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Measuring and applying the social care outcomes
of service users and their carers

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Abstract

In this thesis, I present a narrative that describes and analyses the shifts in outcomes-based social care policy in England over the past decade. In the UK, adult social care refers to a range of long-term care support services, including home care and residential care. The thesis focuses on two broad themes: (1) the measurement of individual quality of life as an outcome of social care support. This includes individual quality of life of people who use social care services, and their carers. (2) The application of social care outcomes to inform policy and practice.

The thesis comprises a selection of my published work from the PSSRU, University of Kent, over the past eight years. This research builds upon the initial development of the Adult Social Care Outcomes Toolkit (ASCOT) by PSSRU colleagues. ASCOT is the only measure specifically designed to capture the quality of life outcomes of social care support. It was initially developed for use with older adults. My work contributes further knowledge of the measurement of outcomes of younger adults (<65 years) and those with mental health problems, as well as carers' outcomes. It also develops a range of approaches to the application of social care outcome data to inform policy and practice. This includes the potential use of outcomes data in secondary analysis of national-level datasets and other survey data, of the value of considering carer/care-recipient outcomes together (as 'dyads'), and also the potential to translate and cross-culturally adapt the tools to inform the development of policy and practice in other countries – specifically here, in Japan.

The thesis examines the potential value of measuring and applying social care outcomes to inform decision-making (e.g. evaluation studies) and practice (e.g. needs assessment). There are, however, also limitations due to a range of practical, organisational, structural, financial and cultural differences in adult social care, compared to healthcare.

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Background

The measurement and application of adult social care outcomes¹ in England has emerged as part of a wider trend to apply the principles of outcomes-based policy and management in public services. Under the UK Conservative and Liberal Democrat coalition government, there was a continuity with the development of an outcomes-based approach in social care under the previous Labour administration. There were also two key conceptual shifts in that transitional period that still broadly apply to the social policy landscape today: (1) the measurement of individual quality of life outcomes; and (2) the application of outcomes data to inform decision-making and accountability for public spending. These two broad shifts will be briefly introduced before then outlining how the published works in this thesis contribute to knowledge in both of these areas.

Measuring individual quality of life outcomes

The social care policy agenda under the Conservative-Liberal Democrat Coalition sought to focus on individual outcomes. The aim was to move away from a social care system led by services and their delivery, with measurement of process outcomes (e.g. the units of care provided) as a way of understanding the effectiveness of the system. Instead, there was a renewed focus on the overall aim or outcome of social care services to promote and improve *quality of life* [1]. This was informed by the wider personalisation agenda. However, the extent to which this refocus from a process-driven to a person-centred perspective has been achieved is a contentious issue (for example, [2, 3]). Nevertheless, it has been an influential concept in policy and strategic oversight of the social care system in England: for example, it informed the **Adult Social Care Outcomes Framework (ASCOF)** in England, which was introduced in 2011/12 and is still in place to-date [4, 5].

The ASCOF is a set of outcome indicators. These are designed to capture the social care system's performance on a national level, as well as to support benchmarking of performance regionally and to support, guide and influence local decision-making by local authorities in strategic planning, oversight and commissioning [4, 5]. The ASCOF was developed through consultation with representatives from the public, local authorities,

¹ In the UK, adult social care (also known as long-term care) refers to personal care and other forms of assistance. The majority of care in the UK is provided informally, by family members, partners or friends, but there are also formal social care services (e.g. home care, residential care homes). The services may be privately purchased by people with support needs or their families. There is also a publicly-funded social care system in England, which is administered by local authorities with adult social care responsibilities.

professional bodies, private and voluntary sector care providers, service users and carers between November 2010 to February 2011. The framework includes a range of outcome indicators in four key areas: (1) enhancing quality of life of people with care support needs and their carers (*individual quality of life outcomes*); (2) delaying and reducing the need for care (*prevention*); (3) ensuring people have a positive experience of care (*user/carer experience*); and (4) safeguarding adults [5] (see Box 1).

Box 1. ASCOF Indicators related to the Adult Social Care Outcomes Toolkit (ASCOT) [5]

1. Enhancing quality of life of people with care support needs and their carers

Indicator 1A. Social care-related quality of life

Indicator 1B. Proportion of service users who say they have as much control over daily life as they would like

Indicator 1D. Carer social care-related quality of life

Indicator 1I. Proportion of service users and carers who say they have as much social contact as they would like

Indicator 1J. Adjusted Social care-related quality of life

2. Delaying and reducing the need for care

3. Ensuring people have a positive experience of care

4. Safeguarding adults

Indicator 4A. Proportion of service users who feel safe

One of the indicators in the ASCOF, the overarching care-related quality of life measure for service users (ASCOF 1A), is the **Adult Social Care Outcomes Toolkit (ASCOT)** [6]. The ASCOT is a suite of quality of life instruments designed to capture the SCRQoL of people who use social care services and their carers² (see Box 2). It has been developed by a research team at the Personal Social Services Research Unit (PSSRU) at the University of Kent, led initially by Professor Ann Netten. The initial ASCOT development work was completed before I joined the PSSRU in January 2012, as part of the *Outcomes of Social Care for older Adults*

² In this thesis, the term *carer* is used to describe someone who looks after a family member, partner or friend, who needs help because of illness, frailty, disability or mental health problem, and cannot cope without support. The focus of this thesis is *adult carers*, aged 18 years or older.

(OSCA) project [6]. This project focussed on the feasibility, acceptability and psychometric properties of the ASCOT instrument with older adults who used community-based social care services [6, 7].

Since the introduction of the ASCOF in 2011/12, the Adult Social Care Outcomes Toolkit self-completion questionnaire (ASCOT SCT4, see Box 2) has been included in the Adult Social Care Survey (ASCS) in England. The ASCS is an annual survey of publicly-funded adult social care service users in England. The ASCS sample is limited to adults who have received support for social care services after an assessment of need by the local authority. It does not include self-funders, who privately purchase care and support services, equipment or assistive technology without an assessment. The sample includes adults (aged 18 years or over), who use community-based and/or nursing or residential care, and who need support due to learning disability, mental health problems, sensory impairment, physical disability, frailty or addiction [8]. The survey is conducted by local authorities in England and overseen by NHS Digital [8]. The ASCS questionnaire includes items to capture the characteristics, needs and experiences of people who use social care services, alongside the ASCOT SCT4. The ASCOT SCT4 questionnaire has nine items that cover eight SCRQoL attributes: *Control over daily life, Occupation, Social participation and involvement, Personal safety, Personal comfort and cleanliness, Accommodation comfort and cleanliness, Food and drink, and Dignity*. Of these, the scores for three items are reported separately as standalone ASCOF Indicators 1B, 1I and 4A (see Box 1). The scores for each item may be combined to generate the overall SCRQoL score (Indicator 1A, see Box 1).

Box 2. The ASCOT suite of instruments (www.pssru.ac.uk/ascot)

ASCOT SCT4 (care-recipient, self-completion)

ASCOT INT4 (care-recipient, interview)

ASCOT CH3 (care-recipient, mixed methods, for use in care homes)

ASCOT-Carer SCT4 (carer, self-completion)

ASCOT-Carer INT4 (carer, interview)

ASCOT-ER SCT4 (care-recipient, 'Easy-Read' for people with learning disabilities, self-completion)

ASCOT-Proxy SCT4 (care-recipient, proxy report by carers, self-completion version) *

*This instrument is in development. It is only available as a beta version, by request.

The ASCOF also includes a corresponding measure of carers' social care-related quality of life (the Carer SCRQoL - Indicator 1D, see Box 1) [6]. This measure is included in the Survey of Adult Carers in England (SACE), again conducted by local authorities and overseen by NHS Digital, although every two years rather than annually. The Carer SCRQoL was also developed by researchers at the PSSRU, University of Kent, as part of a study conducted in 2009/10 [9, 10]. Four of the Carer SCRQoL domains overlap with the ASCOT SCT4: *Control over daily life, Social participation and involvement, Occupation, Personal safety*. There are three additional carer-specific domains: *Feeling supported and encouraged, Self-care and Space and time to be myself*. In discussions with other stakeholders from the Department of Health and Social Care, NHS Digital and local authorities, it was decided that the last of these domains (*Space and time to be myself*) should be omitted, despite the evidence of its importance, content validity, acceptability and good psychometric properties in qualitative interviews followed by a survey of carers [9, 10]. Therefore, the ASCOF includes the score from a single item (*Social participation and involvement, ASCOF 1I, see Box 1*) and also the overall score from the six-item questionnaire included in the SACE (ASCOT 1D, see Box 1).

Along with the other ASCOF indicators (from the ASCS, SACE or other sources), these data are analysed and reported by NHS Digital as annual publicly-available ASCOF metrics. The inclusion of the ASCOT and Carer SCRQoL individual measures of quality of life, self-reported by service users and carers, in the ASCOF is significant, as it represents a shift away from the measurement and reporting of process outcomes, towards focussing on the quality of life outcomes of social care. The aim is to measure the effectiveness of services, not in terms of what the service-focussed outputs of day-to-day processes or tasks (e.g. hours of care, number of beds), but rather based on the extent to which services improve the *quality of life* of individuals by responding to their support needs and personal preferences [1].

[Using outcomes data for accountability and decision-making](#)

The second conceptual shift under the Coalition Government was from the top-down monitoring of performance (as advocated by the preceding Labour government) to a narrative of data collection and application to: (1) empower communities to hold local authorities to account and also to shape their choice(s) in a way that would drive quality improvement by fostering local care markets; and (2) to give local authorities the freedom

and responsibility to use data to shape local decision-making [4]. In practice, there have been significant challenges in realising these aims.

The use of national social care data collections to empower communities and promote a culture of accountability has been limited by the lack of transparency and detail. The publicly-reported ASCOF data is reported at the local authority level. It is difficult to use the data to promote accountability when it does not provide more detailed granularity into the potential areas for improvement within the local system. Indeed, this has even been cited by local authorities as a limitation of the dataset for use internally, even though they could potentially link the data with other sources to aid interpretation and application [11]. Also, as the data is not available or reported by care provider, it is not possible to use such data to shape public, user or carer choice (in terms of market choice) as this is exercised at the level of the care provider (if at all). In reality, there is only one local authority for each area, so the public, users and carers are not able to exercise choice at this level, unless there were willing and able to move to another area on the basis of care quality. This is not a serious possibility for many adults who use publicly-funded social care. Another challenge is that there may be limited formal structures and processes through which service users, carers and local communities may hold local authorities to account. Whilst there are independent and/or user-led organisations, like Healthwatch with its network of local organisations, that seek to support, organise and advocate on behalf of people who use health and social care services, and also there is a wider emerging culture of more *ad hoc* or localised user involvement in service planning and delivery, the way(s) in which this involvement is able to hold local authorities to account is very dependent on local implementation and structures set up by the local authority to engage with these groups.

There are also a number of challenges of using the data to inform decision-making and strategy at the local authority level, to guide decision-making within the organisation. This includes the lack of specialist skills and in-house knowledge in many local authorities to analyse, interpret and apply the data effectively in commissioning or other key strategic decisions [11]. One of the key technical challenges in interpreting and applying outcomes data to drive quality improvement is the *attribution problem*. This relates to whether and how changes in outcomes may be due to the effectiveness of policy and practice-based interventions, rather than other factors [12]. To address this issue within the ASCOF, there

has been work to develop an adjusted care-related user measure (ASCOT 1J, see Box 1), which is an estimate of the impact of services that excludes non-social care-related related factors [13, 14]. However, this approach is an averaged adjustment method that is designed for data collected from large-scale surveys, rather than individual or small sample data [13, 14]. This limits its usefulness in application by local authorities in any analysis of their data, by comparison to the collated national dataset analysed by NHS Digital.

Despite these limitations, there is emerging potential for the use of social care outcome instruments in other ways. While healthcare decision-making and policy is often informed by outcomes-based evidence, it is far less common in social care. This is partly due to the lack of suitable outcomes instruments, which is one of the issues addressed by the development of the ASCOT, and also due to the relative lack of funding for research in social care compared to health care. More recently, however, there has been interest in using these measures to evaluate the impact of policy or practice-based interventions: for example, individual or personal health budgets [15–19], the Shared Lives scheme with older adults [20] or specialist nursing support for carers of people with dementia [21]. There is also interest in applying social care outcome measures directly within practice. This includes use of social care outcome measures for internal monitoring by care providers through internally-driven vision rather than an imposition from external parties (e.g. commissioners) or in care needs assessment, as a way of embedding a focus on outcomes throughout the process [22].

The application of the ASCOT social care outcome measures have been, so far, primarily in England, which is where the instruments were initially developed. However, there has been ongoing research to translate and/or culturally adapt the ASCOT and ASCOT-Carer for use in other contexts, including Japan, Austria, Finland, the Netherlands and Australia [23–26]. There has also been consideration of whether the ASCOT measures could be included in national data collections in Northern Ireland and Scotland. (This is at the stage of initial enquiry with Scotland, and pilot data collection for Northern Ireland.)

Aims and objectives

In this thesis, I present a number of published works from the past decade that relate to (1) the measurement of individual quality of life outcomes for service users and carers and also (2) applying social care outcomes to inform social care policy and practice. These outputs have been undertaken as part of my ongoing employment since January 2012 at the PSSRU, University of Kent. The material in this submission (see Table 1) includes original empirical fieldwork using qualitative and quantitative methods, literature review and secondary data analysis. Of these, there are eight peer-reviewed journal articles and one non-peer reviewed published *Debates and Issues* paper ([25], **submitted text 6**). These papers are introduced and summarised in Table 1 below.

The submission draws together work that addresses the following research questions under the two broad themes of measuring and using social care outcomes, as introduced in the *Background* section:

Theme 1: Measuring individual quality of life outcomes in social care

Research Question 1a. Is ASCOT a feasible, valid and reliable measure of social care-related quality of life for adults, aged 18 to 64 years, and with support needs related to mental health problems?

In the development of the ASCOT SCT4, the focus was on the use of the measure with older adults. There was an evidence gap in whether it is a feasible, valid and reliable measure of SCRQoL for adults aged under 65 years and also with mental health-related care needs. In response, my research sought to establish the measure's psychometric properties in a sample of community-based social care service users, including adults aged 18 to 64 years and with mental health problems (**submitted text 3**).

Research Question 1b. Is the ASCOT-Carer a feasible, valid and reliable measure of carers' social care outcomes?

The Carer SCRQoL measure (Indicator 1D, see Box 1) was based on an early version of the ASCOT. This instrument had only three levels of response for each item that corresponded to: ideal state (best QoL), some needs, high-level needs (worst QoL). At the roll-out of the

ASCOF in 2011/12, the ASCOT had already been developed to include a fourth level of response (no needs) to improve its sensitivity and response distributions [6]. The Carer SCRQoL, however, still only had a three-level response version at its inclusion in the ASCOF 2011/12. My research sought to establish whether the Carer SCRQoL (Indicator 1D) could be adapted into a feasible, valid and reliable four-level response version (the ASCOT-Carer) administered as a self-completion version (SCT4) or interview (INT4) that mirrors the ASCOT SCT4 (ASCOF Indicator 1A) (**submitted texts 1 and 2**, supplemented by the full technical report for the study [27]). The aim of this research was to develop a version of the measure that could eventually replace the Carer SCRQoL in the SACE and/or be used in social care research alongside, or separately from, the ASCOT SCT4 or INT4 (see Box 2).

Theme 2: Using social care outcomes data to inform policy and practice

Research Question 2. How does the ASCOT-Carer, and the concept of carers' SCRQoL, inform our understanding of: (1) the effectiveness of services (i.e. their impact on carers' QoL); and (2) the experience of social care services from the carers' perspective?

Submitted texts 4 and 5 address the question of how the concept of carers' social care-related quality of life may be applied to understand both carers' experience of social care support and also the effectiveness of that support in addressing unmet quality of life needs. There is also exploration of the how the ASCOT-Carer measure of carers' social care-related quality of life may be translated and culturally adapted for use as an assessment tool in Japan (**Submitted text 6**).

Research Question 3. What are the non-social care-related factors associated with social care-related quality of life?

The analysis of individual-level social care outcomes data may be used to understand the non-social care-related factors associated with outcomes (**submitted texts 7 and 8**). These relationships may support the interpretation of large scale data collections (for example, in adjusting out the influence of non-care-related factors when comparing over time) and/or may be important in analyses that seek to understand the wider impact of health-, housing- or individual motivational factors on social care outcomes.

Research Question 4. Are the social care-related quality of life outcomes of service users and carers interdependent?

By focussing on the measurement of social care-related quality of life, whether of service users or carers, there is a tendency to look at impact of services on individuals. However, the quality of life outcomes of care-recipients and carers may be related due to shared external factors (e.g. housing), the influence of one person's characteristics on the other (e.g. level of disability), and/or mutually interdependent via the relationship between carer and care-recipient. **Submitted article 9** explored whether and how the SCRQoL of service users and carers 'dyads' are related and/or mutually interdependent, and discusses the implications for the use of social care outcomes data in policy and practice.

Table 1. Publications included in the submission

Text No.	Theme¹	Research Question¹	Publication	Responsibility	Description
1	1	1b	Rand S, Malley J, Forder J, Netten A (2015) Factor Structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer), <i>Quality of Life Research</i> , 24(11), 2601-2614. https://kar.kent.ac.uk/48181/	Lead author; conducted analysis	Quantitative analysis of survey data collected in the second phase of the IIASC study to establish the feasibility and psychometric properties of the ASCOT-Carer.
2	1	1b	Rand S, Malley J, Vaden F, Forder J (2019) Measuring the outcomes of long-term care for unpaid carers: Comparing the EQ-5D-3L, the Carer Experience Scale and ASCOT-Carer INT4, <i>Health and Quality of Life Outcomes</i> , 17(184). https://kar.kent.ac.uk/78980/	Lead author; conducted analysis	Quantitative analysis of survey data collected from the IIASC study to compare three outcome instruments that may be used to evaluate social care interventions for carers (i.e. the EQ-5D, ASCOT-Carer and Carer Experience Scale).
3	1	1a	Rand S, Malley J, Towers A, Netten A, Forder J (2017) Validity and test-retest reliability of the self-completion adult social care outcomes toolkit (ASCOT-SCT4) with adults with long-term physical, sensory and mental health conditions in England, <i>Health and Quality of Life Outcomes</i> , 15(163). https://kar.kent.ac.uk/62602/	Lead author; conducted analysis	Quantitative analysis of survey data collected in the second phase of the IIASC study to establish the feasibility and psychometric properties of the ASCOT for a diverse sample of social care service users, including younger adults with long-term mental or physical health conditions.
4	2	2	Rand S, Vadean F, Forder J (2020) The impact of long-term care on carers' quality of life, <i>International Journal of Care and Caring</i> , 4(2), 235-259. https://kar.kent.ac.uk/77517/	Lead author; conducted analysis	Mixed methods analysis of data collected in IIASC (phase one and two) to identify the ways in which services may affect carers' QoL using a novel method ('counterfactual self-estimation').
5	2	2	Rand S, Malley J (2014) Carers' quality of life and experiences of adult social care support in England, <i>Health and Social Care in the Community</i> , 22(4), 375-385. https://kar.kent.ac.uk/37735/	Lead author; conducted analysis	Qualitative analysis of the first stage of the IIASC study to explore the definition(s) of services 'for' carers, challenges and barriers to carers' access to support and the meaning of informal care.

Text No.	Theme ¹	Research Question ¹	Publication	Responsibility	Description
6	2	2	Yamaguchi M, Rand S (2019) Issues and Challenges in comparing Carers' Quality of Life in England and Japan: Findings from the Japanese translation of ASCOT-Carer, <i>International Journal of Care and Caring</i> , 3(3), 459-464. https://kar.kent.ac.uk/73640/	Co-author	A debates and issues paper (not peer reviewed) on cross-cultural considerations in the translation of the ASCOT-Carer measure into Japanese.
7	2	3	Rand S, Malley J, Forder J (2019) Are reasons for caregiving related to carers' care-related quality of life and strain? Evidence from a survey of carers in England, <i>Health and Social Care in the Community</i> , 27(1), 151-160. https://kar.kent.ac.uk/67575/	Lead author; conducted analysis	Quantitative analysis of survey data collected in the second phase of the IIASC study to determine whether and how different reasons for providing care are related to carer strain and care-related QoL. The implications of the findings are framed within the wider context and policy, especially the narrative of choice and control within personalisation.
8	2	3	Rand S & Malley J (2017) The factors associated with care-related Quality of Life of adults with Intellectual Disabilities in England: Implications for Policy and Practice, <i>Health and Social Care in the Community</i> , 25(5), 1607-1619. https://kar.kent.ac.uk/51951/	Lead author; conducted analysis	Quantitative analysis of the Adult Social Care Survey (ASCS) data collected from adults with learning disability to determine the (non social care-related) factors related to social care-related QoL.
9	2	4	Rand S, Forder J, Malley J (2017) A study of dyadic interdependence of control, social participation and occupation of adults who use long-term care services and their carers, <i>Quality of Life Research</i> , 26(12), 3307-3321. https://kar.kent.ac.uk/62381/	Lead author; conducted analysis	Quantitative analysis of survey data collected from service user/carer dyads as part of the second phase of the IIASC study to explore the interdependence of QoL within caregiving dyads.

¹ Themes: (1) Measuring individual quality of life outcomes in social care; (2) Using social care outcomes data to inform policy and practice. Please refer to the Aims and Objectives section for full details of the research questions.

Methods

Before exploring these themes and the related research questions in more detail, the methods of data collection, analysis and design of the empirical studies from which the data were drawn will be briefly outlined in this section. The research presented here is primarily applied empirical research using qualitative and quantitative approaches that relates to social care policy, administration and practice, rather than theory-driven. The work relates to a number of distinct research projects, which will be briefly outlined below with regard to their design, sampling and analytical strategy.

Identifying the Impact of Adult Social Care (Phase One)

The first phase on the *Identifying the Impact of Adult Social Care* (IIASC) study (**submitted texts 4 and 5**) was funded by the Department of Health and Social Care (DHSC) an extension to the Quality and Outcomes of person-centred care policy Research Unit (QORU). The first phase of the project was conducted between January and December 2012. The aim was to develop an equivalent measure of carers' social care-related quality of life to the ASCOT that would be used in the Phase Two survey data collection. This study expanded on earlier work to develop the questionnaire items for the Survey of Adult Carers in England (SACE) [9]. Of the draft questionnaire items, seven were identified to form a measure of carer social care-related quality of life [10]. The SACE only includes six of these seven items. These items only have three levels of response for each item, compared to four response levels for the final version of ASCOT [6], and also differ slightly from the ASCOT. Therefore, this study sought to establish the acceptability, face validity and comprehension of revised items that: (1) had four-levels of response; (2) more closely reflected the final wording and format of the ASCOT; and also (3) had an interview format that uses a counterfactual self-estimation method to ask respondents to self-report the impact of social care services on their social care-related QoL [6, 28]. The study considered all seven of the items identified in the early development work for the SACE [9, 10].

Design and sampling

A total of 31 qualitative interviews were conducted with 31 carers from three local authorities in England. These were selected to represent different geographic regions (one Southern, two Northern) and also rural, urban (metropolitan) and suburban areas. The participating local authorities sent a study information pack on behalf of the research team

to 98 carers known to adult social service departments. In addition, carers organisations in two of the three local authorities also distributed study information to the carers who accessed their services.

The study inclusion criteria were: aged 18 years or over; caring for a spouse/partner, relative or friend with a physical disability or health condition, sensory impairment, mental health condition and/or learning disability; and able to understand spoken or written English and communicate fluently in English. (The latter requirement was specified as we were developing an English language version of the questionnaire without translation or cultural adaptation at this stage).

A draft version of the ASCOT-Carer INT4 questionnaire was developed and used as the basis for the interviews [27]. The interviews used cognitive interviewing method of 'think aloud' with follow-up probes to establish whether the respondents were able to understand the questions, weigh up the different response options and make a response [29]. The sample size was determined by allowing up to three rounds of up to ten interviews [29]. In addition, the interviews also probed as to whether other aspects of quality of life had been affected by caregiving and also the carers' experience of social care support and its impact on QoL.

The study was reviewed and approved by the Social Care Research Ethics Committee in England (Reference: 12-IEC08-0009). Local research governance processes were also followed for the participating local authorities.

Analysis

The fieldnotes, audio recordings and verbatim transcripts from each round of cognitive interviews were reviewed by the research team (the Author and Dr Juliette Malley). There was discussion of key observations related to comprehension, weighing up of responses and choosing an answer. The key findings and any subsequent edits to the questionnaire are described narratively in the final study report [27]. This was not included in this submission due to length; however, it is a published discussion paper that is publicly-available at www.pssru.ac.uk/publications/pub-4235.

The transcripts were also analysed in Nvivo using framework analysis. This is a method of qualitative analysis for applied policy research, which is primarily designed to guide

description and interpretation, rather than generate theory [30]. Framework analysis follows a five-step process of: (1) familiarisation; (2) identifying a thematic framework; (3) indexing; (4) charting; and (5) mapping and interpretation. The identification of a thematic framework (2) may be developed from a combination of *a priori* themes that are further refined through familiarisation (1) with the data in a dynamic, iterative analytical process [30]. The indexing (3) and charting (4) was completed in Nvivo, which facilitated the steps of applying sections of text to themes (3) and arranging data by theme (4).

This approach was taken for the analyses presented in **submitted texts 4 and 5**. For **submitted text 4**, a secondary analysis was conducted using *a priori* themes of the positive and negative effects of services on QoL, and no impact on QoL. A number of subthemes to each of these were also applied (see **submitted text 4, Box 1**). The thematic framework applied for **submitted text 5** used the *a priori* themes of the seven ASCOT SCRQoL attributes and the effect of services on each attribute. There were two additional themes: barriers to accessing support and the significance/value of the caregiving role.

Author's contribution

I was the lead researcher and led the day-to-day activities of the research (including all 31 of the interviews and data analysis in NVivo) with minimal supervision. The **submitted texts 4 and 5** were drafted in-full by the author. For **submitted text 5**, Dr Juliette Malley provided advice on the structure and content of the manuscript. All of the presented analyses in **submitted text 4** were conducted by the author. The co-authors reviewed the manuscript. Dr Florin Vadean, a colleague at the PSSRU at the University of Kent, provided advice and assistance with the regression analysis.

Identifying the Impact of Adult Social Care (Phase Two)

The second phase on the IIASC study (**submitted texts 1 to 3**) was also funded by the DHSC under QORU from January 2013 to December 2014. The primary aim of the project was to develop a way of addressing the *attribution problem* when using self-reported QoL outcomes to compare the effect of social care on people's QoL by local authority or over time [14]. Self-reported QoL may be affected by factors beyond the immediate control of local authorities with social care responsibilities (for example, individual characteristics like age, health or disability). The project developed a method by which the ASCOT score (ASCOF

1A) could be adjusted for these factors to give an estimate of the impact of social care services on QoL. This adjustment factor has been applied to the Outcomes Framework (ASCOT 1J) [5] and the underlying method has been developed for broader application in social care evaluation [13].

The works (**submitted texts 1 to 3**) do not include any of the papers that relate to the primary project aim. These papers were led by Professor Julien Forder [13, 14]. Instead, the focus is on my work to address the secondary project aim to establish the psychometric properties of the ASCOT and ASCOT-Carer. With regard to the ASCOT, the development and evaluation of its psychometric properties had previously been conducted primarily with older adults with physical impairment or age-related impairments [6, 7]. The Phase 2 of the IIASC study sought to establish the psychometric properties of the ASCOT with a diverse sample of social care service users, including younger adults with mental health conditions and physical disabilities by comparison to older adults (**submitted text 3**).

Furthermore, the feasibility, construct validity and reliability of the ASCOT-Carer measure, which was developed in Phase 1 of the IIASC study, was also evaluated (**submitted text 1**) and its psychometric performance compared to other related measures of carer experience and health-related quality of life (**submitted text 2**). This work contributes to the evidence that the ASCOT and ASCOT-Carer are reliable, valid and acceptable measures of social care-related quality of life for service users and their carers – and also adds to an understanding of how these measures differ from measures of related, yet distinct, concepts (e.g. carer experience or broader care-related quality of life).

[Design and sampling](#)

The data collection was by a mixed mode (face-to-face or telephone) survey of users of adult social care services across 22 local authorities in England. The survey took place between June 2013 and March 2014. Local authority adult social care services departments were asked to identify a sample of social care service users from their database with the following inclusion criteria:

- Aged 18 years, or older;
- A social care service user of community-based services, including home care, day centre or day activities, home adaptations and/or equipment, and personal budget (direct payment);
- Primary support reason recorded as: (1) physical or sensory impairment; (2) mental health problems; or (3) learning disability;
- Not living in a residential or nursing care home;

Local authorities sent out a letter of invitation and study information sheet to every identified service user or a randomly-selected subsample. The letter asked recipients to contact the fieldwork agency to pass on their contact details and preferences if they wanted to participate in the study. The fieldwork agency interviewers then contacted the person to arrange a convenient time (and location, if face-to-face) for the interview.

Interviews were conducted by staff at a fieldwork agency using a protocol developed by the Author with support and advice from a co-Investigator (Dr Juliette Malley). Written or verbal informed consent was taken before the start of the interview. The survey questionnaire included the ASCOT measure of social care-related quality of life [6], which had previously been used before the *Identifying the Impact of Adult Social Care* (IIASC) study with a sample of older adults using community-based social care services [7]. The other items and measures included in the questionnaire were selected on the basis of a theoretical framework based on the *Production of Welfare* approach of the non-care-related factors that may influence QoL (outlined in [13]) and analyses of the non-care related QoL (for example, [31]). This included items from the Adult Social Care Survey questionnaire [8] and other sources, including the *Social Care Questions for over 65s* [32].

In addition to the selection of items on the basis of the study's primary aim to develop an adjustment method to estimate the impact of social care on QoL [14], the questionnaire also included items and scales designed to enable the evaluation of the construct validity of the ASCOT. As there are no alternative 'gold standard' instruments for the measurement of social care-related quality of life, the construct validity of the ASCOT was assessed using instruments that measure similar or related constructs (convergent validity). The selected instruments were the EQ-5D-3L measure of health-related quality of life [33, 34] and the

ICECAP capability wellbeing measures (i.e. the ICEpop CAPability measure for Older people (ICECAP-O) for older adults [35, 36] and the ICEpop CAPability measure for Adults (ICECAP-A) for adults aged 18-64 years [37, 38]). A number of other items and measures were also included to allow construct validity by hypothesis testing (i.e. to test whether ASCOT SCRQoL scores were related to factors hypothesised to be associated with the construct, e.g. home design suitability for care, social contact and loneliness).

A total of 770 service user interviews were completed with adults with mental health conditions or physical/sensory impairment. (Here, we will not consider the interviews completed with adults with a learning disability ($n=220$) as they were completed using an abbreviated version of the questionnaire using easy-read format [14]). For a subsample of the service users with a primary support reason of physical/sensory impairment ($n=100$), follow-up interviews were completed with the aim of collecting data to enable analysis to determine the test-retest reliability of the ASCOT.

A sample of carers were recruited via the service users who had completed an interview for the *Identifying the Impact of Adult Social Care* (IIASC) study. Service users were asked to provide detail of their social care needs and types/sources of help as part of the *Social Care Questions for over 65s* [32]. These items were used to identify whether the respondent had a carer and, if yes, the carer(s) who had provided the greatest number of hours of support in the previous week. This person or people were identified as the 'primary carer(s)'. The respondent was asked to share a letter of invitation and study information to their primary carer (or one of the primary carers). The carer was invited to contact the fieldwork interviewer if s/he agreed to also participate in the study. An interview was then arranged using the same mode of administration (i.e. face-to-face or by telephone) as for the service user interview. Of the 990 completed service user interviews, a total of 739 carers were identified. Of these, 510 carers were invited to participate via the service user. Interviews were completed with 387 carers.

The carer questionnaire was also based on the theoretical framework of the *Production of Welfare* approach (outlined in [13]) with adaptation based on a scoping review of literature on factors related to carers' QoL conducted as part of the IIASC study (Phase One) [39]. The interview included the ASCOT-Carer INT4 (see Box 2) developed in IIASC (Phase One) [27], as

well as the Carer Strain Index [40], Carer Experience Scale [41–43] and EQ-5D-3L [33, 34] as measures of related constructs (i.e. carer strain, experience and health-related QoL respectively) for construct validity analysis (convergent validity). Other items and measures were included for construct validity by hypothesis testing analysis. Some of these overlapped with the service user interview (e.g. home design suitability for care, social contact and loneliness). Others were carer-specific (e.g. duration and intensity of caregiving, type of care task(s), the impact of caregiving on health, social relationships, leisure and employment/education).

The study was reviewed and approved by the Social Care Research Ethics Committee in England (Reference: 12-IEC08-0049) and also through the local research governance process for each participating local authority.

Analysis

The analyses conducted in these papers were undertaken with the aim of evaluating the measurement properties of the ASCOT and ASCOT-Carer. Psychometric methodology may use two broad approaches: (1) classical test theory (CTT) and/or (2) item response theory (IRT). These two approaches are theoretically distinct. CTT is based on the assumption that the observed score from a psychometric instrument comprises the ‘true score’ (i.e. the individual’s score without measurement error) plus measurement error [44]. In CTT, the measurement error is assumed to be a random (non-systematic) normally-distributed variable. This theoretical assumption is then applied in statistical analyses to establish the measurement properties of the scale: for example, to establish internal reliability using Cronbach’s alpha.

By contrast, IRT has led to the development of psychometric evaluation methods that focus on item responses, rather than test scores. An example of a methodology based on IRT is the Rasch model [45]. Rasch analysis, like other methods informed by IRT, is based on probability curves for the likelihood that each item will be ‘passed’ (affirmed) is a logistic function of the item’s ‘difficulty’ (item location parameter) and the individual respondent’s ‘ability’ (respondent location parameter). IRT using the Rasch model has been applied to educational and psychological measurement, e.g. in developing exam questions. It is also however, widely used in psychological measurement, including for the evaluation of patient-

reported outcome measures (PROMS) in health and social care, where it is used to evaluate whether scales are unidimensional, which is a key requirement for the construct validity of a scale [46].

Although it is increasingly common to find IRT applied in the development of quality of life instruments, either alone or in combination with CTT methods, the works presented here (**submitted texts 1 to 3**) present only analyses based on CTT. Despite the limitations of CTT and advocates of IRT, the use of either approach or a combination is the expert consensus captured by the Delphi study used to develop the Consensus-based standards for the selection of health measurement instruments (COSMIN) checklist [47]. Using the COSMIN taxonomy of measurement properties, the works (**submitted texts 1 to 3**) sought to evaluate aspects of (1) reliability and (2) construct validity as follows:

- **Reliability**

- Internal consistency of the ASCOT and ASCOT-Carer using Cronbach's alpha [48].
- Reliability (test-retest) of the ASCOT using intra-class correlation coefficient (ICC) [49, 50].

- **Validity**

- Construct validity
 - Structural validity. The unidimensionality of the ASCOT-Carer was evaluated using confirmatory factor analysis.
 - Hypothesis-testing. The construct validity of the ASCOT and ASCOT-Carer was evaluated by testing the hypothesised direction and, in some cases, also the magnitude of association with: (1) comparator instruments of related constructs (e.g. the EQ-5D-3L measure of health-related quality of life) and (2) with factors hypothesised to be related to social care-related quality of life based on theory (adapted from the Production of Welfare approach, see [14]) developed by literature review and previous studies.

Author's contribution

The author was the lead researcher and led the day-to-day activities of the research with minimal supervision. All analyses presented in **submitted texts 1 to 3** were conducted by the author. The manuscripts were also drafted in-full by the author, with advice and feedback from co-authors on the draft.

Translation and cross-cultural adaptation of the ASCOT-Carer into Japanese

A study led by Professor Mai Yamaguchi at the Japan Lutheran College was funded by the IJSP (Japanese Society of Promotion of Science) Grant-in-Aid for Scientific Research (KAKEN (B) 16H03715) from April 2016 to March 2020. The aim of the study was to understand the quality of life outcomes of Japanese carers and also develop a comprehensive carers' assessment model for use in Japan. The study included the translation and cross-cultural adaptation of the ASCOT-Carer for potential inclusion in Japanese carers' assessments.

Design

The study sought to develop a Japanese version of the ASCOT-Carer SCT4. The translation and cross-cultural validation followed the translation guidance developed by the ASCOT team available at: www.pssru.ac.uk/ascot/translations. In summary, the translation process was conducted in two phases: (1) developer review and (2) pilot testing. The first phase (developer review) was conducted in partnership between the PI and Japanese research team, the ASCOT team at the University of Kent and a professional translation company. Initially, a forward translation was prepared by a professional translator using the ASCOT-Carer SCT4 questionnaire alongside a concept elaboration guide prepared by the ASCOT team. The forward translation was reviewed by the Japanese and ASCOT team researchers. Any feedback was incorporated into the translation. A professional translator then prepared the backtranslation. This was also reviewed by the Japanese and ASCOT team. After the forward and background translation, the feedback was reviewed and harmonised to prepare a final draft version of the translated questionnaire.

Interviews with Japanese carers (n=5) were conducted using the cognitive debriefing method of 'think aloud' with follow-up probes to explore comprehension, judgement and response [29]. The cognitive debriefing notes were reviewed to prepare the final version of the questionnaire. As part of this finalisation process, the questionnaire was independently proof-read to identify any content or format discrepancies for correction. This final version

of the questionnaire was included in a pilot survey of Japanese carers to explore the validity, reliability and feasibility of the Japanese version of the ASCOT-Carer.

The brief *Debates and Issues* paper (**submitted text 6**) focuses on the broader cultural and conceptual issues identified in cross-cultural adaptation and translation of the ASCOT-Carer for use with Japanese carers for needs assessment. This paper has been included as it illustrates some of the key issues in cross-cultural adaptation and translation of the ASCOT-Carer. As part of other studies, the measure has also been translated into German, Finnish and Norwegian. In Finland, a small pilot study has been conducted (independently, by Finnish researchers) to explore the feasibility and acceptability of using the ASCOT-Carer in care practice. The ASCOT-Carer was found to be a feasible and acceptable instrument for needs assessment and ongoing review [51]. As a result of this study, the Finnish version of the measure has been embedded within care practice in the Finnish municipality that supported this project. Although the Japanese study (at the time of writing) is not yet as fully-developed, it is anticipated that the ASCOT-Carer could likewise form part of a standardised (national or regional) carers' assessment and review programme in Japan.

Author's contribution

The author was the lead ASCOT team researcher in the development of the Japanese version of the ASCOT-Carer. This work was supported by a colleague within the ASCOT team (Kamilla Razik), who provided assistance and reviewed the forward/back translation. The manuscript for the submitted work (**submitted text 6**) was prepared in collaboration with the lead author of the article (Professor Mai Yamaguchi). The manuscript sections that relate to the UK/English context and also to core ASCOT concepts were written by the author. The author also reviewed and commented on drafts and the final version of the full manuscript.

Application of social care-related QoL outcomes data

Design and analysis

Two of the submitted works are secondary analyses of the IIASC Phase Two data (**submitted texts 7 and 9**). The first of these (**submitted text 7**) addresses the question of whether and how the reasons for caring are related to carers' self-reported strain and social care-related quality of life. The data from the survey of carers ($n=387$) were analysed using regression

analysis (Ordinary Least Squares) with (1) ASCOT-Carer SCRQoL and (2) the Carer Strain Index score as the outcome variables in two separate regression models. The independent variables included the carers' self-reported reasons for caring collected using an item from the 2009/10 survey of carers in households [52]. Other independent variables were selected on the basis of a literature review of the factors associated with carers' QoL [39].

The second article (**submitted text 9**) is an analysis of the combined service user and carer data for a dyadic analysis ($n=264$ dyads). The aim of the analysis was to explore the interdependence of quality of life in carer/care-recipient dyads, especially that due to social feedback within the caregiving relationship. The importance of a dyadic view of caregiving has been highlighted as a potential gap in the long-term care evidence base, despite the fact that caregiving often exists within already-established close relationships [53, 54]. Part of the reason for overlooking this perspective is methodological. There are some quantitative studies that apply dyadic analytical methods to carers and care-recipients' quality of life with a view of psychological effects of different approaches to coping/adjustment and experience of distress on caregiving dyads' QoL (for example, see [55–57]). However, there is only one published study apart from this work (**submitted text 9**) that applies the analysis to QoL outcomes with regard to care services [58]. Unlike established quantitative techniques, the potential application of dyadic analytical methods [59] to social care policy research is yet to be fully explored, despite the obvious benefit of enabling a dyadic view of QoL outcomes.

In this work (**submitted text 9**), the analysis used the three overlapping domains of social care-related quality of life from the ASCOT and ASCOT-Carer: *Social participation*, *Control over daily life* and *Occupation*. The actor-partner interdependence model (APIM) was applied to simultaneously test for *actor effects* and *partner effects* [59]. The actor effects indicate the effect of an independent variable on the same person's dependent variable (e.g. the effect of the carer's age on his/her own rating of QoL). The partner effects are interpersonal effects (e.g. the effect of the carer's age on the care-recipient's rating of QoL). The APIM may be calculated in different ways. In this work (**submitted text 9**), a multi-level model was applied. The random effects (level 2) were interpreted as unobserved mutual interdependence (i.e. due to social influence within the dyad), however, we noted the limitation that there may be other non-observed non-independence also captured here.

The submission also includes a third work (**submitted text 8**) that is a secondary analysis of the Adult Social Care Survey (ASCS) datasets [8]. The ASCS is a national data collection conducted annually by local authorities in England and overseen by NHS Digital, which is a non-departmental public body whose remit is to provide health and social care data, information and IT systems for the NHS. The survey is undertaken according to centrally-agreed guidelines published by NHS Digital. There is an oversight steering group, the Social Care User Survey Group (SSUSG) that includes representatives from NHS Digital, local authorities, the Department of Health and Social Care (DHSC), the Care Quality Commission (CQC) and the Personal Social Services Research Group at the University of Kent (PSSRU, Kent). The SSUSG report to the Outcomes and Information Development Board (OIDB), who oversee the user surveys and the way(s) the feed into central reporting – primarily, the Adult Social Care Outcomes Framework (ASCOF) [5]. Each of the 152 local authorities with adult social care responsibilities in England is responsible for the implementation of the survey data collection. This includes sample selection, printing and distributing the postal questionnaires or conducting interviews (if needed), collating the responses, data entry and sending a completed data return to NHS Digital [8]. The survey sample is users of fully or partly publicly-funded social care services in England.

The analysis is of the data collected in the first two rounds of the survey (2010/11 and 2011/12) from adults whose primary support reason was recorded by the local authority as learning disability ($n=13,642$). The aim of the analysis was to determine the non-care-related factors related to QoL. This is to inform the need for methods, like risk adjustment, to adjust for these non-care-related factors to provide a more robust indicator of the impact of services (i.e. to the exclusion of non-care-related factors). The secondary aim of the analysis was to also determine whether there had been any change in QoL over time, from the first to second round of the survey. The analysis presented here adds to other analyses conducted on ASCS data with older adults [31] and also as part of the IIASC study to explore the potential of adjustment methods [14]. The data were analysed using multiple regression, with OLS estimation applied for the model with ASCOT SCRQoL score as the dependent variable. Ordered logit (*ologit*) estimation was initially used for models of the rating of each of the eight ASCOT domains. All eight models failed the assumption of parallel

regression. Therefore, generalised ordered logit (*gologit*) estimation was applied and reported in the work (**submitted text 8**).

Author's contribution

The author conducted the analyses presented in these works and drafted the manuscripts (**submitted texts 7 to 9**). The co-authors reviewed drafts of the manuscripts and provided advice and comments to improve the clarity of presentation. The equation in **submitted text 9** was developed by Professor Julien Forder.

Table 2. Project responsibilities

No.	Year(s)	Title of Study	Submitted works									
				Design	Liaison/negotiation	Sampling/design	Data collection	Questionnaire design	Data preparation	Data management	Data analysis	Preparing manuscript
1	2012	Identifying the Impact of Adult Social Care (Phase One)	4, 5	C	P	P	S	P	P	P	P	P
2	2013 - 2014	Identifying the Impact of Adult Social Care (Phase Two)	1, 2, 3, 4	C	P	C	A	P	A	P	P	P
3	2016 - 2020	Translation of the ASCOT-Carer into Japanese	6	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	C
4	2015-2018	Secondary analysis of IIASC dataset	7, 9	N/A	N/A	N/A	N/A	N/A	S	S	S	P
5	2014-2016	Secondary analysis of ASCS dataset	8	N/A	N/A	N/A	N/A	N/A	S	S	P	P

Key:

- A: Contracted to agency
- C: Co-responsibility
- P: Principal responsibility
- S: Sole responsibility
- N/A: Not applicable

Theme 1: Measuring individual quality of life outcomes in social care

In the following section, I outline the ways in which my work has contributed to knowledge and understanding of the measurement of individual social care-related quality of life. This relates to research questions 1a and 1b (see *Aims and Objectives*).

Research Question 1a. Is ASCOT a feasible, valid and reliable measure of social care-related quality of life for adults, aged 18 to 64 years, and with support needs related to mental health problems?

The submitted works contribute to existing knowledge by addressing gaps in ASCOT development. The initial development and psychometric testing of ASCOT for people with social care needs focussed on older adults [6, 7]. In two systematic reviews, the ASCOT has been recommended as an outcome measure suitable for economic evaluation of social care services for older adults [60, 61]. Of 34 quality of life outcome instruments identified from a literature review (2000 to 2012), Makai *et al.* [60] identified the ASCOT as a promising measure for economic evaluation of older adult care services. In a review of measures suitable for evaluation for social care interventions for older adults, Bulumu *et al.* [61] identified four commonly used measures (i.e. EQ-5D, ASCOT, HUI2/3 and ICECAP-O). The authors recognised the value of using either the ASCOT or ICECAP-O (both measures of QoL ‘beyond health’) alongside a health-related QoL instrument, like the EQ-5D. While older adults represent a significant proportion of users of social care services, however, there is also a need to test and validate the measure with a wider range of service users – specifically, younger adults (18 to 64 years). To address the evidence gap, **Submitted text 3** evaluated the psychometric properties of the ASCOT with a diverse sample of social care service users in England, including younger adults with physical disabilities and people with mental health support needs. This has led to an update of the ASCOT guidance and training materials (available at www.pssru.ac.uk).

The application of the ASCOT in research and evaluation studies to-date reflects its initial development for older adults. In England, ASCOT has been used in the evaluation of older adult services, including help-at-home schemes [62], family-based support in the community (‘shared lives’) [20], bath adaptations [63] and day centres [64], as well as in exploring

potential policy application through an understanding of factors related to older adults' social care-related QoL [31] and also the productivity of older adult residential care in England [65]. There has been interest in the use of ASCOT in research and evaluation in other countries, with translations into Japanese [24] and Dutch [23], with forthcoming translations into Finnish and German. The use of ASCOT with younger adults (18-64 years) and/or people with mental health problems has, so far, been primarily in the reporting of the Adult Social Care Survey data as part of national data collections (for example, [66]) or through the national policy evaluation (for example, the evaluations of individual budgets [16]). The use of ASCOT in national data collections is also being explored by the Northern Irish Health and Social Care Board as part of the self-directed support programme implementation and also in Japan through a project led by Professor Mie Morikawa at Tsuda University (2016 to 2019, Grant-in-Aid for Scientific Research (KAKENHI) for Japan Society for the Promotion of Science (JSPS) 16H03722). There is scope to further establish and promote the use of the ASCOT instrument in academic, practice or policy-based research and evaluation studies of younger users of social care services, including those whose needs relate to mental health problems, on the basis of **submitted work 3**.

Research Question 1b. Is the ASCOT-Carer a feasible, valid and reliable measure of carers' social care outcomes?

The submitted work also contributes to existing knowledge through the development and psychometric testing of an outcome measure for *carers*. **Submitted texts 1 and 2** present work on the development and testing of the ASCOT-Carer self-completion (SCT4) and interview (INT4) instruments (see Box 2). Although not included in the submission, there is also a detailed technical report that expands on the underpinning theoretical basis, literature, methodology and results of the initial development through qualitative interviews ($n=31$ carers) of the ASCOT-Carer, for which the author conducted the interviews, analysis and drafted the report, with advice from co-authors [27].

This work is a significant contribution to the literature in its development and psychometric evaluation of a measure of *social care-related quality of life* of carers. The work includes the development of a self-completion version of the measure (**submitted text 1**) and also an interview version (**submitted text 4**, also [27]), which applied a counter-factual self-

estimation method of estimating the *impact* of social care services that does not require experimental or observational methods commonly-used in evaluation research. Instead, the counter-factual self-estimation methodology, which was first developed for the service user version of ASCOT [6, 28], was adapted in the ASCOT-Carer INT4 to ask carers to rate their expected quality of life for each domain in the questionnaire in the hypothetical situation that services/support were no longer available and no other help would step in (**submitted text 4**, also [27]). An estimate of the impact of social care interventions or policy may, thereby, be calculated as the different between the carer's quality of life *now* (with services) and their *expected* quality of life (without services). The work presented in this thesis, therefore, presents the application of this novel method to carers, as a way of estimating the impact of social care on carers' quality of life outcomes.

In situating the contribution of this work in a wider context, there are a number of available carer-specific outcome measures applied in health and social care research, which capture a range of relevant constructs: for example, the EQ-5D to measure health-related quality of life [33, 34], the Carer Experience Scale to measure broadly carers' experience and care-related quality of life [41–43] and measures that capture carers' perceptions of care-related burden or strain (for example, the Carer Strain Index [40]). The ASCOT-Carer is, however, currently the only available measure that specifically measures social care-related QoL (that is, aspects of quality of life that may be improved by social care support). **Submitted text 2** adds to the literature on understanding the overlaps and distinctiveness of the ASCOT-Carer by comparison to other measures. Independently, other research groups led by Dr Hareth Al-Janabi at the University of Birmingham and Dr Nikki McCaffrey at Deakin University in Australia are conducting similar comparisons of carer outcomes measures (i.e. the ASCOT-Carer, CES, CarerQoL [67, 68]) or general health-related quality of life (i.e. EQ-5D).

The evidence from **submitted text 2** and these other studies supports the perspective that the ASCOT-Carer captures a distinct construct to other available measures and also that it is sensitive to the impact of social care support. As such, there is promising evidence for its use in the evaluation social interventions in healthcare and/or social care services or policy. Indeed, the ASCOT-Carer was identified in a systematic literature review by Dow et al (2017) as a one of ten promising instruments in health and social care research, even if further evidence of its suitability and psychometric properties in samples of carers of people with

dementia is warranted³ [69], and has also been noted for the rigour of its development in a narrative review paper that explored gaps in the research related to carers' outcome measurement [70]. Since the formal launch in June 2015 via the ASCOT website (www.pssru.ac.uk/ascot), there has been interest in its application in research and evaluation studies, needs assessment and care practice by academics, local authorities, policy-makers and commissioners. For example, the ASCOT-Carer was used in an evaluation study of specialist nursing support for carers of people with dementia in the UK [21].

Theme 2: Using social care outcomes data to inform policy and practice

Here, I briefly explore how my work has contributed to knowledge and understanding of how to use social care outcomes data to inform policy and practice. This relates to research questions 2-4 (see *Aims and Objectives*).

Research Question 2. How does the ASCOT-Carer, and the concept of carers' SCRQoL, inform our understanding of: (1) the effectiveness of services (i.e. their impact on carers' QoL); and (2) the experience of social care services from the carers' perspective?

The relationship between formal social care services and carers has been characterised in terms of four frames of reference [71, 72]:

- As **resources**. This perspective assumes that the care provided by family and friends is normative. Formal services assume that carers will and ought to provide care. It is a form of co-option of formal carers into the service provided by formal services, with little or no regard for the carer as an individual in their own right, with health and wellbeing needs. This frame of reference is characterised by concern that formal services will substitute for care that may be (ought to be) provided by the family or wider community.
- As **co-workers**. In this model, social service services will seek to work alongside the carer in the collaborative work of supporting the person with care needs. In this

³ This limitation is being addressed by a research study funded by the National Institute of Health Research (NIHR), with the author as Principal Investigator, to run from September 2019 to August 2021.

frame of reference, the primary concern for services remains the provision of good quality care to the person with care needs. It is underpinned by the assumption that carers want to provide care. Therefore, the primary role of services is to assist carers in their caring role.

- As **co-clients**. In this model, carers are seen as people with their own health and wellbeing needs, which should be addressed by formal services. This frame of reference views all carers as potential clients of services; with a particular focus on those carers most 'at risk' of poor health and quality of life outcomes (e.g. high intensity care). The model is informed by a focus on the carer's own health and wellbeing needs. This is on an equal basis to the person with care needs. There is recognition of the potential tensions that may arise between the needs of the carer and the care-recipient. The role of services is to creatively navigate these tensions to seek the best outcome for both parties in the caregiving dyad.
- As **superseded**. In this frame of reference, the aim is to entirely replace the caregiving relationship with formal care services, rather than support or assist it. This is based on the independence of the care-recipient to enable the person to live without the potential restriction and limiting control within a caregiving relationship. Conversely, it is also to enable the independence of the relative or friend. It also recognises that, in some cases, the removal of responsibility for caregiving is the only intervention that will effectively improve the carer's wellbeing.

Using this framework developed by Twigg (1989) and Twigg & Atkins (1994), **submitted text 5** explored the experiences of carers in England [73]. Despite policy strategy to promote the health and wellbeing of carers 'on an equal footing' to care-recipients (as *co-clients*), the study found that carers were often still positioned as *co-workers* or *resources* within a long-term care system that relies on their contribution [73]. The study explored the ways in which social care support, both 'for' the care recipient (e.g. home care) and 'for' the carer (e.g. carer support groups) could improve quality of life, as well as the ongoing issue of rationing of care with its consequences for carers' wellbeing and health [73]. **Submitted texts 4 and 5** also explore the questions of *whether* and *how* social care services affect carers' quality of life.

These are important questions, especially in light of the Care Act (2014). This legislation gave carers a right to an assessment of needs on an equal basis as care recipients. The assessment of carers' needs, which determines their eligibility to support and services, asks whether carers' outcome needs are at risk due to the caregiving role. The eligibility criteria in the Care Act (2014) define outcome needs based on carers' QoL and wellbeing. Some of these correspond to the ASCOT-Carer domains of *Social participation and involvement*, *Occupation* and *Self-care*. This overlap is not unexpected because the ASCOT-Carer and Care Act (2014) were both developed in the same wider policy context, which was influenced by the national carers' strategy in England [74–76]. These policy documents consistently state the importance of enabling and supporting carers to sustain their health and wellbeing, as *co-workers* or *co-clients*. Since the introduction of the Care Act (2014), however, there is some evidence of gaps between policy rhetoric and practice [77]. Despite the policy rhetoric-reality gap, the legislative framework and policy direction still support a shift away from perceiving carers to be primarily *resources*, even if there are significant challenges to not doing so.

Despite these challenges, there has been interest in ways of embedding a focus on individual outcomes via a 'bottom up' approach. In one English local authority, for example, there was a pilot of using an outcomes-based needs assessment for service users based on the ASCOT prior to the implementation of the Care Act (2014) [22]. Using this concept as a basis, there has been a local pilot and adoption of the ASCOT-Carer as an outcomes-based needs assessment tool in a local authority in Finland [51]. There has also been a study in Japan to adapt and translate the ASCOT-Carer, which is driven by the aim of implementing the instrument as a carers' assessment tool at a national level (**submitted text 6**).

Furthermore, the concepts of ASCOT-Carer domains have been adopted into the company mission statement of *Kaze no Mura*, a national care provider in Japan, to highlight how they seek to support carers through the support they offer to service users.

In England and other parts of the UK, however, there has been less progress, so far, in the adoption of the ASCOT-Carer by care providers and/or for individual needs assessments. This is by contrast to the application of the ASCOT-Carer at the level of national social care data collections. For example, the Carer SCRQoL (an earlier version of the ASCOT-Carer) is included in the English ASCOF. There has also been an initial pilot study and ongoing work

with the Health and Social Care Board in Northern Ireland in using ASCOT in social care data collections (and potentially also, the ASCOT-Carer). Recently, there has been early-stage interest by the Scottish government in using the ASCOT and ASCOT-Carer for national social care data collections, as well as potentially also for local care planning and needs assessments. A key challenge in embedding the use of social care outcome measures, however, regardless of the level of implementation, is the required investment, especially in terms of effectively communicating the potential value to key stakeholders and in implementing data collection into existing structures and processes.

In the context of England, especially, a key barrier to the application of the ASCOT-Carer at the level of individual needs assessment is a concern that outcomes-based assessment tools may uncover levels of unmet need that are beyond the capacity of services to address and/or the established use of other approaches to assessing carers' needs [78–83]. In terms of the latter, some local authorities outsource the responsibility to conduct carers' assessments to local carers' organisations, whose assessment processes typically involve a conversation with a carer support worker, with or without the use of a standardised tool. Where local authorities offer assessments, these are often completed by an online or paper questionnaire. These are often designed in-house by the local authority and use the Care Act (2014) eligibility criteria as a guide to the assessment topics and data collected. Further research is needed to establish whether an outcomes-based tool, like the ASCOT-Carer, either as a self-completion tool or semi-structured interview, would provide any benefit to carers, e.g. by widening access to carers' assessment and/or in tailoring responses to individual health and wellbeing needs.

Research Question 3. What are the non-social care-related factors associated with social care-related quality of life?

There is an emerging literature on the application of self-reported outcomes to inform social care policy through secondary or survey data analysis. Examples of this approach include a study of the productivity of the adult social care system in England, using the ASCOT collected in the Adult Social Care Survey to estimate the 'quality adjusted' output of community-based care [65]. Another study of the ASCOT data in the ASCS explored the associations between social care-related QoL with three potential targets for policy: (1)

accessibility of information and advice; (2) home design and environment; and (3) local area accessibility [31]. The analysis was used as evidence for the potential benefit of co-operation between local services (e.g. social care and housing) to improve the quality of life of community-dwelling older adults [31].

Submitted text 8 is a study that is situated within this broad approach of secondary data analysis of national social care data (specifically, the ASCS) to comment on implications for social care policy. The study reports on data collected via the ASCS using adapted easy-read version of the questionnaire completed by adults with intellectual disabilities. This version of the questionnaire was developed from the original version of ASCOT with limited time and resources, which has led to subsequent work to develop a feasible, acceptable and valid alternative easy-read format [84, 85]. Despite the limitations, data is routinely collected from adults with intellectual disabilities via the ASCS, which offers an insight into the social care outcomes for this subgroup of service users. The study explored the predictors of overall social care-related quality of life, as well as for the individual SCRQoL domain scores. The findings support provide further evidence of a relationship between housing quality, also health indicators, and social care-related QoL. This is important in a group of users of social care support already known to be at risk of health and housing inequalities that may affect aspects of quality of life, including feeling safe, in control, and socially included [86–89]. As with other studies [31], it raises the question of how services could better work together to improve individuals' quality of life.

The study also contributed to the wider literature on the measurement of quality of life of people with intellectual disabilities and the use of these data to drive systems- or organisational-level quality improvement [90, 91]. The study found that there had been an increase in SCRQoL between the two rounds of data considered in the analysis (2010/11, 2011/12), whilst controlling for other non-social-care-related factors. Similar comparisons have been used in other studies or schemes to drive quality improvement feedback on a local or regional level [92, 93]. In practice, however, there are limitations to applying this approach with the Adult Social Care Outcomes Framework (ASCOF) in England:

- Despite a focus on self-reported quality of life outcomes in the ASCOF, which represents a shift from a focus on process towards personal outcomes [4, 6], there

are still significant measurement challenges, for example: (1) the attribution of outcomes to the impact of social care, to the exclusion of other wider factors [13, 14]; the measurement of QoL by self-report with adaptation, e.g. easy-read [84, 85]; and method(s) of collecting data for individuals where self-report is not possible to avoid systematic exclusion and bias, e.g. by observation or proxy-report [94–96].

- While the ASCS data is publicly-available, with summary reports that allow comparison by local authority, the use of the data is limited by its reported form and analysis. Specifically, there is an adjusted value for SCRQoL that addresses the attribution issue (ASCOF 1J) to allow comparison over time and by local authority. However, this is currently only available for the standard version of ASCOT, not the easy-read version [5]. Furthermore, aside from the analysis presented in **Submitted text 8**, there has been no further national-level analysis of the ASCS trends over time. Even if such analyses were available, however, it is difficult to identify how local authorities could then apply these data to guide changes within their own structure, operation and processes. Instead, the ASCS offers primarily a systems-level view that is of most value nationally (i.e. overall performance), rather than at the level of local authorities. It is also unclear whether the system of QoL domain-specific feedback to drive accountability and improvements in care quality (as outlined in the examples discussed in [93]) would be feasible with ASCS data as it is currently reported because it does not offer granularity by care provider (i.e. the smallest unit of analysis is local authority, as a whole).

These limitations do not undermine the principle of an outcomes-focussed approach or the use of national-level data to inform policy, although there are clearly challenges (see also [12]); however, there are evidently barriers to the application of this in practice in England due to the current processes, protocols and practices in data collection and reporting.

In addition to secondary analysis of national datasets, analysis of smaller scale survey data may also provide insights into policy-relevant questions. **Submitted papers 7 and 9** are examples of this. **Submitted paper 7** outlines an analysis of the relationship between carers QoL outcomes and also strain with the self-reported reasons carers give for why they chose to provide care. The findings of this study are policy-relevant in a context where carers' QoL

needs/outcomes are of interest to policy-makers, practitioners and local authorities with adult social care responsibilities. The Care Act (2014) outlines that local authorities have a responsibility to identify/assess and respond to carers' outcome needs. While there is some evidence that this is still an aspiration rather than reality in social care/work practice despite the legislative requirements [77], the analysis outlined in **submitted paper 7** supports the perspective that the reasons for carers' choosing to provide care ought to be considered as they are related to QoL and strain outcomes. This consideration could be at the level of social work practice, as well as in policy strategy and/or political or media narratives (e.g. the well-worn phrase that *families should do more*).

Research Question 4. Are the social care-related quality of life outcomes of service users and carers interdependent?

Submitted paper 9 offers an analysis that demonstrates the value of considering the dyadic view of social care outcomes in policy and practice. The study provides evidence for mutual interdependence between carers' and care-recipients' SCRQoL, with regard to the attribute of *Control over daily life*. If the aim of social care is to support the quality of life of service users and carers, then it ought to consider both perspectives – at least individually, if not as a dyad. This develops the argument in the economic evaluation literature, which argues that healthcare interventions ought to consider 'spill-over' effects of interventions on carers' outcomes [97–101].

While the rationale as to why carers' *health outcomes* should be considered also hold with regard to *social care outcomes*, some modification is required. First, carers are co-clients of social care services, even if there is ambiguity in their relationship with formal care services (**submitted text 5**). Therefore, it may be argued that the consideration of carers' social care outcomes is important in its own right. Indeed, these may not then be 'spill-over' effects (i.e. indirect effects, as an unintended consequence), but rather capturing the outcomes of services on the carer as a *co-client*.

Second, in the measurement of carers' healthcare outcomes, it has been argued that there is a need to disentangle the caregiver effect (the effect of caregiving tasks) and the family effect (the effect of caring about the care-recipient) [97]. The rationale is that healthcare interventions may be reasonably expected to affect the caregiver effect, but the family

effect is beyond the remit of healthcare. To avoid potential issues, it is important to disentangle the two effects. In social care, it is arguably less clear cut. Effective social care interventions (e.g. counselling) may also target the *caregiving effect*, as well as the influence of mutually interdependence of quality of life outcome via the caregiving relationship. Therefore, it may be possible that evaluation of policy and/or specific interventions ought to consider both caregiving and family effects, as well as mutual interdependence (i.e. influence of one person's QoL on another's via a close relationship).

Third, interventions designed to support the carer may either directed at carers (e.g. support groups) and/or at the care-recipient (e.g. replacement care). This ambiguity in the 'target' and 'recipient' of services further adds weight to the argument that the impact of services on carers' QoL ought to be considered – either as spill-over effects, direct benefit from services (via the *family effect* or *caregiving effect*), and also via mutual interdependence within the caregiving relationship.

Conclusion

This thesis focuses on the themes of measuring and applying individual social care outcomes to inform policy and practice. This work presented here has developed methods to robustly assess social care outcomes of service users and their carers, specifically, through the further or initial development and psychometric testing of the ASCOT and ASCOT-Carer measures of social care-related quality of life. The work presented here also contributes to the broader understanding of how to apply social care outcomes in evaluating the impact of social care. It also demonstrates how social care outcomes data may address questions that are relevant to policy and practice: for example, national-level analysis to determine the factors that influence social care outcomes for the population of service users with intellectual disabilities in England. This analysis demonstrated the significant contribution of health and housing quality to social care outcomes, which highlights the potential for well-integrated health, social care and housing services to support well-being, even if this policy goal remains elusive in practice. Other analyses showed how the social care outcomes of people with support needs and their carers are interrelated, which has implications for social care practice. It shows the potential value of looking beyond individuals to consider the wider impact of social care, especially for carers, in how care services are designed and delivered, as well as the importance of inter-personal influences on wellbeing between care-

recipients and their primary carer. Related to this, the thesis has also explored how the QoL outcomes of carers may be applied in carers' needs assessment and care planning. The work presented in this thesis is collaborative research with an academic in Japan; however, there is scope and potential for future work to explore its application in the UK, and elsewhere. While there are a number of challenges and limitations to the implementation of these approaches in practice, the value of an outcomes-based approach is that it places people (service users **and** carers) and their wellbeing at the centre of the planning and delivery of social care support.

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Appendix One

Supporting Statements

1. Professor Julien Forder
2. Dr Juliette Malley
3. Dr Florin Vadean
4. Ann-Marie Towers
5. Professor Mai Yamaguchi

Appendix Two

Submitted publications

1. Rand S, Malley J, Forder J, Netten A (2015) Factor Structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer), *Quality of Life Research*, 24(11), 2601-2614. <https://kar.kent.ac.uk/48181/>
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3. Rand S, Malley J, Towers A, Netten A, Forder J (2017) Validity and test-retest reliability of the self-completion adult social care outcomes toolkit (ASCOT-SCT4) with adults with long-term physical, sensory and mental health conditions in England, *Health and Quality of Life Outcomes*, 15(163). <https://kar.kent.ac.uk/62602/>
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