QORU | quality and outcomes of person-centred care policy research unit

Measuring the Social Care Outcomes of Informal Carers

An Interim Technical Report for the Identifying the Impact of Social Care (IIASC) Study

Stacey E. Rand, Juliette Malley and Ann Netten

PSSRU Discussion Paper 2833

August 2012

University of Kent

LSE The London School of Economics and Political Science

University of Oxford

Acknowledgements

Thanks are due to Rosalyn Bass and Diane Fox who guided the literature search, to Clara Heath for her help with formatting/editing the manuscript, and to the Carers' Organisations and Local Authorities who supported the recruitment of carers for the cognitive interviews. We would also like to acknowledge and thank IIASC project colleagues (Jose-Luis Fernandez, Theresia Baumker, Crispin Jenkinson and Julian Forder), the Project Advisory Group and the service users/carers consulted on this project, for their input and advice with this work.

Disclaimer

This literature review is part of a research study funded by the Department of Health entitled 'Identifying the Impact of Adult Social Care' (IIASC), which is being conducted by the PSSRU. This is an independent report commissioned and funded by the Policy Research Programme in the Department of Health. The views expressed are not necessarily those of the Department.

1. Introduction

Informal care is an integral part of the care provided to people with long term conditions. It is estimated that five million adults in England provide informal care to sick, disabled or elderly adults, of which nearly half provide care for more than twenty hours per week (Department of Health Survey of Carers in Households, 2009/10). In recognition of the contribution of informal care to the overall provision of social care, the support of carers in their caring role has been a key policy concern in recent years (*Recognised, valued and supported: Next steps for the Carers Strategy*, 2010). In order to achieve these policies, the coalition government has proposed to shift away from a culture of performance management of social care support and service provision by local authorities by measuring intermediate 'process' outcomes. Instead, the focus has shifted to the collection of data on the overall, 'final' outcomes of service users and carers, which will be used for comparison between local authorities and as an indication of the strengths of social care provision (Department of Health, 2011).

The Adult Social Care Outcomes Framework (ASCOF) outlines a set of nationally-agreed outcome measures for social care provision in England (Department of Health, 2012). The Framework uses the self-report items from the Adult Social Care Outcomes Toolkit (ASCOT) measure for service users, which is included in the annual Adult Social Care Survey (ASCS), as well as the items on carer-reported quality of life from the Carer Experience Survey (CES). These instruments provide an indication of the social-care related quality of life (SCRQoL) of service users and carers. Quality of life (QOL) is a complex, multidimensional construct and existing measures of QOL include a broad range of domains. A broad measure of quality of life may not be sensitive to the impact of social care services, nor be able to identify effective social care interventions, due to confounding factors. This has led to the development of these measures of 'social care-related quality of life' (SCRQoL) that focus on the domains that are pertinent to service users and carers and which may be affected by social care support and services (Netten et al, 2012).

However, the self-report measures do not currently address the issue of attribution. The self-report items for SCRQoL of service users and carers provide an indication of the overall outcome state of an individual at a given point in time. This overall state is the product of a number of factors. Some of these factors may be unrelated to social care service provision: for example, gender, age or urban/rural location. The primary aim of the 'Identifying the Impact of Adult Social Care' (IIASC) study, for which this piece of work was undertaken, is to identify a means by which data collected from the ASCS and CES could be used to generate a measure of 'added value' reflecting the impact of the support provided by councils on outcomes to the exclusion of other non-social care service-related factors. This adjustment will allow local authorities to make meaningful comparisons with other local authorities, and will enable the use of the ASCOF data for benchmarking, identifying areas of strength, and informing commissioning of social care services (Department of Health, 2012).

The IIASC study is a follow-up survey of 1,500 service users who complete the 2012/13 ASCS. The participants will be interviewed using the ASCOT INT4 interview (a measure of SCRQoL) and to collect supporting data on characteristics hypothesised to affect SCRQoL. The ASCOT INT4 asks service users to rate their 'expected' quality of life in the absence of support and services (www.pssru.ac.uk/ASCOT). The difference between 'current' and 'expected' SCRQoL for service users provides an indication of the 'gain' (or 'value added') of social care services. As it is not feasible to collect annual data from interviews of service users, the data will be used to develop an algorithm by which the current self-report SCRQoL items in the ASCS could be adjusted for the non-social care service-related factors to give an estimate of the impact of social care services. Likewise, a sample of carers (N=500) will also be interviewed to explore the potential of reflecting the 'value added' (SCRQoL gain) of the support provided by councils on carers' quality of life, and the implications of this for measuring outcomes and attributing value to social care interventions.

The work outlined in this report relates to the development and cognitive testing of items to be used in the interviews with carers for the IIASC study. The project builds on the current version of the Carer Experience Survey (see Table 1). These items were developed by researchers at the Personal Social Services Research Unit (PSSRU) at the University of Kent in a series of earlier work for a local authority survey of carers (Holder et al, 2009) and for a national survey of carers (Fox et al, 2010; Malley et al, 2010). The initial work involved a series of focus groups with 20 carers to identify the outcomes that carers felt were most relevant to their lives; this work was conducted with the (then current) ASCOT measure for service users as a basis for their exploratory qualitative work (Holder et al, 2009). The researchers used this work to develop questions that reflect the priorities of carers, which were then refined through cognitive interviews (Willis, 2005) with carers (Holder et al, 2009). The further development of these questions for the Adult Carers Survey involved the cognitive testing of additional questions (Fox et al, 2010) and analysis of data collected from the 35,165 carers who completed the Personal Social Services Survey of Adult Carers 2009/10 in 90 local authorities across England (Malley et al, 2010). This study identified seven items which could be used as a measure of carers' social care related quality of life (see Table 1). The aims of the development work outlined in this report are to:

1. Evaluate the items in the CES measure of carer SCRQoL based on the current literature on carer quality of life and in the context of subsequent development of the ASCOT measure since the initial work on the development of the items (Holder et al, 2009). The aim of this work is to develop an equivalent measure of carer SCRQoL to the ASCOT measure of SCRQoL for service users so that the relationship between outcomes of service users and carers can be explored in the IIASC study and future work.
2. Test the feasibility of adapting these questions to ask carers about the 'expected' situation in the absence of social care support and services. (This based on the approach that has been established for the ASCOT INT4 interview for service users). These items will allow us to identify a means of attributing value to social care interventions based on carers' current SCRQoL from the data collected in the main stage of the IIASC study. The full set of questions for carers (i.e. current SCRQoL plus the 'expected' questions) will be referred to as 'ASCOT-Carer INT4' throughout the report.

This report outlines this exploratory work. First, we undertook a phase of question development that explored the theoretical basis of the items, through a review of the relevant literature, and in the light of changes to the ASCOT measure of SCRQoL for service users and other instruments that measure the SCRQoL for carers. We also considered the current direction and focus of social policy and definitions of 'social care provision' in England. The second stage of question development, through cognitive testing (Willis, 2005) is reported and the key findings are explored in relation to the qualitative evidence gathered in 30 interviews with informal carers. Finally, we consider the implications of this development work for the main stage of the IIASC study.

Table 1. The carer's quality of life measure from the Carer Experience Survey (CES) 2012/13 (Fox et al, 2010; Malley et al, 2010).

Domain / definition	Question
Occupation: being sufficiently occupied in a range of meaningful, enjoyable activities whether it be formal employment, unpaid work, caring for others or leisure activities.	Which of the following statements best describes how you spend your time? • 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, but not enough • I don't do anything I value or enjoy with my time
Self-care: feeling able to look after oneself, in terms of eating well and getting enough sleep.	Thinking about how much time you have to look after yourself – in terms of getting enough sleep or eating well – which statement best describes your present situation? • I look after myself • Sometimes I can't look after myself well enough • I feel I am neglecting myself
Personal safety: feeling safe and secure, where concerns about safety can include fear of abuse or other physical harm or accidents, which may arise as a result of caring.	Thinking about your personal safety, which of the following statements best describes your present situation? By personal safety, we mean feeling safe from fear of abuse, being attacked or other physical harm. • I have no worries about my personal safety • I have some worries about my personal safety • I am extremely worried about my personal safety
Social Participation and involvement: being content with their social situation, where social situation includes the sustenance of meaningful relationships with friends and family as well as feeling involved and part of their community should they wish to.	Thinking about how much social contact you've had with people you like, which of the following statements best describes your social situation? • I have as much social contact as a 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
Control over daily life: choosing what to do and when to do it, and having control over their daily life and activities.	Which of the following statements best describes how much control you have over your daily life? • I have as much control over my daily life as I want • I have some control over my daily life but not enough • I have no control over my daily life
Encouragement and support: feeling encouraged and supported by professionals, care workers and others, in their role as a carer.	Thinking about the encouragement and support in your caring role, which of the following statements best describes your present situation? • I feel I have encouragement and support • I feel I have some encouragement and support but not enough • I feel I have no encouragement and support

Domain / definition	Question
Space and time: feeling there is enough space and time to be oneself; to have time free of worries and burdens of caring; to feel able to relax and 'switch off'.	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? • 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

2. Method

2.1 Question Development: Literature Review and Theoretical Basis for Domains

The questions from the 'carer quality of life measure' (Malley et al, 2010; Fox et al, 2010) were taken as a starting point for question development (see Table 1). The existing domains were evaluated in the light of the literature on carers' outcomes.

A literature search of the electronic databases Web of Science and PubMed was conducted using the search terms outlined in Appendix B to identify the literature on the factors that affect carers' quality of life. Due to the size of the literature in this field, the following limitations were applied to truncate the search:

- Review articles or meta-analyses;
- Published between 2002 and 2012;
- Published in English;
- Studies of carers of adults (i.e. 18+ years).

The abstracts of the identified articles were reviewed by a researcher and assessed based on the following exclusion criteria.

- Only reported studies of care recipients who were under the age of 18 years.
- Reviewed pharmacological treatments.
- Focussed only or mainly on the outcome of the care recipient.
- Focussed only on the outcome of professionals or care workers.
- Reported the findings of primary research.
- Are theoretical papers.
- Refer only to studies conducted outside of the UK, Ireland, USA, Australia or South East Asia.

Where uncertainty regarding the relevance occurred, the full text was obtained and read. Although quality was not evaluated as part of the selection of articles, all of the articles included were published in peer review journals and this was taken as an indication of quality.

2.2 Question Development: Consultation with Users, Practitioners and Policy-Makers

Following this initial conceptual evaluation of the items in the Carer QOL measure (see Table 1) a draft interview schedule was prepared by the authors. The questions were adapted to include items to determine the 'value added' of formal social care services/support on carers' quality of life by asking carers to rate their 'expected' quality of life in the hypothetical situation that they and the person they look after had no support or services. The wording and structure of these questions were based on ASCOT INT4 v2.

These draft questions were reviewed by the authors. The researchers' feedback was used to decide which questions to include/exclude, the wording of the questions, and the ordering of the items. Service users and carers were also consulted through the following service user and carer groups: PSSRU, London School of Economics (LSE) service user and carer group, the National Institute of Health Research User, Carer and Practitioner Research Group (NIHR UCPRG), and the Quality and Outcomes of Person-centred Care Research Unit (QORU) Public Involvement and Implementation Group (PIIG). In addition, an advisory group, including service user/carer representatives, representatives from local authorities, the Information Centre and Department of Health, and academic researchers, met to provide advice on the plans, conduct and outputs of the IIASC project. Feedback from these groups was used to guide the development of the draft questions.

2.3 Question Testing: Cognitive Interviews

The questions developed in the initial two stages of the project (i.e. theoretical evaluation of the questions and consultation) were tested using cognitive interviewing (Willis, 2005). The interviews focussed on the comprehension, recall strategies, judgement and response formulation by the interviewees. This was followed by a short semi-structured interview with the carer to discuss the impact of caring on their everyday life and their experiences of formal support and services.

A purposive sample of 31 carers was recruited from three local authorities in England. The local authorities were selected based on location and circumstances with two Northern local authorities (one rural, one urban) and one Southern local authority covering both suburban and rural areas. A total of 98 carers were invited to participate in the study by their local authority with which they had contact. In addition, further invitations were sent to carers known to carers' organisations in two of the three local authorities. The carers were selected based on the following inclusion criteria:

1. Aged 18 years or over.
2. Looking after or caring for someone with a physical/sensory disability, mental health problem or learning disability who uses adult social care services.
3. Able to speak English fluently.

The exclusion of young carers (i.e. under the age of 18) is due to the focus of the questionnaire in development on adult carers. The survey questions were designed for adult carers, and further work would be needed to adapt the questions to be age-appropriate in order to capture the views and outcomes of young carers. The inclusion of only carers of service users who use adult social care services is due to the aim of the study to determine the impact of these formal services. However, it is recognised that there are carers who look after people who have do not access formal services for various reasons. Finally, the exclusion of carers who are not able to communicate fluently in English was due to the nature of the methodology. Cognitive interviewing requires a degree of fluency in order to be able to respond to probes and/or to 'think aloud'. As the aim of the study was to develop the core set of questions for carers in English, those who were not able to communicate fluently in English and engage in this technique were not included. Should the measure be translated in the future, further work would be required to test the validity and reliability of the translated questions as has been conducted for the ASCOT measure of SCRQoL for service users (Kettunen, 2012).

The invitation letter sent to carers included a return slip and FREEPOST envelope for the carers to return should they agree to be contacted by the researcher to schedule a time for the face-to-face interview. 37 responses to the invitation letters were received, of which six respondents dropped out before the interview due to a change in circumstances or non-response to follow-up correspondence to schedule an interview. 31 interviews were conducted. The carers who participated represented a range of characteristics in terms of caring circumstances and demographics (see table 2).

The interviews were audio recorded and were conducted in the participant's home or another convenient location. Written consent was obtained from all participants. The cognitive interview lasted between 40-75 minutes and involved both 'think aloud' and 'probing' techniques (Willis, 2005). The carers were invited to talk through their responses to the questions. The aim of this 'think aloud' technique is to give an insight into how participants navigate through the question and the non-reactive processes of comprehension, retrieval, judgement and/or response. In addition, the participants were asked to respond to concurrent probes to gain insight into their understanding of the question and how they formulated a response. All participants were given a £20 high street voucher to thank them for their participation.

At the end of each round of interviews, the interviewer met with other members of the research team to discuss the findings and any issues that were identified in the interviews. The questions were then refined before the next round of interviews (Campanelli et al, 1991).

Ethical approval was obtained from the Social Care Research Ethics Committee (SCREC) and research governance was obtained from all participating local authorities.

Table 2. Characteristics of carers

	Number
Gender of carer	
Male	5
Female	26
Age of carer	
18-24	1
25-44	0
35-44	0
45-54	6
55-64	8
65-74	10
75 and over	6
Relationship of cared for person to carer	
Spouse/partner	12
Parent	5
Child	11
Sibling	2
Grandparent	1
Co-residency with cared for person	
Co-resident	23
Not co-resident	8

3. Results

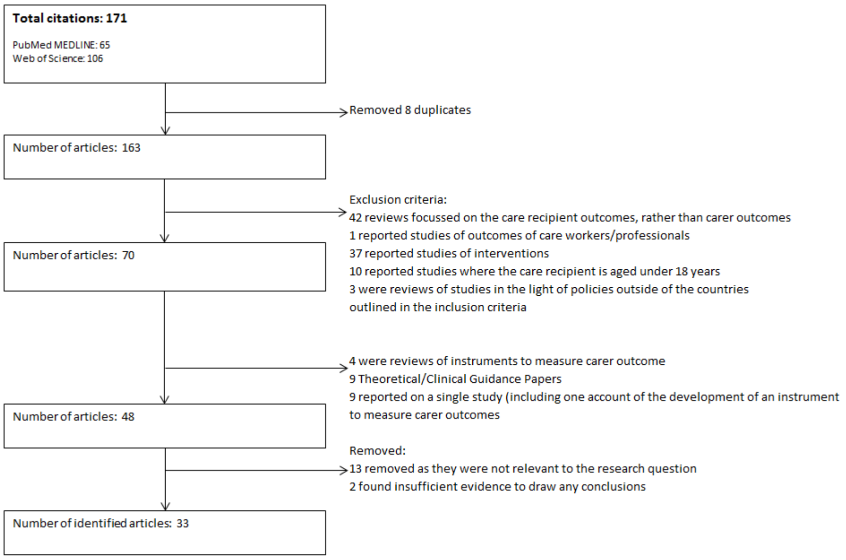
3.1 Literature Review – Evaluation of the Domains in ASCOT-Carer

A total of 171 articles were identified using the search strategy outlined in Appendix B. Following a review of the abstract and/or full text, 138 articles were excluded based on the inclusion/exclusion criteria (see Figure 1).

The remaining 33 articles are reviews of carer outcome for a particular group of care recipients. These articles include informal carers of care recipients with dementia (N=8), stroke survivors (N=6) or older adults (N=4), and care recipients with cancer (N=6), mental illness (3) or other conditions (N=6).

Of the seven review articles of qualitative studies, six articles are reviews of qualitative studies published in peer-reviewed journals. Nicholson (2009) reported a review of a selection of published books written by informal carers of adults with dementia.

Figure 1. Study Selection Process



The identified reviews of carer QOL each encompassed at least one of the ASCOT-Carer INT4 domains. Table 3 below shows how many studies reported outcomes/QoL domains that would be picked up by the Carer SCRQoL domains. In total there are 130 studies (as reported in the 33 review articles) represented in the table, some of which relate to more than one domain.

Table 3. Summary of Carer QOL literature by ASCOT-Carer INT4 domain

ASCOT-Carer INT4 Domain	Number of studies that support this domain
Occupation	7
Self-care	12
Personal safety	6
Social participation and involvement	37
Control over daily life	14
Feeling supported and encouraged	74
Space and Time to be yourself	3

The literature is dominated by studies of the impact of ***Feeling supported and encouraged*** on carers' quality of life. This is perhaps not surprising as caregiving can be facilitated by encouragement and support from family, friends and social care or health professionals. A number of common themes were identified when exploring the concept of 'feeling supported' in the context of professional services; carers spoke of the importance of coordination between services and services that meet the individual needs of the patient (Kang et al, 2011).

In addition to formal support from professionals, this domain also covers informal support from friends, family, neighbours and the wider community. Social support and encouragement has been shown to be associated with lower reported levels of depressive symptomology or stress and improved perceptions of general health and quality of life (Salter et al, 2010; Mockford et al, 2006; Kitrungrote et al, 2006), and an increased likelihood that carers will report the positive aspects of caring (Molloy, 2006). There is some evidence that carer burden is associated with the perceived, as opposed to the amount of support actually received from the carers' social network (Goldstein et al, 2004 in Stenberg et al). However, in a review of studies investigating the association between adjustment to caregiving and social support, Smerglia et al (2007) challenges the assumption that the availability of social support is necessarily a protective factor against caregiver stress. The meta-analysis in this article yielded no significant association between carer depression or burden and informal social support. This lack of association was found for both 'objective' measures (i.e. size of support network or retrospective measures of the support received in a defined time period) and 'subjective' measures (i.e. the carer's perception of the support that they receive) of social support. These counterintuitive results suggest that, although carers naturally seek and may receive support from their existing social network (Madson et al, 2011), this support may not actually meet their needs.

Social support (or the lack thereof) may also act as a stressor rather than a protective factor. For example, the carers of people with mental health problems can experience stigma or prejudice against the person that they care for which is an additional emotional stressor (Reed et al, 2008). The carers' existing social network can also act to add to stress, rather than alleviate it. The experience of friends and family not offering support or understanding may be upsetting to the carer or add to feelings of being undervalued (Gardiner et al, 2010, Greenwood et al, 2009, 2010). Social support networks may introduce negative interactions, conflict and stigma, as well as positive experiences and support (Smerglia et al, 2007; Madson et al, 2011). The literature therefore supports the approach of measuring the outcome of 'feeling supported and encouraged', rather than measures of the perceived amount of support available or the actual amount of support received by a carer.

The item on ***Social participation and involvement*** in the carer SCRQoL measure (see Table 1) asks whether carers have as much social contact with people they like. Although 'people you like' is not defined in the question, carers tend to understand this to mean friends and family other than the care recipient. The literature includes a number of articles that highlight the association between social participation (with people other than the care recipient) and carers' quality of life. Due to the additional emotional and time burden of care tasks, carers may find that they have less time and energy to invest in a range of activities including maintaining relationships with friends and family. This can lead to individuals in the carers' support network drifting away as they become tired or impatient with the situation (Zegwaard et al, 2011; Madson et al, 2011) or are 'not sure what to say' (Mockford et al, 2006), which can lead to the social isolation of carers. Participating in social activities is associated with higher quality of life and lower reported burden among carers (Mockford et al, 2006).

The item on ***Control over daily life*** measures, in part, the disruption of daily life due to care tasks or needs. It also encompasses carers' perceptions that they are bound to the needs of another person rather than feeling free to be able to make plans and control their own lives. Carers speak of a sense of loss of their previously unburdened lifestyle and hopes for the future (Gardinier et al, 2010). Carers report feeling overwhelmed by feelings of uncertainty about what the future holds and the inability to plan for the future because of the restrictions and unknown elements of the care recipient's disease course (Madsen et al, 2011; Greenwood et al, 2009; Greenwood and Mackenzie, 2010) which also contributes to a feeling of loss of control over one's life. The prioritisation of the care recipients' needs over their own needs compounds the carers' sense of a loss of control (Mockford et al, 2006; Greenwood and Mackenzie, 2010). Greenwood and Mackenzie (2010) found that carers spoke about a loss of autonomy; for example, that they felt they did not have a choice in whether they care or not, a loss of freedom and being bound by the dependency of the care recipient, feelings of powerlessness when dealing with the healthcare system, and loss of control over their home due to community care workers. The loss of control has been linked to carers' outcomes. In particular, carers who report that they have less control over their future life and circumstances are more likely to experience adverse mental health outcomes (Mausbach et al, 2006 reported in Sorenson et al, 2006).

The item on ***Self-care*** ('*I look after myself as well as I want'*), in part, asks whether someone neglects their own health due to their caring role. Carers' health is a key policy concern (Department of Health, 2010) as it is recognised that carers may neglect their own health and wellbeing by showing reduced self-care behaviours which may lead to higher mortality rates (Schulz et al, 1997 reported in Sorenson et al, 2006). Carers may neglect their own wellbeing, such as nutrition (Moore et al, 2010), if they are struggling to keep up with care tasks, or if they prioritise the care recipient's needs over their own needs (Greenwood and Mackenzie, 2010). The literature also highlights the issue of sleep deprivation among carers. Co-resident carers experience disruption to their own sleep due to caring at night or insomnia (Kitrungrote et al, 2006; Moore et al, 2010; Molloy et al, 2005), and lack of sleep has been found to be associated with depression and poorer health outcomes for carers (Lee and Thomas, 2011). In two studies of the effect of geographical location on the outcomes of carers, it was found that carers in urban areas tended to seek second opinions more often than carers in rural areas, and that rural carers tended to take physical exercise more frequently than urban carers. However, there was no significant difference in the association between health promotion behaviours of urban and rural carers and their quality of life (Mackenzie et al, 2010).

The ***Occupation*** item asks whether carers are engaged with meaningful and enjoyable activities in their daily life. This item encompasses a range of different activities, from leisure activities and voluntary or paid employment to looking after others, defined by whether the activity is valued *by the carer*. The outcome state of 'being able to do things I value and enjoy' is affected by various factors; for example, the challenge of balancing care tasks with the time for meaningful, enjoyable activities, and being able to choose activities that meet their own preferences and needs, rather than those of others. The physicality of care work and the burden of the day-to-day care activities (Nicholson, 2009; Moore et al, 2010; Sowmini and De Vries, 2009), the disruption to the everyday routine and lack of flexibility or time to follow their own leisure activities (Greenwood et al, 2010; Gardinier et al, 2010) were key themes identified in the accounts of carers' everyday experiences. Carers speak of being overwhelmed by the daily round of care tasks and being captive in the caring role (Zegward et al, 2011). The freedom for carers to have a life outside of caring, to be able to sustain a family and community life, and to not feel forced to give up paid employment if they do not want to do so are key policy strategies (*Recognised, Valued and Supported: Next Steps for Carers Strategy*, Department of Health 2010).

The ***Personal safety*** item asks whether the carer feels safe in their role as a carer and feel free from worry about accidents, abuse or physical harm associated with caring for someone else. Perhaps surprisingly, the literature search did not identify any studies that look specifically at anxiety due to the potential risk of harm to carers as a result of lifting or other strenuous caring tasks, although this theme was identified in the qualitative interviews and focus groups during the development of the carer QOL measure (Holder et al, in preparation). However, the identified articles did discuss the concerns and worries of carers caused by unpredictable or violent behaviour from the care recipient, particularly in patients with dementia (Nicholson, 2009) and mental health problems (Reed, 2008; Zegward et al, 2011).

The item ***Space and time to be myself*** is not widely discussed in the literature but is a key policy concern. *Recognised, Valued and Supported: Next steps for the carer strategy: response to the call for* views (Department of Health, 2010) identifies breaks from caring responsibilities to allow the carer some ‘time and space to myself’ as a priority. The identified literature highlighted two themes relevant to this domain; carers have less time for themselves (Mockford et al, 2006) and the pressure of feeling that they need to be with the person they look after (Greenwood et al, 2009). Carers speak of not being able to ‘switch off’ from the feeling of responsibility for caring, even when the care recipient is not physically present. This item aims to measure the carers’ ability to relax and feel they can ‘switch off’, which may be influenced by the availability and their confidence in the quality (Qureshi et al, 1998) of replacement care or respite services.

3.2 Review of Carer Quality of Life Instruments designed

Although the reviews of carers’ outcome or quality of life instruments were initially excluded from the literature review, the identified articles (Hudson et al, 2010; Harvey et al, 2008; Rombough et al, 2007; Moinz-Cook et al, 2008) were evaluated separately for the purpose of evaluating the domains in ASCOT-Carer INT4. The conceptual basis of the measures identified in these reviews can be broadly categorised as those that are based on the stress/burden model of caregiving (Sorenson et al, 2006), for example measures of carer burden such as the Zarit burden interview (Zarit et al, 1980) or measures of ‘protective factors’ that mediate the impact of stressors on the carer’s quality of life, such the coping (Brief COPE scale (Carver et al, 1997)); instruments that measure general ‘quality of life’ (e.g. WHO-QOL); or measures of ‘health-related quality of life’ (HRQoL), for example the EQ5-D (The EuroQOL group, 1990; Brooks, 1996). These constructs are conceptually different from social care-related quality of life’ (SCRQoL). Whereas HRQoL focuses only on health-related domains of quality of life, and measures of carer stress/burden are limited to the negative impact of caring on carers, social-care related quality of life aims to capture the overall effect of caring on the carer’s quality of life, with a focus on domains that are affected by social care services.

The reviews identified two carer-specific quality of life measures which are similar to the construct of SCRQoL in the ASCOT-Carer INT4 and have been designed to be used in economic evaluations of informal care (Al Janabi et al, 2008; Brouwer et al, 2006). The CarerQol instrument (Brouwer et al, 2006) comprises a 7-item self-completion questionnaire (the CarerQol-7D) and a VAS scale for happiness (CarerQOL VAS). The instrument was developed based on the review and selection of dimensions of caregiver burden from existing measures, and the feasibility (response rate), convergent and clinical validity of the instrument was assessed based on a sample of Dutch carers. The Carer Experience Scale (Al Janabi et al, 2008) was developed using a combination of review of the qualitative literature and interviews with informal carers (N=16). These interviews identified a number of themes which make up the six domains included in the final measure. The domains in these two measures and the Carer QOL measure (Fox et al, 2010; Malley et al, 2010 – see Table 1.) are compared in Table 4 below.

Table 4: A comparison of domains in the CarerQol, the Carer Experience Scale and the Carer QOL Measure (Fox et al, 2010; Malley et al, 2010)

	Occupation	Control	Fulfilment	Finances	Health	Relationship with the Care Recipient	Space and Time	Self-care	Safety	Encouragement and support	Social participation and involvement
CarerQOL (Brouwer et al, 2006)	**Item** "Problems with combining care tasks with daily activities"	Not included	**Item** "fulfilment from carrying out care tasks"	**Item** "Financial problems due to care tasks"	**Item** "Problems with mental health" and "problems with physical health"	**Item** "Relational problems with the care receiver"	Not included	Not included	Not included	**Item** "Support with carrying out care tasks, as needed"	Not included
Carer Experience Scale (Al-Janabi et al, 2009)	**Item** "Activities outside of caring"	**Item** "control over caring"	**Item** "fulfilment from caring"	Not included	Not included	**Item** "getting on with the person you care for"	Not included	Not included	Not included	**Item** "Support from friends and family" and "assistance from organisations and government"	Not included as a separate item – included under "activities outside of caring"
Carer QOL Measure (Fox et al, 2010; Malley et al, 2010)	**Item** "Doing things I value and enjoy", which can include caring, paid work or leisure activities	**Item** "control over daily life"	Not included	Not included	Not included	Not included	**Item** "Time and space to be yourself"	**Item** "Time you have to look after yourself"	**Item** "Feeling safe from fear of abuse, being attacked or other physical harm".	**Item** "Feeling supported and encouraged"	**Item** "social contact with people you like"

The CarerQOL (Brouwer et al, 2006) is based on the stress-burden model of caring. As such, it includes items that relate to the stress process and appraisal models of carer stress and burden (see Sorenson et al, 2006): for example, the role of care tasks in limiting daily activity or whether caring has caused financial problems or has increased conflict with the care recipient. As well as these items on the 'secondary stressors' of care, the instrument also includes items that measure moderators of carer stress (i.e. social resources, such as support, fulfilment from caring). Finally, the instrument also includes items on outcomes (i.e. the impact of caring on the carer's physical and mental health). In contrast, the Carer Experience Scale (Al-Janabi et al, 2009) is a measure of the 'experience of caring'. The items set out to capture conceptual attributes of caring rather than attributes based on a model of informal care. The items were selected to avoid potential 'double counting': for example, the 'experience attribute' of activities outside of caring may affect the health of the carer. As such, the authors included the 'experience attribute' rather than an item on the final health outcome of the carer.

The conceptual basis of the Carer QOL instrument (Fox et al, 2010; Malley et al, 2010) is distinct from the CarerQOL (Brouwer et al, 2006) and the Carer Experience Scale (Al-Janabi et al, 2009). It is neither based on the stress / burden model of informal care nor sets out to be a measure of the experience of care. The Carer QOL instrument aims to measure the ***Outcomes of social care*** (Netten, 2011; Malley et al, 2011; Qureshi et al, 1998) for informal carers. The instrument is designed to capture information about an individual's social care-related quality of life; that is, the aspects of quality of life that could be affected by social care services and support. The instrument is part of a broader programme of work on the Adult Social Care Outcomes Toolkit (ASCOT) which is a measure of social-care related quality of life and outcomes for service users (Netten et al, 2012; Malley et al, 2012; Caiels et al, 2010; Forder and Caiels, 2011). The domains of outcome in the ASCOT instruments are all 'final outcomes' - the overall psychosocial and health behaviour outcomes of service users. (Health-related domains can be conceptualised as 'final outcomes' of social care, but were excluded from ASCOT due to the availability of a range of other health-related outcome instruments). The measure does not include domains that capture information on the 'process outcomes' of social care (Qureshi et al, 1998) to avoid potential double-counting.

The Carer QOL instrument (Fox et al, 2010; Malley et al, 2010), on which the development of ASCOT-Carer INT4 is based, comprises a number of domains of SCRQoL that overlap with the ASCOT instruments for service users; specifically, the domains of Occupation, Social Participation and Control. The domains of Self-care and Safety are based on similar domains in ASCOT (service users) but have been adapted to be aligned with the specific concerns of carers: for example, the item in the Carer QOL instrument (Fox et al, 2010; Malley et al, 2010) focuses on aspects of self-care relevant to carers (i.e. eating healthily and sleep, which may be disrupted by caregiving) as opposed to basic self-care (i.e. washing and dressing) as they may be more relevant to service users. Finally, two additional domains (Feeling Supported and Encouraged, and Time and Space) were added to the measure, based on the findings of qualitative interviews and focus groups with carers (Holder et al, 2009). The 'Time and Space' domain was identified as a key concern in this work. Although this domain had been removed from the Carer Experience Survey 2012/13, it was considered in this development phase because there is some evidence that it is distinct from other domains in the measure (Malley et al, 2010) and the domain fits with the conceptual framework for the measure. 'Time and Space' is a final outcome domain and is similar to the domain of 'peace of mind' identified in Qureshi et al (1998)'s work on outcomes in community care. The domain may also be impacted by social care support and services: for example, a lack of confidence in replacement care services (Jackson et al, 2012) may affect the 'final outcome' of a carer's ability to have time and space to themselves. The care recipient may physically be in replacement care but the carer may still not be able to find 'time and space' to disengage from anxieties over the care recipient's welfare.

There are also four domains that are included in one or both of the Carer Experience Scale (Al Janabi et al, 2009) and CarerQOL (Brouwer et al, 2006) but not in the Carer QOL measure (Fox et al, 2010; Malley et al, 2010); fulfilment, financial worries, physical/mental health, and the relationship with the care recipient. The conceptual basis for the inclusion/exclusion of these domains in the cognitive interviews for the ASCOT-Carer INT4 (see Appendix A) is discussed below.

1. **Fulfilment:** The Carer Experience Scale (Al-Janabi et al, 2009) and CarerQOL (Brouwer et al, 2006) both include an item on the carer's sense of fulfilment from caring. Fulfilment is defined in these measures as positive experiences associated with caregiving. The positive experience of caring has been associated with the carer's motivation to care and his or her ability to find meaning in caregiving. These have been associated with the outcomes of both service users and carers (Quinn et al, 2010). However, it is not clear how social care services could impact the outcome state of feeling 'fulfilled' by caring where fulfilment is defined as 'feeling appreciated by the person you look after and the feeling that you are contributing to the care of the person you look after' or other positive evaluations of the experience of caregiving. The domain does not therefore fit into the conceptual framework for the ASCOT-Carer. However, this may be a characteristic that could contribute to the overall SCRQoL of carers. As such, we felt that it was important to develop a single item measure of fulfilment from caring. A question was drafted to measure 'feeling fulfilled in the caring role' as a potential supplemental single-item measure of the positive aspects of caring and/or motivation for caring.
2. **Financial Worries:** Financial worries have been linked to carer outcomes (Gaugler, 2010; Reed et al, 2008) and are included as an outcome domain in the CarerQOL (Brouwer et al, 2006). The Carer QOL measure (Fox et al, 2010; Malley et al, 2010) does not include financial worries as an outcome domain as this is conceptualised as an intermediate outcome of social care rather as a final outcome state. That is, financial worries may be an intermediate outcome (a 'causal indicator') that would

affect the outcomes states or ‘effect indicators’ of social participation, occupation, self-care and control, and may contribute to a lack of ‘space and time to be myself’ (Fayers and Hand, 1997).

3. **Relationship with the Care Recipient:** This is included as an outcome domain in both measures. The quality and satisfaction with the relationship between the carer and care recipient has been linked to carers’ health-related quality of life (Kitrungrote et al, 2006; Ablitt et al, 2009) and was identified as an important aspect of quality of life by carers who participated in focus group discussions during the development of the Carer QOL questions (Holder et al, 2009). The relationship between the carer and care recipient may also be impacted by service provision, for example, replacement care and support for carers may affect the relationship quality by allowing the carer to focus on more enjoyable care tasks while a care worker substitutes for activities that may cause strain in the relationship, or by the impact of replacement care, or advice or support from outside in understanding changed behaviour or needs of the care recipient. It was decided to draft and test an item designed to measure the outcome domain of ‘quality of the relationship’ between the carer and care recipient.
4. **Physical/Mental Health:** Informal care has been shown to impact the health outcomes of carers (Schulz and Beach, 1999; Sorenson et al, 2006), and the CarerQOL (Brouwer et al, 2006) includes two separate items for mental and physical health. However, as outlined above, the final outcome of physical and/or mental health are not included in ASCOT nor the Carer QOL measure (Fox et al, 2010; Malley et al, 2010) because there are already a number of widely-used instruments that measure health outcomes (for example, EQ5D).

3.3 Question Development

Following the initial conceptual evaluation of the items in the Carer QOL measure (Fox et al, 2010; Malley et al, 2010 – see Table 1) a draft interview schedule for the ASCOT-Carer INT4 was prepared by the authors. This phase of development was informed by the literature review and by feedback from service users, carers, practitioners and policy-makers in the Project Advisory Group and other existing groups that participated in the process of consultation for this project.

The questions in the ASCOT-Carer INT4 followed the same structure as the ASCOT INT4 v2.1 (for service users) as follows:

1. **Present Situation:** For example, *‘Which of the following statements best describes how you spend your time in your present situation?’*
2. **Filter Question:** For example*, ‘Do the support and services that you and [Name of Service User] get from <<EXAMPLES of social care services based on earlier questions>> help you to spend your time doing things you value and enjoy?’*

3. **Expected situation:** *(If filter question = yes)* For example*, 'Imagine you and [Name of Service User] didn't have the support and services from <<EXAMPLES of social care services based on earlier questions>> that you do now, and no other help stepped in. In that situation, which of the following would best describe how you'd spend your time?'*

The main considerations addressed in the development of the interview schedule for the ASCOT-Carer INT4 are outlined below.

3.3a. Response Levels

The questions developed for the Carer Experience Survey 2012/13 (Fox et al, 2010) have three response options which reflect the following outcome states for each domain:

- ***Ideal state****:* The individual's preferences and wishes in that area are met;
- ***Some needs:*** There are needs but these do not have an immediate or longer-term health implication;
- ***High-level needs:*** There are needs and these have an immediate or longer-term health implication.

The initial development of these questions was based on the then-current version of ASCOT self-completion tool (SC3) which had three response levels corresponding to the ideal state, some needs and high-level needs. However, further development work on ASCOT in recent years identified the need for an additional, further level of response (Netten et al, 2012). This fourth level corresponds to a ***No needs*** state where the individual's needs are met but not to the desired level. This enables the distinction between the ideal state, where all needs are met to the individual's satisfaction, and a state where the individual has no needs but the situation could be improved.

As one of the aims of this work was to develop an ASCOT-Carer INT4 that is aligned with the current version of the ASCOT INT4 v2.1, the Carer QOL measure questions (see Table 1) were adapted to include an additional response level that corresponds to the ***No needs*** state for each domain. The consultation of service users and carers from the LSE Service User and Carer Group (SUCG) about the draft questions supported this approach as carers felt that the three response levels were not sufficient to differentiate between different outcome states. The implications of including this additional response level on comparisons of the ASCOT-Carer INT4 and the Carer Experience Survey 2012/13 are discussed in Section 4 of this report (Conclusion).

3.3b. Changes to the Carer QOL questions

The carer QOL questions from the Carer Experience Survey 2012/13 (Fox et al, 2010) were developed based on a previous draft of ASCOT self-completion (SC). In the interim, there have been some minor changes to the ASCOT definition of 'doing things I value and enjoy'. As one of the aims of the IIASC project is to understand the relationship between service user and carer outcomes, it was decided to change the wording of the ASCOT-Carer INT question in to match the wording in the latest version of ASCOT INT4 v2.1. The details of these minor changes to the wording of questions are outlined in Appendix A.

During the review of the questions by the authors and other members of the IIASC team two further changes were implemented. First, the ***Ideal state*** response level for 'self-care' was reworded in order to more clearly define the difference between this ***Ideal state*** and the ***No needs*** state (i.e. from 'I look after myself' to 'I look after myself *as well as I want*'). Second, the definition of 'feeling safe' was adapted to include 'physical harm, including accidents, as a result of the caring role' to further clarify the definition and link this domain to the experiences of carers. These changes were tested during the cognitive interviews with carers.

3.3c. Service Receipt Questions

The social care service receipt questions developed for the Carer Experience Survey (Holder et al, 2009; Fox et al, 2010) were reviewed in the light of the aims of the IIASC study. With the introduction of personal budgets for service users and carers (Glendinning et al, 2008, Department of Health, *Carers and Personalisation: Improving Outcomes*) and the diversification of the definition and providers of social care services, it was decided to expand the section on service use by informal carers. The draft questions were either adapted from the service receipt questions in the Social Care for People aged 65+ questionnaire (Blake et al, 2010) or from the Department of Health Survey of Carers In Households 2009/10 (Department of Health, 2010). These questions are designed not only to provide information on the use of social care services by carers but also to guide the definition of social care services for the 'expected' situation questions.

One of the objectives of the development phase of the IIASC project was to develop a clear definition of 'social care support and services' which would be used in the interviews (both ASCOT INT4 v2.1 and ASCOT-Carer INT4) for the main fieldwork stage of the project. This phase was informed by consultation with local authority and policy representatives in the Project Advisory Group.

Due to the changes in funding of social care and introduction of personal budgets, the boundary between 'traditional' social care services and other associated services is less clear. The separation of social care services provided or funded by adult social services (Local Authorities) from services provided by the voluntary sector or purchased by individuals privately from their own resources, such as pensions, benefits or savings, may no longer be meaningful. Voluntary organisations may be part-funded by the Local Authority and part-funded as a charity. Although a personal budget funded by the Local Authority may not be able to completely cover the costs of a service, it may enable an individual to access a service that would have previously been unavailable to them by part-funding the service. As the aim of the questions is to measure the impact of social care services provided by the Local Authority (both directly and indirectly), the following definition of social care support and services was developed, tested and refined in the cognitive interviews and in subsequent consultation with local authorities (see Appendix A for further details).

> *"When we talk about 'services and support' in the next set of questions we mean for you to think about services provided by different organisations, such as voluntary organisations, private agencies or your local authority / council. For example, << INTERVIEWER TO GIVE EXAMPLES BASED ON RESPONSES TO THE QUESTIONS ON SERVICE RECEIPT >>*
>
> *NOTE to Interviewer: Please include the following, as applicable.*
>
> - *Home care/home help/personal assistant*
> - *Day centre, Respite/replacement care*
> - *Direct payments / personal budgets*
> - *Voluntary helpers, e.g. sitting or befriending services*
> - *Meal services*
> - *Equipment (including minor adaptations to the home and assistive technology, such as life line alarms)*
> - *Handyman services*
> - *Professional support (including Support Worker, Care Manager, Social Worker and/or warden or sheltered housing manager, Community Mental Health Team (CMHT) and/or Occupational Therapists).*
>
> *This may be support you receive directly from your local authority or voluntary organisations, or which you pay for yourself, or with a personal/individual budget or direct payment. We do **not** mean any help you may get from friends, neighbours or family, or support from health professionals, such as doctors/GPs, nurses, or physiotherapists".*

The example wording in ASCOT INT4 V2.1 for the filter question asks service users to indicate whether the '*support and services from social services'* affect each domain of SCRQoL. It was decided to replace the example wording (*'support and services from social services'*) with specific examples of the social care support and services based on the interviewee's responses to the service receipt questions.

> **ASCOT INT4 v2.1:** *Do the support and services that you get from Social Services help you to maintain control over your daily life?*
>
> **ASCOT-Carer INT4 (IIASC):** *Do the support and services that you and [Name of service user] get from << EXAMPLES based on responses to service receipt questions>> help you to have control over your daily life?*

It was found in the cognitive interviews that giving specific examples improved comprehension and response to the questions. The following prompt (adapted from ASCOT INT4 v2.1) was used, as needed, to bring the respondent back to thinking about social care support and services as opposed to unpaid help from friends, family or neighbours.

> *"By support and services we mean, for example, < <INTERVIEWER TO GIVE EXAMPLES BASED ON THE RESPONSES TO THE QUESTIONS ON SERVICE RECEIPT>>".*

The definition of 'support and services' includes both services used by the service user as well as services used by the carer. From a policy perspective, it would be informative to measure separately the effect of these two categories of formal services. That is, the direct impact of carers' services on carers' outcomes as well as the indirect benefit of service users' services on carers' outcomes. However, the development of questions to measure this proved to be a challenge (see section 3.4c.ii for further discussion). Therefore, the 'expected' situation questions ask the carers to imagine a situation where all formal support and services are no longer available (i.e. both carer services such as counselling, information and advice and training, as well as services aimed specifically at the service user, such as home care and equipment).

Finally, a question which asks how easy or difficult the 'expected' situation questions were to answer was developed and tested. This question was adapted from the question included in the PSSRU low level services study (Caiels et al, 2010) and is designed to indicate whether the respondent had any difficulties in answering the 'expected' (in the absence of services) situation questions. These questions are cognitively demanding and place a burden on the respondent as they answer the question. This item is designed to highlight any respondents who may have had difficulty in understanding, evaluating or responding to these questions.

3.3d. Integration of Health and Social Care

The commissioning, management and evaluation of adult social care services in England is currently the responsibility of Local Authorities. This is separate from health care services, the majority of whose executive responsibilities lie with local NHS Trusts. The current policy direction is to support both collaboration within different services within the NHS as well as between NHS and social care services *(Improving Integration of Services*, Health and Social Care Bill Factsheet, February 2012). These changes are designed to focus service delivery on patient outcomes rather than working within silos to different process-orientated targets as well as to achieve cost efficiencies through collaboration. In the context of this agenda, it was decided to draft and test a question that measures the carers' perception of the integration of health and social care services to work together to improve his or her outcomes, or the outcomes of the care recipient. (See Appendix A, Question 30).

3.4 Cognitive Interviews

31 informal carers were interviewed using the principles of cognitive testing (Willis, 2005). The wording of the questions were adapted and refined in each round of interviews. The

key findings are outlined below. The detailed findings for each individual question are reported in Appendix A.

3.4a. Current Situation: Carer quality of life in the present situation

The cognitive interviews explored the carers' comprehension and understanding of the terminology used in the questions to describe the different outcome domains in the ASCOT-Carer INT4. The interviews did not identify any major issues with comprehension, as would be expected since the questions, with the exception of the new domain of '*getting on with the person you look after*', are based on previous development and cognitive testing (Holder et al, 2009; Fox et al, 2010). A summary of the key findings by domain are outlined below.

'***Doing things I value and enjoy'*** seemed to capture the type of things we intended. People talked about voluntary or paid work and activities they do with others, such as visiting friends, as well as activities they do on their own, such as gardening or walking the dog.

'***Space and time to be myself'*** seemed to capture, as intended, the carer's ability to relax and have time away from cares and worries.

> *"Well I think it could mean either physical time and space for myself but also emotional time and space... I can go off and do activities but my head is concerned about my mother". [CR3]*
>
> *"Space and time for you to be on your own….to be able to do something you want without sitting on pins, waiting for things to happen".[CR5]*

Although this question has been removed from the latest version of the national Carers' Experience Survey (2012/13), as it was felt to closely overlap with the *Occupation* domain, in analyses of the voluntary Carer Experience Survey in 2009, the polychoric correlations did not exceed 0.8 for any item (Malley et al, 2010) which indicates that each item is captured a distinct attributeof SCRQoL. The item pairs of *Control-Space and Time* and *Occupation-Space and Time* had the highest correlations of 0.79 and 0.77 respectively. This seems to match the qualitative evidence from cognitive interviews. The carers define 'having space and time to be myself' in terms of both the ability to do activities that they'd like to do, as well as having the control or freedom to choose to do these things when they choose to. Despite this conceptual overlap, the carers did understand this domain to mean also the ability to find emotional 'space for yourself', which is conceptually distinct from *Occupation* and/or *Control*, and has been identified in the literature on carers' quality of life as a factor that affects carers' wellbeing (Greenwood et al, 2009, Mockford et al, 2006).

The term ***'control over daily life'*** was understood by the people we interviewed. They spoke of being able to do the things they want to, when they want to do them. The carers described how the burden of care tasks, or the prioritisation of the needs of the service user over their own needs, limited the control that they had over their daily lives.

'Self-care' captured a broad range of health protection behaviours, such as taking regular exercise, eating healthily, showering and self-care, sleeping well, and attending medical appointments for the carer's own health conditions. Although the majority of carers understood 'self-care' to mean looking after their own health and wellbeing, some carers found it difficult to disentangle the concept of self-care, from their care of the service user.

> *"I sleep fairly well, [care recipient] sleeps well, we eat quite well. No, I don't think it's anything to do with the support services, no" [CR4]*

The loss of a sense of self is highlighted clearly in the following quote:

> *"Myself disappeared a long time ago [laughs]. I'm an adapted self". [CR4]*

'Feeling safe' was understood by carers to cover feeling safe inside and outside of the home. Many respondents spoke of feeling safe from violence perpetrated by the care recipient due to condition-specific behavioural symptoms.

> *"Again with mental illness … there was an element there of risk, and that has happened occasionally and … we as a family were always able to deal with it."* [CR1]
>
> *"I know quite a lot of people whose young people can be quite violent, can have temper tantrums, can hit their parents, can pull them to the floor… my son's very gentle and he's never (done that)".* [CR5]

Carers also spoke of the impact of accidents, either directly or indirectly associated with their caring role, for example the worries about injury due to lifting the service user, or accidents that had taken place due to the psychological distraction and tiredness associated with caring. The definition of 'feeling safe' also encompassed the carers' concerns about verbal abuse or stigma associated with disability that they have encountered in the community. Some carers also spoke of 'feeling safe' in terms of the safety of their home or neighbourhood, and how this impacts on their ability to leave the care recipient alone in the home while they go out.

> *"Where I live is safe … I can actually leave [Care Recipient] there because my neighbours are very good as well, and they're safe. You can't get in the place, it's all keyed".* [CR8]

Despite the definition in interviewer prompt of *'feeling safe from fear of abuse, being attacked or other physical harm, such as accidents, which is* ***as a result of your caring role'***, some carers spoke of the impact of their neighbourhood environment, age and other factors on their general feeling of safety.

> *"Well because of our age … the older you get the more vulnerable you feel".* [CR11]

'Social Participation and involvement' was understood to mean face-to-face or telephone contact with friends, family, work colleagues and neighbours, and the ability to maintain friendships and/or a relationship with a partner. The carers spoke of the impact of caring on their ability to 'go out' or meeting with friends, either due to the prioritisation of the needs of the care recipient, for example;

> *"If I have to look after my wife then I have to forget about social life with the other people. I don't go to the pub or anything like that now, I wouldn't bother."* [CR6]

Or due to anxiety over the care recipient's behaviour or a lack of understanding of the care recipient's behaviour and/or stigma by former friends;

> *"You know the good friends we have accept him, but it does very much restrict who your friends are... it has caused quite a lot of trouble having him. You know who your friends are, sort of thing".* [CR4]
>
> *"My friend actually witnessed once the two of them kicking off. She was horrified. So, you don't want anybody to see that."* [CR5]

Or difficulties in maintaining friendships due to a lack of understanding of the constraints that the caring role places on their ability to go out or meet up more spontaneously with friends or acquaintances.

> *"And she felt quite (upset, and said), "Oh well, you know, couldn't you make the effort?" And I said, "Well it's not about the effort, it's about that is not possible for me to do".* [CR8]

'Feeling supported and encouraged' captured the feeling of being emotionally supported, as well as the perceived availability of practical support. The wording of the question does not specify the people who are doing the supporting or encouraging but carers tend to identify professional care workers, social workers, friends and family members as providing support through existing professional or personal relationships. In terms of professional support, some carers explained how good relationships with particular care workers relieved some of the burden. Some carers defined '*I feel I have no encouragement and support'* in terms of geographical distance of family members, thus not being able to offer practical support, or as a lack of understanding or empathy from friends or family members.

'Getting on with the person you care for or look after' (new domain) was understood by carers to mean the quality of their relationship with the care recipient. The question seemed to capture what we had intended; the carers defined 'getting on' as being able to openly and honestly communicate with the care recipient and to undertake everyday tasks without conflict or arguments.

The 'current situation' questions are based on the people's experiences in their present situation. The questions on *Self-care, Time and Space, Safety and Encouragement and Support* (see Table 1) include a specified timeframe for response to the question ("in your present situation"). However, the questions *on Occupation, Control and Social Participation*, which are based on ASCOT (Netten et al, 2012), do not specify a time period. In the development of the ASCOT questions, it was found that, because many people had conditions that fluctuated, people tended to ignore the instruction and answered with respect to an average day (Netten et al, 2012). In the cognitive interviews for this study, carers also tended to answer based on an 'average day' based on recent experience over the preceding weeks or months. However, it also was found that the reference to a timeframe helped people to understand whether the questions were asking about their situation at the present time as opposed to the 'expected' situation that they no longer had the support and services that they do at the moment. The inclusion of the prompt ("your present situation") for all questions, including *Occupation, Control and Social Participation*, was found to aid comprehension and reduced confusion about whether each question was asking about their 'current' or the 'expected' situation.

In addition to the carers' comprehension of the wording of the questions, the interviews also explored comprehension, judgement and response selection for the four-level responses. The Carer QOL measure (Fox et al, 2010; Malley et al, 2010) had previously used three response options that corresponded to 'high needs', 'low needs' and 'ideal' states[1]. The introduction of a fourth response level ('no needs') was based on the development of the ASCOT questions for service users (Netten et al, 2012). In the cognitive interviews, carers generally understood the response options as intended and were able to distinguish between them without difficulty. The only issue identified was with the word 'adequate' which was used in the response options for the following domains; *Control, Social Participation, Safety, Space and Time to myself, Feeling Encouraged and Supported.* Some interviewees were not familiar with the word and asked for clarification of its meaning. In the final rounds of interviews (CR19-31) both 'Okay' and 'Enough' were tested as alternatives to 'adequate'. Although some respondents indicated that they felt these words were easier to understand, others noted that 'enough' indicated satisfaction in a way that 'adequate' does not. Since the second level aims to capture a state of no immediate needs, but these are not met to the desired level, the word 'adequate' was not replaced nor the wording further adapted.

3.4b. Filter Questions: Do support and services make a difference?

The cognitive interviews highlighted two issues with the comprehension and judgement/response to the filter questions, as follows:

1. The initial rounds of interviews (CR1–19) were conducted using the same wording for the filter questions as are used for ASCOT INT4 version 2.1 (i.e. *Do the support and services from Social Services help you to….*'). However, we identified three issues. First, it was found that there was sensitivity towards the terminology 'Social Services' which elicited responses such as '*We get nothing from them'* or '*They're rubbish'*, where 'they' refers to Social Workers and/or the Adult Social Services departments of Local Authorities (i.e. 'The Social Services'). As discussed in section 3.3c, due to the changing landscape of social care funding, we wanted respondents to answer the filter and expected questions based on the support they receive from

---

[1] The high needs option indicates the respondent has needs that may have a medium or long-term health impact, low-level needs indicates that the respondent has needs, but they would not have a medium or long-term health impact, and the ideal state indicates that all of the respondent's needs are met to their preferred level.

social care support and services both from the local authority as well as from adaptations to the house or specialist equipment support from voluntary organisations or charities, and services that are part-funded through personal budgets or direct payments. Second, there was also a tendency for carers to spontaneously focus on the services accessed and/or funded for the service user rather than services that they used themselves as carers, even though the questions on service receipt asked carers about all services, both for service users and for carers. Third, there was considerable variation in the carers' understanding of the phrase 'support and services from social services'.

In the final rounds of interviews (CR 20-31), the introduction and definition of support and services, and filter question wording outlined in Section 3.3c were tested. It was found that these improved the comprehension of the filter question and avoided the issue of sensitivity to the phase 'support and services from social services'.

Summary of Changes: As outlined in section 3.3c, the following changes were implemented:

i. The introduction to the ASCOT-Carer interview was adapted to include a clear and comprehensive definition of 'support and services';
ii. The wording of the 'filter' and 'expected' questions were redrafted. The reference to 'support and services from Social Services' was replaced by <u>specific examples</u> of the services and support received by the carer or care recipient (i.e. *'Do the support and services from the* << EXAMPLES, such as Carers' Support group, Day Care Centre, Personal Assistant etc., based on responses to service receipt questions>> *help you to…*'), and;
iii. An interviewer prompt was included for all of the filter questions to define services for each question by giving examples based on the responses to the service receipt questions. The interviewer is guided to include examples of both carer and service user services and, if necessary, to prompt the carer to exclude help from family and friends, or from health care professionals (e.g. GPs, nurses).

2. Some people had difficulty with the filter question as they tended to respond in general (i.e. do support and services *<u>help you</u>*?) rather than with respect to the specific quality of life domain (i.e. do support and services help you *to <u>have time and space to yourself</u>*?) In the interviews, it was found that the comprehension of the questions was supported by the emphasis of the domain definition by the interviewer when asking the filter questions.

Summary of Changes: The training of the interviewers for the IIASC will highlight this finding. The interviews will be guided to place emphasis on the domain (e.g. help you to *<u>do things you value and enjoy)</u>* in the filter questions and asked to note if respondents comment that they have already answered that question before, as this may be an indication that the respondent has not picked up that the question is asking whether services help them to do things they value and enjoy etc. as opposed to whether support and services help them in general.

With these changes to wording and interviewer prompts, the carers were able to understand these questions, formulate a response and justify the reason for whether or not support and services help them with respect to a particular domain of quality of life.

A number of interviews were conducted without the filter questions to test the impact of the questions on comprehension, evaluation and response. It was found that, although there were no comprehension issues, the filter questions did help carers to reflect on how service may or may not impact on a certain aspect of their lives and which services have had an effect. In this way, the filter questions acts as a prime for responses to the 'expected' question. Therefore, it was decided to retain the filter questions for the remaining cognitive interviews and in the ASCOT-Carer INT4 to be used in the IIASC main stage interviews.

Table 5 gives further examples of the justification of the responses to the filter questions which asked carers to indicate whether support and services affected the different domains of quality of life.

Table 5. Why do support and services help the carer (or not) in each ASCOT-Carer INT4 domain?

Domain	Examples of the definition of the 'expected situation'
Occupation: being sufficiently occupied in a range of meaningful, enjoyable activities whether it be formal employment, unpaid work, caring for others or leisure activities.	**Example [CR14]:** The carer felt that the support met the care recipient's needs. However, the care workers who came into the house did not allow her to do things she values and enjoys, as they left a mess behind and she needed to spend time after they had gone cleaning and clearing things away. **Example [CR17]:** Home care enables the carer to go out for one morning a week, either to go shopping or to pursue interests/hobbies. **Example [CR19]:** Home care enables the carer to have the time to pursue her interests in reading and gardening. **Example [CR22]:** Respite care enables the carer to go away for trips and switch off completely, without worrying about safety or potential hazards around the home.
Self-care: feeling able to look after oneself, in terms of eating well and getting enough sleep.	**Example [CR8]:** The service user has a shower chair and other adaptations in the house. The equipment enables the service user to be able to shower unaided. The carer had previously had shoulder and back pain from lifting or pushing the service user, but this had much improved with the availability of new equipment. Likewise, the equipment has enabled the service user to have better mobility, enabling the carer to sleep through the night for longer. **Example [CR12]:** The carer said that without the help and support the service user receives at the moment, from home care, meals on wheels etc., she would have to step in and do more physical care, or perhaps even move in with the service user in order to provide care. The carer said she would feel exhausted and would not be able to sleep properly. **Example [CR19]:** Without the help from home care, the carer said that she would feel overwhelmed and find it difficult to find time for everyday tasks, such as shopping, cooking, and showering. **Example [CR25]:** The support from a carer's organisation helps her to look after herself, as the motivation of days out / trips with the group enables her to make time for herself and to dress as she wants, to do her hair nicely and to put on make-up.
Persnonl safety: feeling safe and secure, where concerns about safety can include fear of abuse or other physical harm or accidents, which may arise as a result of caring.	**Example [CR16]:** The service user has equipment in the bathroom (e.g. handrails and adaptations). The carer spoke of feeling safer, as the equipment reduces the risk of injury from lifting the service user. **Example [CR17]:** The carer felt that the support from home care and a carer's organisation did not help her to feel safe from fear of physical harm, and that there would be no difference in terms of safety if the services were no longer there.

Domain	Examples of the definition of the ‘expected situation’
Social participation and involvement: being content with their social situation, where social situation includes the sustenance of meaningful relationships with friends and family as well as feeling involved and part of their community should they wish to.	**Example [CR15]:** The carer had support from a carer’s organisation, in terms of telephone support or help with filling in paperwork. The carer felt that this support did not help her to have social contact with people she likes; although the carer’s organisation offered day trips and outings, she did not have the time or energy to go on these. **Example [CR17]:** Day care enables the carer to go out and visit friends for the day. Without support and services, the carer would still have some social contact locally, but would not be able to travel to meet with friends. **Example [CR18]:** The carer was involved with a carers’ organisation and had met new people and made friends through support groups, training and social activities organised by the charity.
Control over daily life: choosing what to do and when to do it, and having control over their daily life and activities.	**Example [CR17]:** Home care enables the carer to get out of the house; this enables the carer to feel less tied to being around the house and means that she feels more in control or what she does and when she does it. **Example [CR19]:** The home help, hoist and adaptations around the home mean that the carer does not need to lift the care recipient as often, and reduces the burden of the physicality of care. The carer spoke of feeling tired at the present time, and reasoned that without support and services she would feel too tired to do anything. This would reduce her ability to have control over her daily life.
Feeling encouraged and supported: feeling encouraged and supported by professionals, care workers and others, in their role as a carer.	**Example [CR17]:** The carer felt that the support and services helped her to feel supported and encouraged; without this support she said that she would “*be completely on my own and it would be purely down to me to take care of him”.*
Time and space to be yourself: feeling there is enough time and space to be oneself; to have time free of worries and burdens of caring; to feel able to relax and ‘switch off’.	**Example [CR17]:** The carer said that home care services enable her not only to physically get out of the house, but also to leave the house without continually worrying about the safety of the care recipient. *“I don’t have that constant in the back of my mind, is he alright?”* **Example [CR18]:** The carer felt that social activities and day trips organised by the carers’ organisation helped her to have time for herself and to relax. She spoke of how the organisation is aware of carers’ needs, and would plan ahead so that people had the opportunity to arrange replacement care.

Domain	Examples of the definition of the ‘expected situation’
Relationship with the Care Recipient: feeling able to get on with the care recipient; able to communicate well, and look after them without arguing	**Example [CR6]:** Equipment enables the care recipient to be independent in everyday activities; without the equipment, the carer felt that there would be more strain on the relationship, as the care recipient would need to cooperate with him to enable them to undertake basic everyday activities, such as washing. **Example [CR12]:** The carer felt that support and services do not affect their relationship with the service user; any tensions in the relationship are due to personality differences. **Example [CR17]:** The carer spoke of how day and home care enabled her and the service user to maintain some independence and this helped to sustain their relationship. *“Yes, I think it’s quite essential because being two independent people, both of sound mind…it gives [Care Recipient] an interest (separate) from me and it gives us something that we can talk about, you know”* **Example [CR25]:** The carer spoke of the importance of having time away from the care recipient and out of the house to avoid feeling trapped and to relieve stress that may build up and impact the relationship with the care recipient. *“I would say generally I’d get on okay… because when Crossroads come in. I’m the free woman and the lady that comes in plays cards and games and that with him [the care recipient]-- And they’re quite happy and they--, they’ve got a rapport between them. So I just feel that I’m fine, I can say, “Goodbye, I’ll see you in three hours,” and that’s the difference. That’s why it changes generally, because if we’re locked in the house for 24/7--You’d end up committing hari kari”.*

3.4c. ‘Expected’ Situation: Carer quality of life in the absence of services

The ‘expected’ situation questions ask the respondent to rate their SCRQoL in the imaginary situation that the support and services they currently receive are no longer available and no other help stepped in. Generally, people were able to imagine a situation without any formal services, where this was defined as both services aimed primarily at the service user and carer services, and give a justification why they selected a particular response. They were able to speak of specific examples of the effects of the withdrawal of services on their lives, for example, further restrictions on their daily routine, ability to meet up with friends, or maintain voluntary or paid work. The respondents were also able to describe the impact of a situation without support or services on their health and psychological wellbeing as well as on their relationship with family, friends and the care recipient.

Some carers commented that they were easily able to imagine a situation without any services or support, as this was a situation that they have actually experienced at some point in the past, although the use of a previous experience of being a carer without support or services as a point of reference did lead to the recall of upsetting memories for some carers.

> *"If I think back it was horrendous. Eight months I did it, I nearly killed myself (doing it)". [CR8]*

There were also some interviews where the service user had recently experienced the withdrawal of services or support due to funding cuts. The respondents in these interviews were sensitive to the 'expected' situation questions and found them, in some cases, to be upsetting even with the reassurances that their responses would not impact the support and services they currently receive. The cognitive testing highlights the potential sensitivity of these questions to individuals who are currently, or have recently, experienced the reduction or withdrawal of social care services. The interviewer should discuss the nature of the 'expected' questions carefully with the carer before the interview so they are in a position to judge whether they are in a position to answer these questions without undue distress. The interviewer should take care to note any potential sensitivity to these questions with a view to pausing or terminating the interview if necessary.

Some people found it difficult to imagine a situation without support and services and would indicate that the situation would be the same in the 'expected' as for the 'current' situation because they were confident they would find a way to manage.

> *"Because we're not the sort of people not to do anything about a situation, we're not like that".* [CR11]

The interviewer should emphasise that the carer should assume that no other help would step in when answering the 'expected questions'. The interview schedule was adapted to include the optional prompt to each of the 'expected situation' questions based on the wording from ASCOT INT4 version 2.1.

> INTERVIEWER NOTE: *It is important that people do not base their answers on the assumption that any help steps in, please emphasise this to interviewees.*

The carers' understanding of the 'expected situation' questions was aided by the definition given in the introduction to the interview (see section 3.3c) and was further supported by the adaptation of the wording of the question from that used in ASCOT INT4 version 2.1, from:

'*Support and services from Social Services*' (ASCOT INT4 v2.1) to;

'Support and services from <<EXAMPLES based on responses from service receipt questions, e.g. 'the carers support group, day centre and home care'>>'. (IIASC Carer QOL, based on interviews with CR19 to 30)

3.4c.i. Expected Situation –Additional Informal Care?

During the interviews, it was noted that carers assumed for the 'expected situation' that they would need to step in to help the service user more than they do at the present time. It was decided that it would be useful to have an indication of whether carers were making this assumption and/or a measure of the intensity of the additional informal care in the 'expected' situation as it would be expected that this would affect carers' 'gain' or value added of services. These two additional questions were drafted and tested in later rounds of cognitive interviews (see Appendix A, questions 27 and 28).

The carers did not identify any issues with the comprehension or response to question 27 (i.e. did carers assume that they would *"step in to help the service user more than they do at the moment",* when they were answering the 'expected' questions?). However, the carers found it difficult to quantify the number of additional hours they would spend helping or looking after the service user in the 'expected' situation. Where the service user was receiving home care or day care services, the carers generally approached this question by adding up the number of hours of formal care per week. There were a couple of examples where carers included additional hours to indicate the impact in terms of the additional strain this would put on their psychological wellbeing or the relationship with the service user. Some carers noted that the number of hours care per week would remain the same but the quality of the care they provide would change. For carers of service users who receive less frequent services (e.g. occasional respite care), people noted that they found it difficult to give a response based on a number of hours per week. Due to these issues, it was decided not to include question 28 in the interview for IIASC.

3.4c.ii. Expected Situation – Impact of Services for Carers compared to Services for Service Users

In the first three interviews, carers were asked to rate the impact of services they use themselves compared to the impact of the services aimed at the service user. Although carers were able to describe the services used by the service user separately from the services targeted at themselves as carers, they found it difficult to understand and respond to these questions, which asked them to rate the impact of the carer versus service user services on their outcome for each individual QOL domain[2]. As these questions caused

---

[2] An example of the questions tested, as follows:

Optional – if the carer is receiving services <u>and</u> identifies an impact of services
Just thinking about the support and services from social services that support you as a carer, do *they* help you to have control over your daily life?

significant confusion it was decided to develop and test a single item question (see Appendix A, Question 29) which asks the carer to rate the overall relative impact of carer compared to service user services. Even with this single item, people commented on how it felt unusual to separate the services into 'services for carers' and 'services for the person they look after'.

> *"You know, I find that--, I'm finding that very difficult to separate out" [CR2]*

The carers spoke of an overlap of the impact of these services regardless of whether the service is targeted at the service user or carer. This overlap could be either through the direct impact of the service, for example a care worker who had been employed to look after the service user but had also been a source of support for the carer during a difficult time, or indirectly through the benefit to the service user.

> '*If [the service user] is looked after, then I feel supported and encouraged'. [CR1]*

A further issue was the difference between traditional definitions of services 'for the carer' or 'for the service user' and the carers' own perceptions of service provision. For example, one carer said that she felt that the help from a Personal Assistant purchased through the service user's personal budget was really a service for the her own benefit to alleviate the strain of caregiving [CR2].

A further difficulty was how to define respite or replacement care as it could be seen to be both for the service user or the carer and, although it is typically funded from a service user's social care budget, it is an intervention primarily aimed for the support of carers.

> *"Mind you, I suppose the respite is actually respite for me, so, yes, I didn't think about it like that. So, respite is a break for me, so I suppose that would be something for me wouldn't it?" [CR4]*

The respondents recognised that both carers and the service users can benefit from respite/replacement care although these services are often funded as services 'for' the service user rather than the carer. This creates complexity in the definition of services 'for' the service user or 'for' the carers. Due to these issues, this item will not be included in the interview for the main stage of the IIASC study.

How much would you say they help you to have control over your daily life?

1. More than the services that are provided for the person I look after.
2. About the same as the services that are provided for the person I look after.
3. Less than the services that are provided for the person I look after.
4. SPONTANEOUS - Can't say

4. Conclusion

The work summarised in this report was undertaken during the development phase of the Identifying the Impact of Adult Social Care (IIASC) study. The aims of this work were to:

1. Evaluate the domains in the self-completion Carer QOL instrument included in the Carer Experience Survey 2012/13 (Fox et al, 2010; Malley et al, 2010) in order to develop an interview (ASCOT-Carer INT4) to be used in the main stage of the IIASC project. This evaluation was conducted through a review of the relevant literature, an exploration of theoretical basis of the domains included in the instrument, and by consulting service users, carers, local government and policy representatives. Based on this phase of the project, it was decided to develop and test an additional domain in the ASCOT-Carer INT4 (*Relationship with the Care Recipient*).

2. Establish the feasibility of the ASCOT INT4 method for carers through cognitive interviews with carers (N=31). The cognitive interviews provide evidence that carers are able to understand and respond to these questions (i.e. they are able to judge whether support and services help them with respect to a particular domain of SCRQoL, and to indicate their SCRQoL in the imaginary ('expected') situation that the support and services were no longer available and no other help stepped in). It was found that carers found it difficult to distinguish the impact of services 'for' carers vs. services 'for' service users on their SCRQoL, so the questions ask carers to indicate the impact of social care services for carers as well as services for the person they care for.

The findings of this developmental work will feed into the main stage fieldwork of the IIASC project, a follow-up survey to the Adult Social Care Survey 2012/13. The findings of the cognitive interviews have informed the development of a section of the interview for carers to collect information on social care outcomes (see Appendix A). The qualitative data collected in the interviews will also be used to guide the training of the fieldwork interviewers who will conduct the interviews for the main stage of the study. This training will cover the following key points based on the findings of the cognitive interviews:

1. The definition of social care support and services developed for the IIASC study (see Section 3.3c) should be clearly explained to the respondent. This definition should be used to prompt the respondent during the interview, as needed;
2. The interviewer may need to emphasise that the filter questions are asking whether social care services help the carer (not anyone else) and whether social care services help with respect to a particular domain of SCRQoL (e.g. occupation) rather than 'in general';
3. The ASCOT-Carer QOL may be sensitive as the carers are asked to think about aspects of their lives and experiences of support and services. This may evoke unpleasant or upsetting memories for some carers. The interviewer should carefully

explain the nature of the questions before the interview and reassure the carer that they may pause or stop the interview at any time.

Finally, the qualitative evidence gathered during the cognitive interviews raised some questions to be considered in the analysis of the quantitative data collected in the main stage of the study. For example, the cognitive interviews highlighted the difference in the approaches for estimating the 'expected' SCRQoL for carers (ASCOT-Carer INT4) and service users (ASCOT INT4). The ASCOT INT4 asks service users to rate their 'expected' SCRQoL in the absence of services based on the assumption that no other help would step in. The ASCOT-Carer INT4 also asks carers to assume that no other help would step in but allows carers to assume that they would step in to help the service user more in the 'expected' situation in the absence of social care support/services. It was found that many carers did assume that they would step in to help the service user when answering the 'expected' situation questions.

The difference in definitions of the 'expected' situation for ASCOT INT4 and ASCOT-Carer INT4 can be explained by considering each instrument in isolation. The ASCOT INT4 sets out to measure the overall impact of social care services on SCRQoL to the exclusion of the impact of informal care. This is because not all service users have informal carer(s), so this would introduce a potential confounding effect. Furthermore, by allowing service users to assume that their informal carer(s) would step in to help in the 'expected' situation would reduce the estimate of the impact of social care services on service users' SCRQoL 'gain'. This would risk underestimating the impact of formal social care support and services especially if the impact on the carers' SCRQoL is not considered.

In contrast, the ASCOT-Carer INT4 questions ask carers to assume that they would step in to help the service user in the 'expected' situation without services but that no other help would step in. This enables us to estimate the impact of social care services on the carers SCRQoL; it is a measure of the 'treatment effect' of social care services on carers' outcomes. Because of the differences in methodology, the ASCOT INT4 and ASCOT-Carer INT4 may not simply be combined to give an overall carer-care recipient dyad outcome measure as they are asking the respondents to make different assumptions when rating the 'expected' situation. Even if the ASCOT INT4 questions were adapted to ask the service user to assume that the carer would step in, it may be the case that the carer and care recipient in the dyad may have different understandings of the extent to which the carer would be able to help. In order to further explore these considerations, there are plans to include in the main stage of the IIASC project follow-up interviews with a subsample of 100 service users whose carers have been interviewed for the study. The service users will be asked the ASCOT INT4, adapted to allow the respondent to assume that their carer would step in. The respondents will also be asked some further supplemental questions about the assumptions that they made in answering the 'expected' questions. These additional data will allow us to further explore how respondents answer the 'expected' questions, whether ASCOT INT4 could be adapted into an interview measure that could be used with the ASCOT-Carer INT4 as a measure of combined service user-carer dyad outcome, and to determine the relationship between the two different scenarios.

Finally, the IIASC project should be set in the context of the broader programme of work conducted by the PSSRU/QORU at the University of Kent and LSE on the outcomes of social care. In particular, this project links into the on-going work on the Carer Experience Survey (Fox et al, 2010; Holder et al, 2009) and the Adult Social Care Survey / ASCOT (Netten et al, 2012), and the indicators of social care-related quality of life (SCRQoL) for service users and carers in the Adult Social Care Outcomes Framework (Department of Health, 2012). The question development and testing has led to a number of minor changes to the wording of the Carer QOL instrument which is currently included in the national Carers Experience Survey 2012/13. These changes were based on the qualitative evidence from the 31 cognitive interviews and other strands of development work reported here. Some of the items were also adapted in order to develop an ASCOT-Carer interview tool (INT4) which is comparable to the ASCOT INT4 for service users: for example, the number of response levels has been increased from three to four. This will allow better comparison of outcome information for service users and carers. However, the changes to these questions mean that there may be a discontinuity between the carer SCRQoL data collected for IIASC and the Carer Experience Survey 2012/13. The main stage of the IIASC study will ask a subsample of carers to complete the Carer QOL measure from the Carer Experience Survey, as well as the ASCOT-Carer INT, to map between the two versions and determine any important differences between the two versions. These findings will be fed back into the on-going work on the national Carer Experience Survey which is conducted every two years.

References

General

Ablitt A, Jones GV, Muers J (2009) Living with dementia: a systematic review of the influence of relationship factors, *Aging and Mental Health*, 13, 4, 497-511.

Blake M, Gray M, Balarajan M, Darton R, Hancock R, Henderson C, King D, Malley J, Pickard L Wittenberg R (2010) Social Care for older people aged 65+, questionnaire documentation.

Brooks R (1996) EuroQol: the current state of play, *Health Policy*, 37, 1, 53-72.

Caiels J, Forder J, Malley J, Netten A, Windle K (2010) Measuring the outcomes of low-level services: Final report. Personal Social Services Research Unit Discussion Paper 2699.

Campanelli P, Martin E, Rothgeb J (1991) The Use of Respondent and Interviewer, Debriefing Studies as a Way to Study the Response Error in Survey Data, *The Statistician*, 40, 3, 253-264.

Carver (1997) You want to measure coping, but your protocol is too long: consider the brief COPE, *International Journal of Behavioural Science*, 4, 1, 92-100.

Department of Health (2010), Survey of Carers in Households 2009/10. URL: http://www.ic.nhs.uk/webfiles/publications/009_Social_Care/carersurvey0910/Survey_of_Carers_in_Households_2009_10_England.pdf.

Department of Health (2010), Carers and personalisation: Improving outcomes.

Department of Health (2010), Recognised, valued and supported: Next steps for the Carers Strategy.

Department of Health (2011), Transparency in Outcomes: a framework for adult social care.

Department of Health (2012), *Improving Integration of Services*, Health and Social Care Bill Factsheet C3. URL: http://www.dh.gov.uk/health/2012/02/bill-factsheets/.

Department of Health (2012), Transparency in outcomes: a framework for quality in adult social care. The 2012/13 Adult Social Care Outcomes Framework.

Fayers PM, Hand DJ (1997) Factor analysis, causal indicators and quality of life, *Quality of Life Research*, 6, 139–150.

Fox D, Holder J, Netten A (2010) Personal Social Services of Adult Carers in England 2009-10: Survey development project – Technical Report. PSSRU Discussion Paper No. 2643 (2), Personal Social Services Research Unit, University of Kent.

Gardiner, C., Gott, M., Payne, S., Small, N., Barnes, S., Halpin, D., Ruse, C. & Seamark, D. 2010. Exploring the care needs of patients with advanced COPD: An overview of the literature. Respiratory Medicine, 104, 159-165.

Gaugler JE (2010) The Longitudinal Ramifications of Stroke Caregiving: A Systematic Review, *Rehabilitation Psychology*, 55, 2, 108-125.

Glendinning C, Challis D, Fernandez JL, Jacobs S, Jones K, Knapp M, Mathorpe J, Moran N, Netten A, Stevens M, Wilberforce, M (2008) Evaluation of the Individual Budgets Pilot: Final Report. Social Policy Research Unit, University of York.

Greenwood N, Mackenzie A (2010) Informal caring for stroke survivors: Meta-ethnographic review of qualitative literature, *Maturitas*, 66, 3, 268-276.

Greenwood N, Mackenzie A, Cloud G C & Wilson N (2009) Informal primary carers of stroke survivors living at home-challenges, satisfactions and coping: A systematic review of qualitative studies. Disability and Rehabilitation, 31, 337-351.

Harvey K, Catty J, Langman A, Winfield H, Clement S, Burns E, White S, Burns T (2008) A Review of Instruments Developed to Measure Outcomes for Carers of People with Mental Health Problems, *Acta Psychiatrica Scandinavic,* 117, 3, 164-76.

Holder J, Smith N, Netten A (2009) Outcomes and Quality for Social Care Services for Carers: Kent County Council Carers Survey Development Project 2007-2008. Internal Technical Report (not publicly available). Personal Social Services Research Unit, University of Kent.

Hudson PL, Trauer T, Graham S, Grande G, Ewing G, Payne S, Stajduhar KL, Thomas K (2010) A Systematic Review of Instruments Related to Family Caregivers of Palliative Care Patients, *Palliative Medicine*, 24, 7, 656-68.

Kettunen A (2012) Evaluating outcomes in social care: Experiences from home care and care homes, 8th International Conference on Evaluation for Practice.
URL: http://www.ucpori.fi/linkkitiedosto.aspx?taso=2&id=962&sid=1165

Kitrungrote L, Cohen MZ (2006) Quality of life of family caregivers of patients with cancer: A literature review, *Oncology Nursing Forum,* 33, 3, 625-632.

Madsen K, Poulsen HS (2011) Needs for everyday life support for brain tumour patients' relatives: systematic literature review, *European Journal of Cancer Care (Engl)*, 20, 1, 33-43.

Malley J, Fox D, Netten A (2010) Developing a Carers' Experience Performance Indicator. PSSRU Discussion Paper No. 2734, Personal Social Services Research Unit, University of Kent

Malley J, Towers A-M, Netten AP (2011). Measuring Social Care-Related Quality of Life. PSSRU Discussion Paper No. 2751, Personal Social Services Research Unit, University of Kent

Malley J, Towers A-M, Netten AP, Brazier JE, Forder JE, Flynn T (2012) An assessment of the construct validity of the ASCOT measure of social care-related quality of life with older people, *Health and Quality of Life Outcomes*, 10, 21

Mockford C, Jenkinson C & Fitzpatrick R (2006) A review: Carers, MND and service provision. *Amyotrophic Lateral Sclerosis*, 7, 132-141.

Moore S, Darlison L & Tod A M (2010) Living with mesothelioma. A literature review. *European Journal of Cancer Care*, 19, 458-468.

Netten AP, Burge P, Malley J, Potoglou D, Towers AM, Brazier B, Flynn T, Wall J (2012). Outcomes of social care for adults: developing a preferences weighted measure, *Health Technology Assessment,* 16, 16.

Netten AP (2011) Overview of outcome measurement in social care, Personal Social Services Research Unit, University of Kent.

Nicholson KA (2009). Carers' narratives: Finding dementia with Lewy bodies experiences, *Australasian Journal on Ageing*, 28, 4, 177-181.

Quinn C, Clare L, Woods RT (2010) The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review, *International Psychogeriatrics*, 22, 1, 43–55

Qureshi H, Patmore C, Nichols E, Bamford C (1998) Outcomes in Community Care Practise. Overview: Outcomes of Social Care for Older People and Carers, Social Policy Research Unit, University of York, York.

Reed SI (2008) First-episode psychosis: A literature review, *International Journal of Mental Health Nursing*, 17, 2, 85-91.

Sarason IG, Levine HM, Basham RB, Sarason BR (1983). Assessing social support: the Social Support Questionnaire, *Journal of Personality and Social Psychology*, 44, 127–39.

Schulz R, Beach SR (2009) Caregiving as a risk factor for mortality, *Journal of the American Medical Association*, 282, 2215–2219.

Smerglia V L, Miller N B, Sotnak D L & Geiss C A (2007) Social support and adjustment to caring for elder family members: A multi-study analysis. *Aging and Mental Health*, 11, 205-17.

Sowmini CV, De Vries R (2009) A cross cultural review of the ethical issues in dementia care in Kerala, India and The Netherlands, *International Journal of Geriatric Psychiatry*, 24, 4, 329-334.

The EuroQol Group (1990) EuroQol-a new facility for the measurement of health-related quality of life. *Health Policy,* 16(3), 199-208.

Willis, G (2005). Cognitive Interviewing: A Tool for Improving Questionnaire Design. Sage, London.

Zarit SH, Reever KE, Bach-Peterson J (1980) Relatives of the impaired elderly: correlates of feeling of burden, *The Gerontologist* 20, 649–55

Zegwaard MI, Aartsen MJ Cuijpers, P. & Grypdonck, M. H. (2011) Review: a conceptual model of perceived burden of informal caregivers for older persons with a severe functional psychiatric syndrome and concomitant problematic behaviour, *Journal of Clinical Nursing*, 20, 15-16, 2233-2258.

Literature review – Carers' quality of life (N=33)

Ablitt A, Jones GV, and Muers J. (2009) Living with dementia: a systematic review of the influence of relationship factors, *Aging and Mental Health*, 13, 4, 497-511.

Bauer M, Fitzgerald L, Haesler E & Manfrin M (2009) Hospital discharge planning for frail older people and their family. Are we delivering best practice? A review of the evidence. *Journal of Clinical Nursing*, 18, 2539-46.

Del-Pino-Casado R, Frias-Osuna A, Palomino-Moral P A & Pancorbo-Hidalgo P L (2011) Coping and subjective burden in caregivers of older relatives: a quantitative systematic review. *Journal of Advanced Nursing*, 67, 2311-22.

Forder JE, Caiels J (2011) Measuring the Outcomes of Long-term Care, *Social Science& Medicine*, 73, 1766-1774.

Gardiner, C., Gott, M., Payne, S., Small, N., Barnes, S., Halpin, D., Ruse, C. & Seamark, D. 2010. Exploring the care needs of patients with advanced COPD: An overview of the literature. Respiratory Medicine, 104, 159-165.

Gaugler JE (2010) The Longitudinal Ramifications of Stroke Caregiving: A Systematic Review, *Rehabilitation Psychology*, 55, 2, 108-125.

Gottlieb BH, Wolfe J (2002) Coping with family caregiving to persons with dementia: a critical review, *Aging and Mental Health*, 6, 4, 325-342.

Greenwood N, Mackenzie A (2010) Informal caring for stroke survivors: Meta-ethnographic review of qualitative literature, *Maturitas*, 66, 3, 268-276.

Greenwood N, Mackenzie A, Cloud G C & Wilson N (2008) Informal carers of stroke survivors - factors influencing carers: A systematic review of quantitative studies. *Disability and Rehabilitation*, 30, 1329-1349.

Greenwood N, Mackenzie A, Cloud G C & Wilson N (2009) Informal primary carers of stroke survivors living at home-challenges, satisfactions and coping: A systematic review of qualitative studies. Disability and Rehabilitation, 31, 337-351.

Hancock K, Clayton J M, Parker S M, Wal Der S, Butow P N, Carrick S, Currow D, Ghersi D, Glare P, Hagerty R & Tattersall M H (2007) Truth-telling in discussing prognosis in advanced life-limiting illnesses: a systematic review. *Palliative Medicine*, 21, 507-17.

Harden J (2005) Developmental life stage and couples' experiences with prostate cancer: a review of the literature, *Cancer Nursing*, 28, 2, 85-98.

Harmell A L, Chattillion E A, Roepke S K & Mausbach B T (2011) A Review of the Psychobiology of Dementia Caregiving: A Focus on Resilience Factors. *Current Psychiatry Reports*, 13, 219-224.

Kang, X. F., Z. Li, et al. (2011). Informal Caregivers' Experiences of Caring for Patients With Chronic Heart Failure Systematic Review and Metasynthesis of Qualitative Studies. *Journal of Cardiovascular Nursing*, 26(5), 386-394.

Kitrungrote, L. and Cohen, M. Z. (2006). Quality of life of family caregivers of patients with cancer: A literature review. *Oncology Nursing Forum,* 33(3), 625-632.

Lee, D. R. and Thomas, A. J (2011). Sleep in dementia and caregiving--assessment and treatment implications: a review. *International Psychogeriatrics*, 23(2), 190-201.

Madsen, K. and Poulsen, H. S. (2011). Needs for everyday life support for brain tumour patients' relatives: systematic literature review. *European Journal of Cancer Care (Engl)*, 20(1), 33-43.

McKenzie, S. J., D. McLaughlin, et al. (2010). Urban-rural comparisons of outcomes for informal carers of elderly people in the community: A systematic review. *Maturitas*, 67(2), 139-143.

McKeown, L. P., A. P. Porter-Armstrong, et al. (2003). The needs and experiences of caregivers of individuals with multiple sclerosis: a systematic review. *Clinical Rehabilitation,* 17(3), 234-248.

Mockford, C., C. Jenkinson, et al. (2006). A review: Carers, MND and service provision. *Amyotrophic Lateral Sclerosis*, 7(3), 132-141.

Molloy, G. J., Johnston, D. W., et al. (2005). Family caregiving and congestive heart failure. Review and analysis. *European Journal of Heart Failure*, 7(4), 592-603.

Moore, S., L. Darlison, et al. (2010). Living with mesothelioma. A literature review. *European Journal of Cancer Care*, 19(4), 458-468.

Nicholson, K. A. (2009). Carers' narratives: Finding dementia with Lewy bodies experiences. *Australasian Journal on Ageing*, 28(4), 177-181.

Ogilvie, A. D., N. Morant, et al. (2005). The burden on informal caregivers of people with bipolar disorder. *Bipolar Disorders*, 7, 25-32.

Pringle, J., C. Hendry, et al. (2008). A review of the early discharge experiences of stroke survivors and their carers. *Journal of Clinical Nursing*, 17(18), 2384-2397.

Reed, S. I. (2008). First-episode psychosis: A literature review. *International Journal of Mental Health Nursing*, 17(2), 85-91.

Salter, K., Zettler, L., et al. (2010). Impact of caring for individuals with stroke on perceived physical health of informal caregivers. *Disability and Rehabilitation*, 32(4), 273-281.

Schoenmakers B, Buntinx F & Delepeleire J (2010) Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas*, 66, 191-200.

Smerglia V L, Miller N B, Sotnak D L & Geiss C A (2007) Social support and adjustment to caring for elder family members: A multi-study analysis. *Aging and Mental Health*, 11, 205-17.

Sorensen S, Duberstein P, Gill D & Pinquart M (2006) Dementia care: mental health effects, intervention strategies, and clinical implications. *Lancet Neurology*, 5, 961-973.

Sowmini CV, De Vries R (2009) A cross cultural review of the ethical issues in dementia care in Kerala, India and The Netherlands, *International Journal of Geriatric Psychiatry*, 24, 4, 329-334.

Stenberg U, Ruland CM, & Miaskowski, C (2010) Review of the literature on the effects of caring for a patient with cancer, *Psycho-Oncology*, 19, 10, 1013-1025.

Williams AL, McCorkle R (2011) Cancer family caregivers during the palliative, hospice, and bereavement phases: a review of the descriptive psychosocial literature, *Palliative Support and Care*, 9, 3, 315-325.

Zegwaard MI, Aartsen MJ Cuijpers, P. & Grypdonck, M. H. (2011) Review: a conceptual model of perceived burden of informal caregivers for older persons with a severe functional psychiatric syndrome and concomitant problematic behaviour, *Journal of Clinical Nursing*, 20, 15-16, 2233-2258.

Literature review – Carers' quality of life instruments (N=4)

Harvey K, Catty J, Langman A, Winfield H, Clement S, Burns E, White S & Burns T (2008) A review of instruments developed to measure outcomes for carers of people with mental health problems. *Acta Psychiatrica Scandinavica*, 117, 164-176.

Hudson P L, Trauer T, Graham S, Grande G, Ewing G, Payne S, Stajduhar K I & Thomas K (2010) A systematic review of instruments related to family caregivers of palliative care patients. *Palliative Medicine*, 24, 656-668.

Moniz-Cook E, Vernooij-Dassen M, Woods R, Verhey F, Chattat R, De Vugt M, Mountain G, O'connell M, Harrison J, Vasse E, Droes R M & Orrell M (2008) A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging and Mental Health*, 12, 14-29.

Rombough R E, Howse E L, Bagg S D & Bartfay W J (2007) A comparison of studies on the quality of life of primary caregivers of stroke survivors: A systematic review of the literature. *Topics in Stroke Rehabilitation*, 14, 69-79.