	1695	17.4	4767			
I am very satisfied	6.1	1672	17.4	4760	12.7	3472	36.2	9904			
I am fairly satisfied	5.2	1415	13.4	3659	10.5	2864	29.0	7938			
I am neither satisfied nor dissatisfied	1.7	470	3.8	1043	3.5	945	9.0	2458			
I am fairly dissatisfied	0.8	206	1.8	479	1.6	428	4.1	1113			
I am very dissatisfied	0.4	118	1.0	267	0.8	220	2.2	605			
I am extremely dissatisfied	0.4	112	0.8	217	0.8	219	2.0	548			
% of Total	17.3	4731	46.7	12759	36.0	9843	100.0	27333	62.257	(12)	p<0.001**
Q9: Have support/services made things easier											
easier	15.5	2906	40.5	7568	27.6	5155	83.5	15629			
no difference	2.8	528	6.1	1150	5.2	968	14.1	2646			
harder	0.4	74	1.0	185	0.9	173	2.3	432			
% of Total	18.8	3508	47.6	8903	33.7	6296	100.0	18707	30.75	(4)	p<0.001**
Q10: Do you have the right amount of support/services											
more than we need	0.4	49	0.8	106	0.6	86	1.8	241			
amount is about right	14.3	1930	38.5	5208	22.2	3000	75.0	10138			
need a few more hours/days	3.9	524	8.8	1185	6.3	849	18.9	2558			
need a lot more hours/days	0.8	113	1.9	256	1.6	213	4.3	582			
% of Total	19.4	2616	50.0	6755	30.7	4148	100.0	13519	36.795	(6)	p<0.001**

	Carers by association		Carers with a joint assessment		Carers with a separate assessment		Total		Pearson Chi-Square	(df)	Significance
	%	n	%	n	%	n	%	n			
Q14: Satisfaction with break lasting >24hrs											
extremely satisfied	3.7	358	11.4	1092	10.1	971	25.2	2421			
very satisfied	5.5	532	16.4	1573	14.7	1409	36.6	3514			
fairly satisfied	3.6	346	10.1	972	8.6	829	22.4	2147			
neither satisfied nor dissatisfied	1.4	134	3.5	336	2.7	262	7.6	732			
fairly dissatisfied	0.5	52	1.3	129	1.0	99	2.9	280			
very dissatisfied	0.2	19	0.7	70	1.0	95	1.9	184			
extremely dissatisfied	0.8	73	1.3	122	1.3	126	3.3	321			
% of Total	15.8	1514	44.7	4294	39.5	3791	100.0	9599	37.493	(12)	p<0.001**
Q16: Satisfaction with break lasting <24hrs											
extremely satisfied	3.7	420	11.6	1310	11.7	1323	27.0	3053			
very satisfied	6.0	680	16.8	1900	15.7	1770	38.5	4350			
fairly satisfied	3.7	418	9.5	1079	8.8	994	22.0	2491			
neither satisfied nor dissatisfied	1.4	161	2.9	324	2.9	324	7.2	809			
fairly dissatisfied	0.2	27	0.9	103	0.8	96	2.0	226			
very dissatisfied	0.2	20	0.5	61	0.5	62	1.3	143			
extremely dissatisfied	0.4	46	0.8	91	0.8	91	2.0	228			
% of Total	15.7	1772	43.1	4868	41.2	4660	100.0	11300	31.793	(12)	p<0.001**
Q17: Overall quality of life											
could not be better	0.4	110	0.7	224	0.5	165	1.6	499			
Very good	2.3	703	5.6	1706	3.6	1087	11.4	3496			
Good	4.2	1298	10.7	3277	8.1	2489	23.1	7064			
Alright	8.4	2577	21.2	6486	17.8	5446	47.4	14509			
Bad	1.8	547	4.8	1466	4.6	1413	11.2	3426			
Very bad	0.6	171	1.3	386	1.3	400	3.1	957			
could not be worse	0.4	113	0.8	253	0.9	277	2.1	643			
% of Total	18.0	5519	45.1	13798	36.9	11277	100.0	30594	120.653	(12)	p<0.001**

	Carers by association		**Carers with a joint assessment**		**Carers with a separate assessment**		**Total**		**Pearson Chi-Square**	**(df)**	**Significance**
	%	**n**	**%**	**n**	**%**	**n**	**%**	**n**			
Q18: Are you able to do things you value or enjoy											
able to spend my time as I want	4.6	1391	11.5	3488	7.5	2280	23.5	7159			
do some but not enough	11.3	3434	28.6	8690	23.9	7261	63.8	19385			
don't do anything	2.2	663	5.7	1725	4.8	1473	12.7	3861			
% of Total	18.0	5488	45.7	13903	36.2	11014	100.0	30405	78.741	(4)	p<0.001**
Q19: Do you have time and space to be yourself											
have the space and time I need	6.4	1284	12.7	2530	8.5	1695	27.6	5509			
have some of the space or time I need	11.0	2189	24.3	4836	21.2	4232	56.5	11257			
do not have any space or time	3.0	603	6.8	1361	6.0	1206	15.9	3170			
% of Total	20.4	4076	43.8	8727	35.8	7133	100.0	19936	92.33	(4)	p<0.001**
Q20: Do you have control over your daily life											
have as much control as I want	6.5	1976	15.4	4653	10.2	3076	32.1	9705			
have some control but not enough	10.1	3037	25.7	7750	22.1	6667	57.8	17454			
have no control over my daily life	1.7	523	4.2	1266	4.1	1247	10.1	3036			
% of Total	18.3	5536	45.3	13669	36.4	10990	100.0	30195	151.604	(4)	p<0.001**
Q21: Do you have time to look after yourself											
look after myself	11.3	3507	29.5	9160	21.6	6698	62.3	19365			
can’t look after myself well enough	4.5	1394	10.7	3324	9.8	3049	25.0	7767			
feel I am neglecting myself	2.1	639	5.4	1689	5.2	1609	12.7	3937			
% of Total	17.8	5540	45.6	14173	36.6	11356	100.0	31069	94.562	(4)	p<0.001**

	Carers by association		**Carers with a joint assessment**		**Carers with a separate assessment**		**Total**		**Pearson Chi-Square**	**(df)**	**Significance**
	%	**n**	**%**	**n**	**%**	**n**	**%**	**n**			
Q22: Do you have any worries about personal safety											
have no worries	15.1	4639	38.9	11932	30.6	9387	84.6	25958			
have some worries	2.6	808	5.7	1746	5.5	1702	13.9	4256			
I am extremely worried	0.3	92	0.5	163	0.6	199	1.5	454			
% of Total	18.1	5539	45.1	13841	36.8	11288	100.0	30668	52.974	(4)	p<0.001**
Q23: Do you have as much social contact as you'd like											
have as much social contact as I want	8.5	2612	21.7	6628	14.6	4464	44.8	13704			
have some social contact with people but not enough	7.7	2344	18.2	5584	16.8	5143	42.7	13071			
feel socially isolated	1.9	590	5.2	1579	5.4	1655	12.5	3824			
% of Total	18.1	5546	45.1	13791	36.8	11262	100.0	30599	216.488	(4)	p<0.001**
Q24: Do you feel you have encouragement & support											
feel I have encouragement and support	8.5	2566	22.6	6776	16.6	4973	47.7	14315			
feel I have some but not enough	7.0	2090	16.9	5087	15.2	4552	39.1	11729			
feel I have no encouragement and support	2.5	752	5.6	1681	5.2	1549	13.3	3982			
% of Total	18.0	5408	45.1	13544	36.9	11074	100.0	30026	66.986	(4)	p<0.001**

	Carers by association		**Carers with a joint assessment**		**Carers with a separate assessment**		**Total**		**Pearson Chi-Square**	**(df)**	**Significance**
	%	**n**	**%**	**n**	**%**	**n**	**%**	**n**			
Q30: Responsiveness of Social Services to queries											
Someone always got back to me	9.6	2017	30.0	6286	22.3	4665	62.0	12968			
Sometimes they got back to me	4.5	950	11.6	2426	9.8	2046	25.9	5422			
I had to contact them more than twice	1.7	351	3.9	807	3.4	714	8.9	1872			
They didn’t get back to me	0.7	154	1.4	288	1.1	228	3.2	670			
% of Total	16.6	3472	46.9	9807	36.6	7653	100.0	20932	58.894	(6)	p<0.001**
Q31: Ease of finding information											
Very easy	3.7	791	11.9	2514	9.8	2068	25.5	5373			
Fairly easy	8.2	1722	22.5	4739	17.7	3738	48.3	10199			
Fairly difficult	3.3	705	8.2	1737	7.2	1522	18.8	3964			
Very difficult	1.3	279	3.2	673	2.9	607	7.4	1559			
% of Total	16.6	3497	45.8	9663	37.6	7935	100.0	21095	29.723	(6)	p<0.001**
Q32: Helpfulness of information											
Very helpful	6.2	1342	18.7	4065	15.2	3297	40.1	8704			
Quite helpful	8.6	1874	23.9	5192	19.5	4225	52.0	11291			
Quite unhelpful	1.0	221	2.4	512	2.3	493	5.7	1226			
Very unhelpful	0.4	88	0.9	190	0.9	194	2.2	472			
% of Total	16.2	3525	45.9	9959	37.8	8209	100.0	21693	21.359	(6)	p=0.002**
Q33: Ease of getting support/services for cared for person											
Very easy	4.2	725	13.2	2310	8.0	1390	25.4	4425			
Quite easy	8.6	1494	24.3	4243	17.0	2962	49.9	8699			
Quite difficult	3.5	617	8.0	1394	6.9	1200	18.4	3211			
Very difficult	1.3	230	2.4	426	2.6	459	6.4	1115			
% of Total	17.6	3066	48.0	8373	34.4	6011	100.0	17450	103.76	(6)	p<0.001**

	Carers by association		Carers with a joint assessment		Carers with a separate assessment		Total		Pearson Chi-Square	(df)	Significance
	%	n	%	n	%	n	%	n			
Q34: Ease of getting support/services for carer											
Very easy	3.7	757	11.3	2284	8.7	1767	23.7	4808			
Quite easy	7.6	1538	21.8	4421	18.6	3767	47.9	9726			
Quite difficult	3.8	765	8.9	1803	8.4	1702	21.0	4270			
Very difficult	1.5	295	2.8	561	3.1	635	7.3	1491			
% of Total	16.5	3355	44.7	9069	38.8	7871	100.0	20295	63.557	(6)	p<0.001**
Q35: Did you have to wait to get support/services											
haven't had to wait	7.4	1051	20.6	2926	12.0	1704	40.0	5681			
the wait was not a problem	5.4	773	15.1	2146	9.3	1321	29.9	4240			
the wait should be a bit shorter	3.2	460	8.1	1149	5.6	788	16.9	2397			
the wait should be a lot shorter	2.9	414	5.9	844	4.4	621	13.2	1879			
% of Total	19.0	2698	49.8	7065	31.2	4434	100.0	14197	32.612	(6)	p<0.001**
Q36: Amount of contact with care manager											
contact should be reduced	0.1	17	0.4	58	0.4	55	0.9	130			
contact is about right	10.9	1498	32.2	4442	25.5	3513	68.5	9453			
contact should be increased a little	3.5	486	9.4	1301	7.9	1096	20.9	2883			
contact should be increased a lot	1.6	225	4.1	564	4.0	547	9.7	1336			
% of Total	16.1	2226	46.1	6365	37.8	5211	100.0	13802	14.477	(6)	p=0.025*
Q37: Involved in discussions (social care)											
always felt involved/consulted	7.8	1749	24.2	5429	18.3	4091	50.3	11269			
usually felt involved/consulted	4.7	1042	13.0	2912	10.5	2362	28.2	6316			
sometimes felt involved/consulted	2.8	627	6.6	1485	5.9	1316	15.3	3428			
never felt involved/consulted	1.4	323	2.5	570	2.2	500	6.2	1393			
% of Total	16.7	3741	46.4	10396	36.9	8269	100.0	22406	77.618	(6)	p<0.001**

	Carers by association		Carers with a joint assessment		Carers with a separate assessment		Total		Pearson Chi-Square	(df)	Significance
	%	n	%	n	%	n	%	n			
Q39: Support/services reactive to changes											
Always	4.3	458	12.3	1312	9.1	972	25.8	2742			
Usually	8.2	871	22.9	2440	16.1	1713	47.2	5024			
Sometimes	3.7	399	8.7	931	6.8	721	19.3	2051			
Never	1.4	144	3.5	372	2.9	308	7.7	824			
% of Total	17.6	1872	47.5	5055	34.9	3714	100.0	10641	12.273	(6)	p=0.129
Q40: Kept informed of changes to support/services											
always let me know	5.6	637	16.6	1901	14.9	1708	37.1	4246			
usually let me know	6.1	702	16.2	1853	12.3	1412	34.7	3967			
hardly ever let me know	2.8	320	8.1	931	5.7	654	16.6	1905			
never let me know	2.2	249	5.7	647	3.8	434	11.6	1330			
% of Total	16.7	1908	46.6	5332	36.8	4208	100.0	11448	43.903	(6)	p<0.001**
Q41: Treated with courtesy/ respect by care workers											
Always	13.1	2093	36.4	5842	27.6	4420	77.1	12355			
Usually	3.5	555	9.1	1457	6.8	1091	19.4	3103			
Sometimes	0.5	84	1.3	207	1.1	179	2.9	470			
Never	0.1	22	0.3	45	0.2	38	0.7	105			
% of Total	17.2	2754	47.1	7551	35.7	5728	100.0	16033	4.777	(6)	p=0.193

Excludes non-substantive responses and cases where sample group was unknown.

****significant at 1% level * significant at 5% level**

12 Appendix C – Variations in proportion of valid and invalid responses to potential performance items by sample group

	Carers by association		Carers with a joint assessment		Carers with a separate assessment		Total		Pearson Chi-Square	(df)	Significance
	%	n	%	n	%	n	%	n			
Q7											
answered	14.7	4731	39.7	12759	30.6	9843	85.1	27333			
not applicable	2.5	796	4.3	1387	4.5	1436	11.3	3619			
no response	0.8	259	1.7	553	1.1	369	3.7	1181			
Total	18.0	5786	45.7	14699	36.2	11648	100.0	32133	118.87	(4)	p<0.001**
Q9											
answered	15.3	3508	38.9	8903	27.5	6296	81.7	18707			
not applicable	3.2	733	5.3	1211	5.4	1232	13.9	3176			
no response	1.0	234	1.9	439	1.5	352	4.5	1025			
Total	19.5	4475	46.1	10553	34.4	7880	100.0	22908	108.007	(4)	p<0.001**
Q10											
answered	12.9	2616	33.3	6755	20.4	4148	66.6	13519			
not applicable	5.1	1046	12.9	2613	9.3	1879	27.3	5538			
no response	1.3	267	2.9	589	2.0	399	6.2	1255			
Total	19.3	3929	49.0	9957	31.6	6426	100.0	20312	23.514	(4)	p<0.001**
Q14											
answered	4.8	1514	13.6	4294	12.0	3791	30.3	9599			
not applicable	11.1	3516	26.0	8237	20.6	6513	57.7	18266			
no response	2.4	756	5.6	1782	4.0	1268	12.0	3806			
Total	18.3	5786	45.2	14313	36.5	11572	100.0	31671	88.013	(4)	p<0.001**
Q16											
answered	5.6	1772	15.4	4868	14.7	4660	35.7	11300			
not applicable	10.4	3285	24.3	7686	18.2	5765	52.8	16736			
no response	2.3	729	5.6	1759	3.6	1147	11.5	3635			
Total	18.3	5786	45.2	14313	36.5	11572	100.0	31671	199.15	(4)	p<0.001**

	Carers by association		**Carers with a joint assessment**		**Carers with a separate assessment**		**Total**		**Pearson Chi-Square**	**(df)**	**Significance**
	%	**n**	**%**	**n**	**%**	**n**	**%**	**n**			
Q30											
answered	11.0	3472	31.0	9807	24.2	7653	66.1	20932			
not applicable	6.4	2024	12.4	3943	11.2	3536	30.0	9503			
no response	0.9	290	1.8	563	1.2	383	3.9	1236			
Total	18.3	5786	45.2	14313	36.5	11572	100.0	31671	151.582	(4)	p<0.001**
Q31											
answered	10.9	3497	30.1	9663	24.7	7935	65.6	21095			
not applicable	6.2	2007	13.8	4440	10.4	3338	30.5	9785			
no response	0.9	282	1.9	596	1.2	375	3.9	1253			
Total	18.0	5786	45.7	14699	36.2	11648	100.0	32133	110.307	(4)	p<0.001**
Q32											
answered	11.0	3525	31.0	9959	25.5	8209	67.5	21693			
not applicable	5.9	1911	12.3	3951	9.1	2927	27.4	8789			
no response	1.1	350	2.5	789	1.6	512	5.1	1651			
Total	18.0	5786	45.7	14699	36.2	11648	100.0	32133	166.243	(4)	p<0.001**
Q33											
answered	13.2	3066	36.1	8373	25.9	6011	75.1	17450			
not applicable	4.3	996	8.5	1965	7.1	1657	19.9	4618			
no response	1.1	265	2.3	543	1.5	350	5.0	1158			
Total	18.6	4327	46.8	10881	34.5	8018	100.0	23226	74.858	(4)	p<0.001**
Q34											
answered	10.6	3355	28.6	9069	24.9	7871	64.1	20295			
not applicable	6.4	2027	13.8	4363	9.8	3091	29.9	9481			
no response	1.3	404	2.8	881	1.9	610	6.0	1895			
Total	18.3	5786	45.2	14313	36.5	11572	100.0	31671	174.702	(4)	p<0.001**
Q35											
answered	13.5	2698	35.3	7065	22.2	4434	71.0	14197			
not applicable	5.4	1082	10.8	2157	7.6	1516	23.8	4755			
no response	1.2	247	2.5	501	1.5	297	5.2	1045			
Total	20.1	4027	48.6	9723	31.2	6247	100.0	19997	49.169	(4)	p<0.001**

	Carers by association		Carers with a joint assessment		Carers with a separate assessment		Total		Pearson Chi-Square	(df)	Significance
	%	n	%	n	%	n	%	n			
Q36											
answered	10.5	2226	29.9	6365	24.5	5211	64.8	13802			
not applicable	4.9	1053	13.8	2936	11.1	2357	29.8	6346			
no response	1.1	236	2.5	523	1.8	379	5.3	1138			
Total	16.5	3515	46.2	9824	37.3	7947	100.0	21286	19.266	(4)	p<0.001**
Q37											
answered	11.6	3741	32.4	10396	25.7	8269	69.7	22406			
not applicable	5.3	1710	11.1	3566	9.0	2904	25.5	8180			
no response	1.0	335	2.3	737	1.5	475	4.8	1547			
Total	18.0	5786	45.7	14699	36.2	11648	100.0	32133	99.57	(4)	p<0.001**
Q39											
answered	8.3	1872	22.3	5055	16.4	3714	47.0	10641			
don't know	2.3	526	6.4	1448	4.9	1111	13.6	3085			
not applicable	5.5	1252	14.6	3305	12.1	2750	32.3	7307			
no response	1.6	362	3.4	765	2.1	477	7.1	1604			
Total	17.7	4012	46.7	10573	35.6	8052	100.0	22637	54.399	(6)	p<0.001**
Q40											
answered	8.2	1908	22.9	5332	18.1	4208	49.2	11448			
hasn't been changes	1.8	414	5.1	1178	4.5	1039	11.3	2631			
don't receive services	5.6	1310	14.4	3349	13.6	3160	33.6	7819			
no response	1.3	300	2.6	614	1.9	440	5.8	1354			
Total	16.9	3932	45.0	10473	38.0	8847	100.0	23252	68.157	(6)	p<0.001**
Q41											
answered	10.8	2754	29.7	7551	22.5	5728	63.1	16033			
not applicable	5.8	1485	13.7	3482	11.9	3021	31.4	7988			
no response	1.4	355	2.4	616	1.7	420	5.5	1391			
Total	18.1	4594	45.8	11649	36.1	9169	100.0	25412	86.671	(4)	p<0.001**

Excludes cases where question was omitted by CASSRs and those where sample group was unknown.
**** significant at 1% level**

13 Appendix D– Scoring algorithms for valid responses to potential performance items

13.1 Carer QOL

Each of the questions (q18-24) relating to quality of life has three options. For **each** of the seven questions assign a score of 2, 1 or 0 following the example below to reflect the carer's answers.

For example:

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

Please tick [✓] one box

I have as much control over my daily life as I want	☐	**2**
I have some control over my daily life but not enough	☐	**1**
I have no control over my daily life	☐	**0**

To calculate carer QOL, total the seven values together. The final score will be between 0 indicating the poorest outcomes and 14 indicating optimum outcomes.

13.2 Question 7

Assign a score of 1 or 0, following the example shown below.

Overall, how satisfied are you with the support and services you and the person you care for have received from Social Services in the last 12 months?

Please tick [✓] one box

I am extremely satisfied	☐	**1**
I am very satisfied	☐	**1**
I am fairly satisfied	☐	**0**
I am neither satisfied nor dissatisfied	☐	**0**
I am fairly dissatisfied	☐	**0**
I am very dissatisfied	☐	**0**
I am extremely dissatisfied	☐	**0**

13.3 Question 9

Assign a score of 1 or 0, following the example shown below.

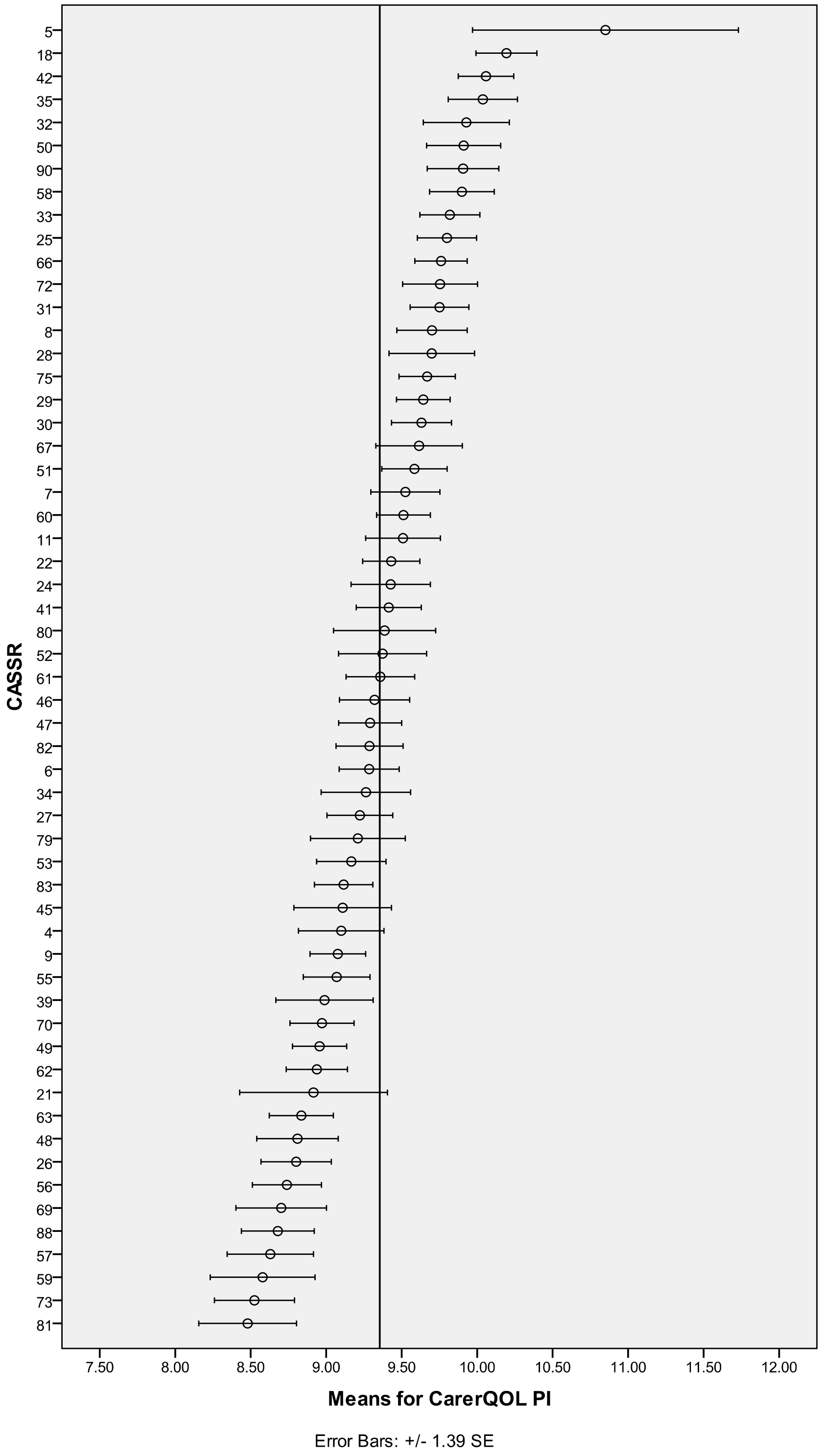
Thinking about the support and services the person you care for has received (provided by a voluntary organisation, a private agency of Social Services) in the last 12 months, which of the following statements best describes your present situation?

Please tick [✓] one box

The support or services have made things easier for me	☐	**1**
The support or services have made no difference to me	☐	**0**
The support or services have made things harder for me	☐	**0**

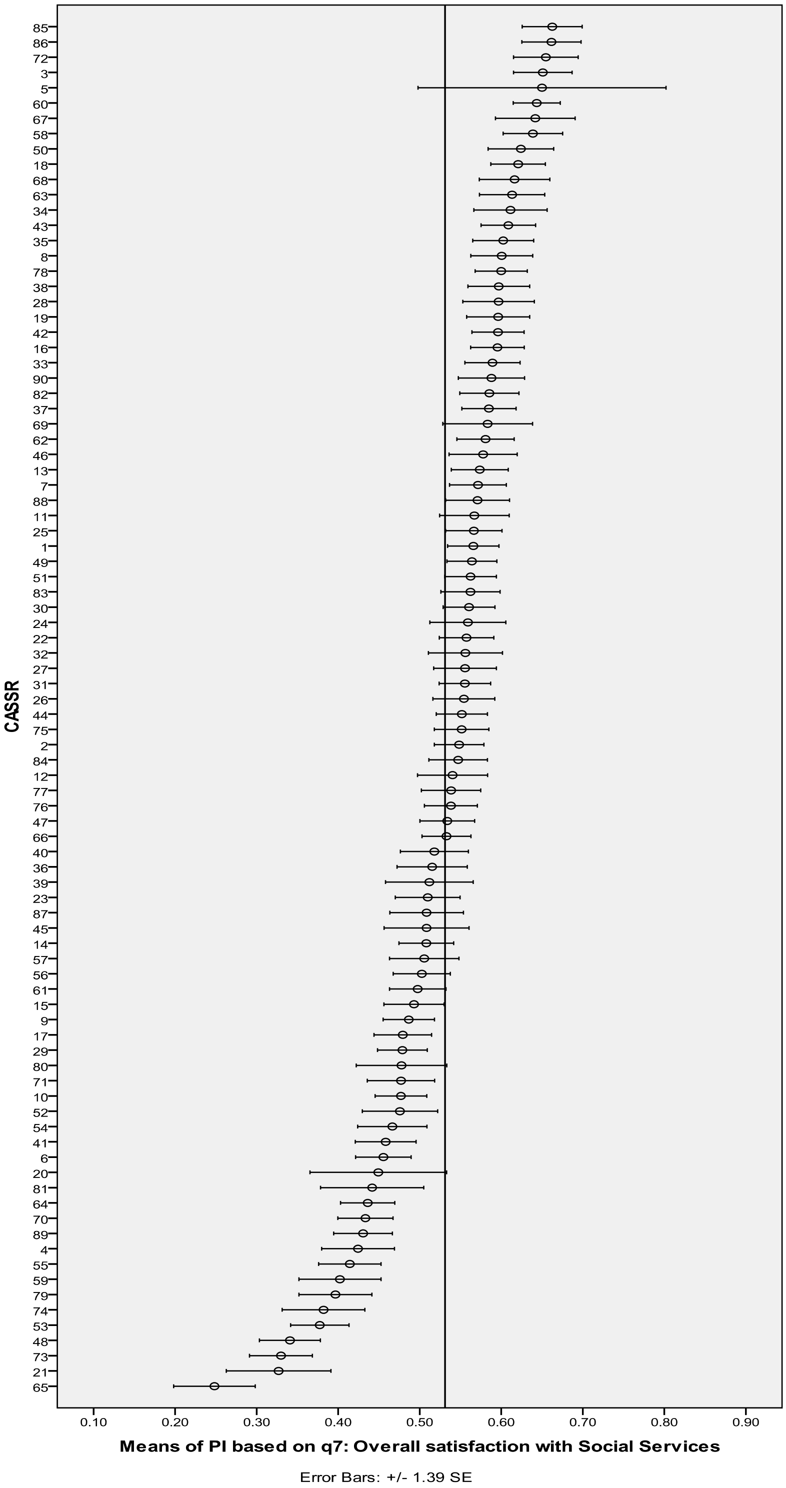
14 Appendix E–Error bar charts showing 1.39 x standard error of the mean

Carer QOL

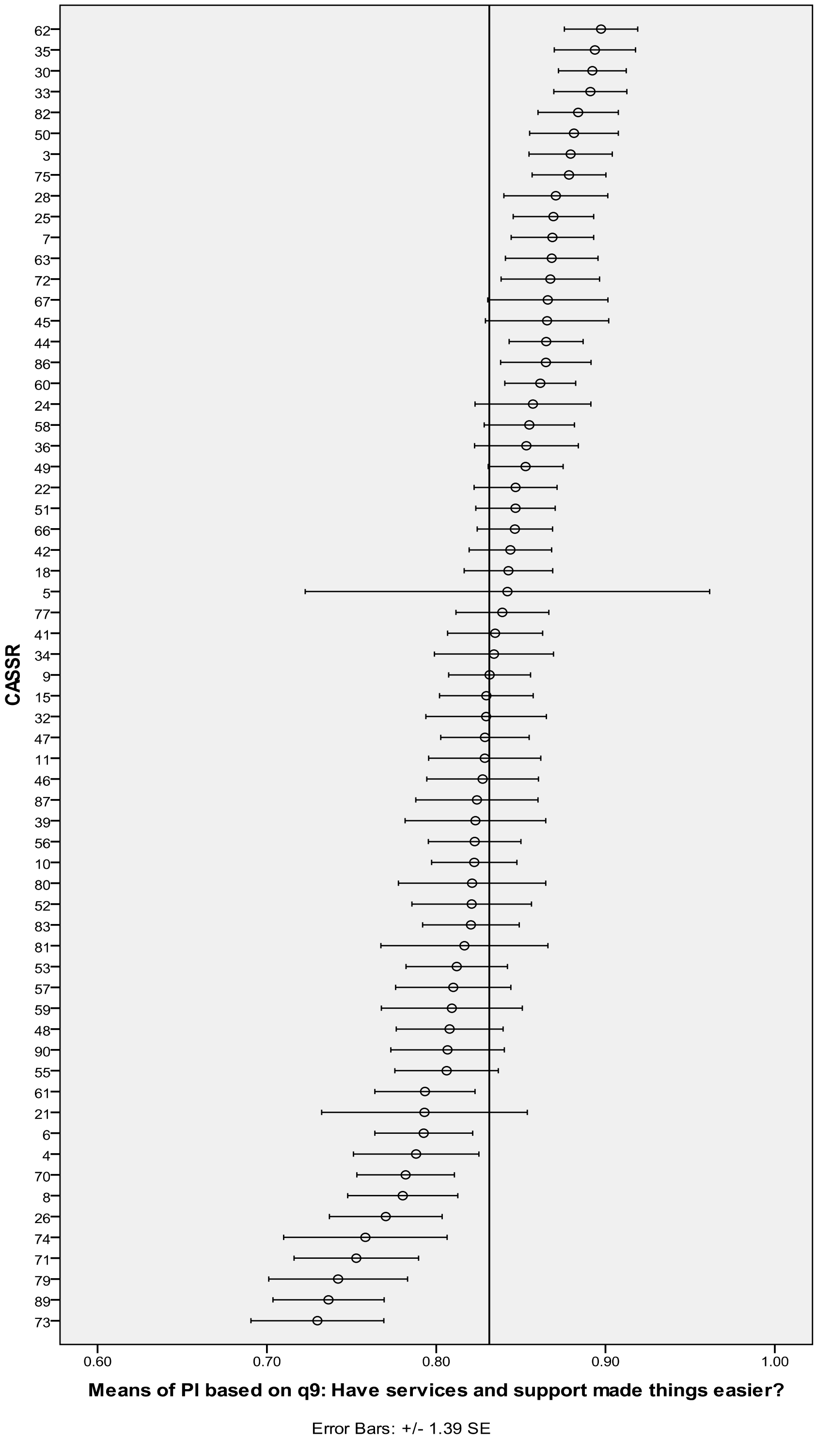


Carer QOL could not be calculated for carers in the 33 CASSRs which omitted q19 or q20.

Question 7


CASSR
85
86
72
3
5
60
67
58
50
18
68
63
34
43
35
8
78
38
28
19
42
16
33
90
82
37
69
62
46
13
7
88
11
25
1
49
51
83
30
24
22
32
27
31
26
44
75
2
84
12
77
76
47
66
40
36
39
23
87
45
14
57
56
61
15
9
17
29
80
71
10
52
54
41
6
20
81
64
70
89
4
55
59
79
74
53
48
73
21
65
0.10
0.20
0.30
0.40
0.50
0.60
0.70
0.80
0.90
Means of PI based on q7: Overall satisfaction with Social Services
Error Bars: +/- 1.39 SE

Question 9



Excludes 27 CASSRs that omitted question 9

15 Appendix F - Number of respondents, means and 95% confidence intervals of potential PIs by carer sampling group

Table 12: Comparison of means and confidence intervals by sample group – Carer QOL

Carer QOL												
CASSR	All carers				Carers by association				Assessed carers			
	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound
4	9.10	271	8.70	9.50	0.00	0	0.00	0.00	8.98	242	8.56	9.39
5	10.85	20	**9.61**	**12.09**	11.36	14	**9.84**	**12.88**	9.67	6	**7.66**	**11.67**
6	9.28	453	9.00	9.57	9.54	118	8.98	10.10	9.21	306	8.87	9.55
7	9.52	387	9.20	9.85	9.65	304	9.28	10.02	8.93	56	**8.05**	**9.80**
8	9.70	344	9.37	10.03	0.00	0	0.00	0.00	9.70	344	9.37	10.03
9	9.08	507	8.82	9.34	9.44	18	**8.34**	**10.54**	9.06	489	8.80	9.33
11	9.51	285	9.16	9.86	9.87	46	**8.91**	**10.83**	9.44	239	9.07	9.81
18	10.19	464	9.91	10.48	0.00	0	0.00	0.00	10.21	288	9.85	10.57
21	8.92	107	**8.23**	**9.61**	0.00	0	0.00	0.00	8.92	107	**8.23**	**9.61**
22	9.43	485	9.16	9.70	0.00	0	0.00	0.00	9.43	485	9.16	9.70
24	9.43	220	9.06	9.80	10.02	62	**9.32**	**10.71**	9.20	158	8.76	9.63
25	9.80	435	9.52	10.08	8.00	1	N/A	N/A	9.80	434	9.53	10.08
26	8.80	342	8.47	9.13	0.00	0	0.00	0.00	8.80	342	8.47	9.13
27	9.22	363	8.92	9.53	x	x	x	x	x	x	x	x
28	9.70	236	9.30	10.10	9.50	14	**7.76**	**11.24**	9.71	222	9.30	10.12
29	9.64	558	9.39	9.89	10.39	208	10.00	10.79	9.20	350	8.88	9.51
30	9.63	469	9.35	9.91	9.67	399	9.37	9.98	9.39	70	**8.73**	**10.04**
31	9.75	482	9.48	10.03	0.00	0	0.00	0.00	9.75	482	9.48	10.03

Carer QOL												
CASSR	**All carers**				**Carers by association**				**Assessed carers**			
	Mean	**n**	**lower bound**	**upper bound**	**Mean**	**n**	**lower bound**	**upper bound**	**Mean**	**n**	**lower bound**	**upper bound**
32	9.93	237	9.53	10.33	0.00	0	0.00	0.00	9.93	237	9.53	10.33
33	9.82	443	9.54	10.10	0.00	0	0.00	0.00	9.82	443	9.54	10.10
34	9.26	224	8.85	9.68	0.00	0	0.00	0.00	9.26	224	8.85	9.68
35	10.04	345	9.71	10.36	0.00	0	0.00	0.00	10.04	345	9.71	10.36
39	8.99	184	8.53	9.44	0.00	0	0.00	0.00	8.99	184	8.53	9.44
41	9.41	398	9.11	9.72	9.72	231	9.34	10.10	8.94	164	8.44	9.44
42	10.06	479	9.80	10.32	10.67	83	10.14	11.21	9.93	396	9.64	10.22
45	9.11	183	8.65	9.56	9.79	14	**7.63**	**11.94**	9.05	169	8.59	9.51
46	9.32	306	8.99	9.65	x	x	x	x	x	x	x	x
47	9.29	460	9.00	9.59	9.66	124	9.07	10.25	9.15	336	8.82	9.49
48	8.81	321	8.43	9.19	8.91	253	8.47	9.34	8.46	68	**7.66**	**9.26**
49	8.96	549	8.70	9.21	9.37	237	8.98	9.76	8.65	310	8.31	8.98
50	9.91	302	9.56	10.26	12.00	7	**10.34**	**13.66**	9.78	271	9.41	10.15
51	9.58	486	9.28	9.89	9.68	241	9.22	10.14	9.49	245	9.09	9.90
52	9.37	233	8.96	9.78	0.00	0	0.00	0.00	9.37	233	8.96	9.78
53	9.17	402	8.84	9.49	8.97	111	**8.35**	**9.60**	9.24	291	8.86	9.62
55	9.07	404	8.76	9.38	9.14	356	8.81	9.47	8.54	48	**7.55**	**9.53**
56	8.74	415	8.42	9.06	0.00	0	0.00	0.00	8.74	411	8.42	9.07
57	8.63	265	8.23	9.03	x	x	x	x	x	x	x	x
58	9.90	357	9.60	10.20	0.00	0	0.00	0.00	9.90	357	9.60	10.20
59	8.58	183	8.09	9.07	0.00	0	0.00	0.00	8.58	183	8.09	9.07
60	9.51	555	9.26	9.76	0.00	0	0.00	0.00	9.51	555	9.26	9.76
61	9.36	432	9.04	9.68	9.58	156	9.05	10.11	9.15	215	8.69	9.62
62	8.94	405	8.65	9.22	0.00	0	0.00	0.00	8.94	405	8.65	9.22
63	8.84	322	8.54	9.13	0.00	0	0.00	0.00	8.84	319	8.54	9.14
66	9.76	577	9.52	10.00	9.46	229	9.08	9.85	9.92	312	9.59	10.25
67	9.62	195	9.21	10.02	0.00	0	0.00	0.00	9.88	124	9.38	10.38

Carer QOL												
CASSR	All carers				Carers by association				Assessed carers			
	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound
69	8.70	178	8.28	9.12	8.84	96	**8.22**	**9.47**	8.53	78	7.95	9.10
70	8.97	464	8.67	9.27	0.00	0	0.00	0.00	8.97	464	8.67	9.27
72	9.75	289	9.41	10.10	0.00	0	0.00	0.00	9.75	289	9.41	10.10
73	8.52	284	8.15	8.90	8.66	96	**7.98**	**9.33**	8.44	183	7.99	8.90
75	9.67	483	9.41	9.93	10.02	241	9.65	10.39	9.32	242	8.95	9.69
79	9.21	248	8.77	9.65	10.24	17	**8.81**	**11.66**	9.13	231	8.67	9.60
80	9.39	168	8.91	9.86	0.00	0	0.00	0.00	9.39	168	8.91	9.86
81	8.48	125	8.02	8.94	0.00	0	0.00	0.00	8.48	125	8.02	8.94
82	9.29	366	8.97	9.60	9.55	145	9.08	10.03	9.11	221	8.70	9.53
83	9.12	492	8.84	9.39	0.00	0	0.00	0.00	9.12	492	8.84	9.39
88	8.68	334	8.34	9.02	0.00	0	0.00	0.00	8.68	334	8.34	9.02
90	9.91	322	9.57	10.24	0.00	0	0.00	0.00	9.91	322	9.57	10.24

x = data unavailable

N/A = not applicable as n=1 and confidence interval is incalculable

Bold = the confidence interval does not meet the desired criteria of +/- 4%

Table 13: Comparison of means and confidence intervals by sample group –Question 7

PI q7												
	All carers				Carers by association				Assessed carers			
CASSR	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound
1	0.57	479	0.52	0.61	0.48	168	0.41	0.56	0.61	311	0.56	0.67
2	0.55	518	0.51	0.59	0.56	466	0.51	0.60	0.50	50	**0.36**	**0.64**
3	0.65	341	0.60	0.70	0.57	44	**0.42**	**0.72**	0.66	297	0.61	0.72
4	0.42	238	0.36	0.49	0.00	0	0.00	0.00	0.43	217	0.36	0.49
5	0.65	20	**0.44**	**0.86**	0.57	14	**0.30**	**0.84**	0.83	6	**0.51**	**1.16**
6	0.46	415	0.41	0.50	0.47	94	**0.37**	**0.57**	0.44	294	0.39	0.50
7	0.57	392	0.52	0.62	0.59	301	0.54	0.65	0.48	64	**0.36**	**0.61**
8	0.60	323	0.55	0.65	0.00	0	0.00	0.00	0.60	323	0.55	0.65
9	0.49	485	0.44	0.53	0.38	16	**0.13**	**0.62**	0.49	469	0.45	0.54
10	0.48	478	0.43	0.52	0.40	75	**0.29**	**0.51**	0.49	403	0.44	0.54
11	0.57	261	0.51	0.63	0.57	44	**0.42**	**0.72**	0.57	217	0.50	0.63
12	0.54	261	0.48	0.60	0.00	0	0.00	0.00	0.54	261	0.48	0.60
13	0.57	387	0.52	0.62	0.00	0	0.00	0.00	0.57	387	0.52	0.62
14	0.51	429	0.46	0.56	x	x	x	x	x	x	x	x
15	0.49	357	0.44	0.54	0.00	0	0.00	0.00	0.49	356	0.44	0.55
16	0.60	430	0.55	0.64	x	x	x	x	x	x	x	x
17	0.48	386	0.43	0.53	0.00	0	0.00	0.00	0.47	278	0.42	0.53
18	0.62	406	0.57	0.67	0.00	0	0.00	0.00	0.62	247	0.56	0.68
19	0.60	312	0.54	0.65	0.54	59	**0.41**	**0.67**	0.61	253	0.55	0.67
20	0.45	69	**0.33**	**0.57**	0.00	0	0.00	0.00	0.45	69	**0.33**	**0.57**
21	0.33	104	**0.24**	**0.42**	0.00	0	0.00	0.00	0.33	104	**0.24**	**0.42**
22	0.56	427	0.51	0.60	0.00	0	0.00	0.00	0.56	427	0.51	0.60
23	0.51	306	0.45	0.57	0.00	0	0.00	0.00	0.51	306	0.45	0.57
24	0.56	220	0.49	0.62	0.62	61	**0.50**	**0.75**	0.53	159	0.46	0.61
25	0.57	399	0.52	0.62	1.00	1	N/A	N/A	0.57	398	0.52	0.61
26	0.55	332	0.50	0.61	0.00	0	0.00	0.00	0.55	332	0.50	0.61
27	0.56	324	0.50	0.61	x	x	x	x	x	x	x	x

PI q7

CASSR	All carers				Carers by association				Assessed carers			
	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound
28	0.60	243	0.53	0.66	0.65	17	**0.41**	**0.88**	0.59	226	0.53	0.66
29	0.48	518	0.44	0.52	0.48	184	0.41	0.56	0.48	334	0.42	0.53
30	0.56	471	0.52	0.61	0.56	401	0.51	0.61	0.56	70	**0.44**	**0.67**
31	0.56	479	0.51	0.60	0.00	0	0.00	0.00	0.56	479	0.51	0.60
32	0.56	232	0.49	0.62	0.00	0	0.00	0.00	0.56	232	0.49	0.62
33	0.59	409	0.54	0.64	0.00	0	0.00	0.00	0.59	409	0.54	0.64
34	0.61	229	0.55	0.67	0.00	0	0.00	0.00	0.61	229	0.55	0.67
35	0.60	332	0.55	0.66	0.00	0	0.00	0.00	0.60	332	0.55	0.66
36	0.52	262	0.45	0.58	0.00	0	0.00	0.00	0.52	262	0.45	0.58
37	0.58	424	0.54	0.63	0.00	0	0.00	0.00	0.58	424	0.54	0.63
38	0.60	325	0.54	0.65	0.00	0	0.00	0.00	0.60	325	0.54	0.65
39	0.51	168	0.44	0.59	0.00	0	0.00	0.00	0.51	168	0.44	0.59
40	0.52	278	0.46	0.58	x	x	x	x	x	x	x	x
41	0.46	347	0.41	0.51	0.47	191	0.40	0.54	0.45	154	0.37	0.53
42	0.60	453	0.55	0.64	0.59	75	**0.47**	**0.70**	0.60	378	0.55	0.65
43	0.61	414	0.56	0.66	0.79	24	**0.63**	**0.96**	0.60	390	0.55	0.65
44	0.55	484	0.51	0.60	0.58	52	**0.44**	**0.71**	0.55	432	0.50	0.60
45	0.51	179	0.43	0.58	0.58	12	**0.29**	**0.87**	0.50	167	0.43	0.58
46	0.58	270	0.52	0.64	x	x	x	x	x	x	x	x
47	0.53	429	0.49	0.58	0.53	114	**0.43**	**0.62**	0.54	315	0.48	0.59
48	0.34	311	0.29	0.39	0.32	243	0.26	0.38	0.41	68	**0.29**	**0.53**
49	0.56	507	0.52	0.61	0.57	225	0.51	0.64	0.56	280	0.50	0.62
50	0.62	282	0.57	0.68	0.67	6	**0.25**	**1.08**	0.62	257	0.56	0.68
51	0.56	473	0.52	0.61	0.54	225	0.47	0.60	0.58	248	0.52	0.65
52	0.48	227	0.41	0.54	0.00	0	0.00	0.00	0.48	227	0.41	0.54
53	0.38	355	0.33	0.43	0.39	92	**0.29**	**0.49**	0.37	263	0.31	0.43
54	0.47	268	0.41	0.53	0.47	76	**0.36**	**0.59**	0.46	192	0.39	0.53
55	0.41	321	0.36	0.47	0.42	278	0.37	0.48	0.35	43	**0.20**	**0.49**

PI q7												
	All carers				**Carers by association**				**Assessed carers**			
CASSR	**Mean**	**n**	**lower bound**	**upper bound**	**Mean**	**n**	**lower bound**	**upper bound**	**Mean**	**n**	**lower bound**	**upper bound**
56	0.50	394	0.45	0.55	0.00	0	0.00	0.00	0.50	392	0.45	0.55
57	0.51	267	0.45	0.57	x	x	x	x	x	x	x	x
58	0.64	335	0.59	0.69	0.00	0	0.00	0.00	0.64	335	0.59	0.69
59	0.40	184	0.33	0.47	0.00	0	0.00	0.00	0.40	184	0.33	0.47
60	0.64	533	0.60	0.68	0.00	0	0.00	0.00	0.64	533	0.60	0.68
61	0.50	404	0.45	0.55	0.47	149	0.39	0.55	0.53	199	0.46	0.60
62	0.58	384	0.53	0.63	0.00	0	0.00	0.00	0.58	384	0.53	0.63
63	0.61	287	0.56	0.67	0.00	0	0.00	0.00	0.61	285	0.56	0.67
64	0.44	431	0.39	0.48	0.00	0	0.00	0.00	0.44	431	0.39	0.48
65	0.25	145	0.18	0.32	0.00	0	0.00	0.00	0.25	145	0.18	0.32
66	0.53	533	0.49	0.58	0.47	207	0.41	0.54	0.59	297	0.53	0.64
67	0.64	187	0.57	0.71	0.00	0	0.00	0.00	0.64	121	**0.56**	**0.73**
68	0.62	245	0.56	0.68	0.00	0	0.00	0.00	0.62	245	0.56	0.68
69	0.58	156	0.51	0.66	0.58	83	**0.47**	**0.69**	0.62	69	**0.51**	**0.74**
70	0.43	413	0.39	0.48	0.00	0	0.00	0.00	0.43	413	0.39	0.48
71	0.48	283	0.42	0.54	0.46	170	0.39	0.54	0.50	113	**0.40**	**0.59**
72	0.65	278	0.60	0.71	0.00	0	0.00	0.00	0.65	278	0.60	0.71
73	0.33	288	0.28	0.38	0.33	103	**0.24**	**0.42**	0.33	180	0.26	0.40
74	0.38	178	0.31	0.45	0.00	0	0.00	0.00	0.38	178	0.31	0.45
75	0.55	428	0.50	0.60	0.56	208	0.49	0.63	0.55	220	0.48	0.61
76	0.54	457	0.49	0.58	0.00	0	0.00	0.00	0.54	457	0.49	0.58
77	0.54	364	0.49	0.59	0.00	0	0.00	0.00	0.54	364	0.49	0.59
78	0.60	455	0.55	0.65	0.00	0	0.00	0.00	0.60	455	0.55	0.65
79	0.40	232	0.33	0.46	0.40	15	**0.14**	**0.66**	0.40	217	0.33	0.46
80	0.48	157	0.40	0.56	0.00	0	0.00	0.00	0.48	157	0.40	0.56
81	0.44	120	**0.35**	**0.53**	0.00	0	0.00	0.00	0.44	120	**0.35**	**0.53**
82	0.59	357	0.53	0.64	0.60	147	0.52	0.68	0.58	210	0.51	0.64
83	0.56	361	0.51	0.61	0.00	0	0.00	0.00	0.56	361	0.51	0.61

PI q7												
	All carers				Carers by association				Assessed carers			
CASSR	**Mean**	**n**	**lower bound**	**upper bound**	**Mean**	**n**	**lower bound**	**upper bound**	**Mean**	**n**	**lower bound**	**upper bound**
84	0.55	371	0.50	0.60	0.00	0	0.00	0.00	0.55	371	0.50	0.60
85	0.66	320	0.61	0.71	0.00	0	0.00	0.00	0.66	320	0.61	0.71
86	0.66	328	0.61	0.71	0.58	12	**0.29**	**0.87**	0.66	316	0.61	0.72
87	0.51	238	0.44	0.57	0.51	78	**0.40**	**0.62**	0.51	160	0.43	0.58
88	0.57	310	0.52	0.63	0.00	0	0.00	0.00	0.57	310	0.52	0.63
89	0.43	367	0.38	0.48	0.00	1	N/A	N/A	0.43	366	0.38	0.48
90	0.59	284	0.53	0.65	0.00	0	0.00	0.00	0.59	284	0.53	0.65

x = data unavailable

N/A = not applicable as n=1 and confidence interval is incalculable

Bold = the confidence interval does not meet the desired criteria of +/- 4%

Table 14: Comparison of means and confidence intervals by sample group – Question 9

PI q9												
	All carers				Carers by association				Assessed carers			
CASSR	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound
3	0.88	340	0.84	0.91	0.78	40	**0.64**	**0.91**	0.89	300	0.86	0.93
4	0.79	236	**0.74**	**0.84**	0.00	0	0.00	0.00	0.80	217	**0.75**	**0.86**
5	0.84	19	**0.67**	**1.01**	0.77	13	**0.53**	**1.01**	1.00	6	1.00	1.00
6	0.79	381	0.75	0.83	0.75	80	**0.65**	**0.85**	0.80	279	**0.76**	**0.85**
7	0.87	373	0.83	0.90	0.85	287	0.81	0.89	0.92	62	**0.85**	**0.99**
8	0.78	314	**0.73**	**0.83**	0.00	0	0.00	0.00	0.78	314	**0.73**	**0.83**
9	0.83	463	0.80	0.87	0.56	16	**0.31**	**0.81**	0.84	447	0.81	0.88
10	0.82	445	0.79	0.86	0.78	72	**0.68**	**0.87**	0.83	373	0.79	0.87
11	0.83	251	**0.78**	**0.88**	0.82	38	**0.69**	**0.94**	0.83	213	**0.78**	**0.88**
15	0.83	358	0.79	0.87	0.00	0	0.00	0.00	0.83	357	0.79	0.87
18	0.84	375	0.81	0.88	0.00	0	0.00	0.00	0.82	227	**0.77**	**0.87**
21	0.79	87	**0.71**	**0.88**	0.00	0	0.00	0.00	0.79	87	**0.71**	**0.88**
22	0.85	418	0.81	0.88	0.00	0	0.00	0.00	0.85	418	0.81	0.88
24	0.86	203	**0.81**	**0.91**	0.91	53	**0.83**	**0.99**	0.84	150	**0.78**	**0.90**
25	0.87	390	0.84	0.90	1.00	1	N/A	N/A	0.87	389	0.84	0.90
26	0.77	309	**0.72**	**0.82**	0.00	0	0.00	0.00	0.77	309	**0.72**	**0.82**
28	0.87	232	**0.83**	**0.91**	0.81	16	**0.61**	**1.01**	0.88	216	**0.83**	**0.92**
30	0.89	464	0.86	0.92	0.89	393	0.86	0.92	0.89	71	**0.81**	**0.96**
32	0.83	217	**0.78**	**0.88**	0.00	0	0.00	0.00	0.83	217	**0.78**	**0.88**
33	0.89	404	0.86	0.92	0.00	0	0.00	0.00	0.89	404	0.86	0.92
34	0.83	217	**0.78**	**0.88**	0.00	0	0.00	0.00	0.83	217	**0.78**	**0.88**
35	0.89	320	0.86	0.93	0.00	0	0.00	0.00	0.89	320	0.86	0.93
36	0.85	259	**0.81**	**0.90**	0.00	0	0.00	0.00	0.85	259	**0.81**	**0.90**
39	0.82	164	**0.76**	**0.88**	0.00	0	0.00	0.00	0.82	164	**0.76**	**0.88**
41	0.83	339	0.80	0.87	0.85	184	**0.80**	**0.90**	0.82	154	**0.76**	**0.88**
42	0.84	429	0.81	0.88	0.83	75	**0.74**	**0.91**	0.85	354	0.81	0.88

PI q9												
	All carers				**Carers by association**				**Assessed carers**			
CASSR	**Mean**	**n**	**lower bound**	**upper bound**	**Mean**	**n**	**lower bound**	**upper bound**	**Mean**	**n**	**lower bound**	**upper bound**
44	0.86	474	0.83	0.90	0.85	53	**0.75**	**0.95**	0.87	421	0.83	0.90
45	0.87	171	**0.81**	**0.92**	0.83	12	**0.61**	**1.05**	0.87	159	**0.82**	**0.92**
46	0.83	255	**0.78**	**0.87**	x	x	x	x	x	x	x	x
47	0.83	403	0.79	0.87	0.84	107	**0.77**	**0.91**	0.82	296	**0.78**	**0.87**
48	0.81	302	**0.76**	**0.85**	0.80	64	**0.75**	**0.85**	0.84	238	**0.75**	**0.93**
49	0.85	496	0.82	0.88	0.83	218	**0.78**	**0.88**	0.87	276	0.83	0.91
50	0.88	295	0.84	0.92	1.00	7	1.00	1.00	0.87	267	0.83	0.91
51	0.85	457	0.81	0.88	0.83	220	**0.78**	**0.88**	0.86	237	**0.82**	**0.90**
52	0.82	229	**0.77**	**0.87**	0.00	0	0.00	0.00	0.82	229	**0.77**	**0.87**
53	0.81	330	0.77	0.85	0.84	86	**0.76**	**0.92**	0.80	244	**0.75**	**0.85**
55	0.81	325	**0.76**	**0.85**	0.81	283	**0.76**	**0.85**	0.81	42	**0.69**	**0.93**
56	0.82	378	0.78	0.86	0.00	0	0.00	0.00	0.82	377	0.79	0.86
57	0.81	258	**0.76**	**0.86**	x	x	x	x	x	x	x	x
58	0.86	338	0.82	0.89	0.00	0	0.00	0.00	0.86	338	0.82	0.89
59	0.81	173	**0.75**	**0.87**	0.00	0	0.00	0.00	0.81	173	**0.75**	**0.87**
60	0.86	527	0.83	0.89	0.00	0	0.00	0.00	0.86	527	0.83	0.89
61	0.79	363	0.75	0.84	0.79	127	**0.72**	**0.86**	0.80	185	**0.74**	**0.86**
62	0.90	380	0.87	0.93	0.00	0	0.00	0.00	0.90	380	0.87	0.93
63	0.87	296	0.83	0.91	0.00	0	0.00	0.00	0.87	295	0.83	0.91
66	0.85	508	0.82	0.88	0.81	190	**0.75**	**0.87**	0.87	290	0.83	0.91
67	0.87	179	**0.82**	**0.92**	0.00	0	0.00	0.00	0.85	115	**0.79**	**0.92**
70	0.78	399	0.74	0.82	0.00	0	0.00	0.00	0.78	399	**0.74**	**0.82**
71	0.75	267	**0.70**	**0.80**	0.73	162	**0.66**	**0.80**	0.79	105	**0.71**	**0.87**
72	0.87	264	0.83	0.91	0.00	0	0.00	0.00	0.87	264	0.83	0.91
73	0.73	248	**0.67**	**0.79**	0.76	88	**0.67**	**0.85**	0.71	156	**0.63**	**0.78**
74	0.76	153	**0.69**	**0.83**	0.00	0	0.00	0.00	0.76	153	**0.69**	**0.83**
75	0.88	436	0.85	0.91	0.84	211	**0.79**	**0.89**	0.91	225	0.87	0.95
77	0.84	348	0.80	0.88	0.00	0	0.00	0.00	0.84	348	0.80	0.88
79	0.74	221	**0.68**	**0.80**	0.77	13	**0.53**	**1.01**	0.74	208	**0.68**	**0.80**

PI q9												
	All carers				Carers by association				Assessed carers			
CASSR	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound	Mean	n	lower bound	upper bound
80	0.82	151	**0.76**	**0.88**	0.00	0	0.00	0.00	0.82	151	**0.76**	**0.88**
81	0.82	120	**0.75**	**0.89**	0.00	0	0.00	0.00	0.82	120	**0.75**	**0.89**
82	0.88	353	0.85	0.92	0.88	141	**0.83**	**0.93**	0.89	212	**0.84**	**0.93**
83	0.82	351	0.78	0.86	0.00	0	0.00	0.00	0.82	351	0.78	0.86
86	0.86	318	0.83	0.90	0.90	10	**0.70**	**1.10**	0.86	308	0.83	0.90
87	0.82	216	**0.77**	**0.87**	0.90	73	**0.84**	**0.97**	0.78	143	**0.72**	**0.85**
89	0.74	349	**0.69**	**0.78**	1.00	1	N/A	N/A	0.74	348	**0.69**	**0.78**
90	0.81	269	**0.76**	**0.85**	0.00	0	0.00	0.00	0.81	269	**0.76**	**0.85**

x = data unavailable

N/A = not applicable as n=1 so confidence interval is incalculable

Bold = the confidence interval does not meet the desired criteria of +/- 4%