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**Title**: Exploring the feasibility and validity of a pragmatic approach to estimating the impact of long-term care: The 'expected' ASCOT method

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# Abstract

Context: Measuring the impact of long-term Care (LTC) is essential to ensure effective allocation of limited resources.

Objectives: We explored the feasibility and validity of a pragmatic approach to evaluation, known as the counterfactual self-estimation of programme participants (CSEPP). CSEPP forms part of the Adult Social Care Outcomes Toolkit (ASCOT), and is referred to as the 'expected' method since participants estimate their expected quality of life in the absence of services.

Methods: We used survey data from interviews with 748 LTC users in 22 English local authorities. Questions on self- and interviewer-assessed understanding of the 'expected' questions were used to assess feasibility. Construct validity was assessed by examining hypothesised associations between the expected score and individual characteristics. Bias was assessed by comparing the expected impact estimate to one produced using Forder et al.'s (2014) instrumental variables approach on the same dataset.

Findings: We found evidence that the expected method was feasible and the self-estimated counterfactual outcome score valid. There were indications that the method is less appropriate for some groups and it may slightly overestimate the impact of LTC.

Limitations: Due to the opportunistic design, exploration of the method's appropriateness for people with mental health problems was limited. The assumption of the betweenmethods comparison that the instrumental variables estimate of the effect of LTC is unbiased is unlikely to be true.

Implications: The expected method is a promising tool for the LTC context, but more research is needed to understand potential sources of bias and its feasibility with certain groups.

**Keywords:** Long-term care, ASCOT, counterfactual, self-estimation bias, impact evaluation, treatment effect

# Introduction

Research into the effectiveness of treatment, interventions and policy programmes is an important source of the evidence required to deliver evidence-based policy and practice (Nutley et al., 2003). Effectiveness research is challenging, particularly in the field of long-term care, not least because of what is referred to as the 'fundamental evaluation problem' (Heckman & Smith, 1995). To determine the effectiveness of an intervention it is not enough to know how it affects participants; we also need to know what would have happened to them if they had not received it – the counterfactual. Since only one of the two states (actual or counterfactual) can be measured for any given individual at any one point in time, it is not possible to observe the true effect of a given treatment on an individual.

A variety of research designs are used to estimate effectiveness, including randomised experiments, observational studies, pre-test–post-test, and other non-experimental evaluation designs, but the evidence obtained from different designs is generally not viewed as equally valid and reliable. The hierarchy of evidence has favoured the randomised controlled trial (RCT) because the design provides the best mechanism for minimising the risk that the results are due to confounding influences rather than the treatment (Evans, 2003). All designs, however, have their limitations, in terms of their ability to provide unbiased estimates of the true treatment effect, cost, and applicability to the full range of evaluation settings, interventions and policy questions (Byford & Sefton, 2003; Heckman & Smith, 1995; McKee et al., 1999; Petticrew & Roberts, 2003). While acknowledging the superiority of RCTs for particular research questions, most researchers accept the need for a range of methods to provide evidence about effectiveness (Petticrew & Roberts, 2003).

Which approach is most appropriate depends in part on the nature of the intervention being evaluated, with some settings providing the scope for approaches that would be inappropriate in others. Mueller et al. (2014) describe a novel approach to the evaluation problem that they call the 'counterfactual self-estimation of programme participants' – CSEPP. The CSEPP design attempts to solve the evaluation problem by asking individuals to imagine their own counterfactual in the absence of the intervention, and estimate what their situation would be like then. Mueller and Gaus (2015) report on a study in the field of consumer education designed to explore the validity of estimates of the true treatment effect using the CSEPP method. The CSEPP method performed fairly well for estimates of short- and medium-term attitudes and behavioural intentions when compared with estimates derived from a randomised experiment. It performed less well for self-reported behaviour, producing biased estimates compared with the randomised experiment. They conclude that the CSEPP method may be suitable for certain types of intervention and the estimation of self-reported mental constructs, but not self-reported behaviour.

The CSEPP method would be inappropriate for much of health care, where self-evaluation of the counterfactual would be difficult if not impossible for patients. However, the compensatory nature of social care, which makes up much of long-term care, means that on

a daily basis many service users face the question of what would happen if they had no help or support. The 'expected' method, equivalent to the CSEPP method, was developed independently by Netten et al. (2012a) as part of the Adult Social Care Outcomes Toolkit (ASCOT) for use within the long-term care (LTC) setting. Given Mueller and Gaus's findings, the LTC setting is ideal for this type of approach because the focus of evaluation is the effect of interventions on quality of life (QoL) – an attitudinal construct.

Using question-testing methods, including cognitive interviews and think aloud responding, Netten et al. (2012a) explored LTC service users' comprehension of questions designed to elicit the counterfactual situation. In general, they found that people could estimate their QoL in the counterfactual situation. While the study provided tentative evidence for the feasibility of the CSEPP method as it is implemented within ASCOT, it did not provide an opportunity to test the validity of the method, and is limited in the generalisability of the findings because of the small samples involved. In this paper, therefore, we seek to improve the evidence base for the CSEPP approach within LTC. Using ASCOT data from a study of a sample of LTC service users in England, we explore (i) the feasibility of the CSEPP approach, and (ii) the validity of the method in terms of providing (a) an estimate of the counterfactual situation, and (b) an unbiased estimate of the effect of LTC interventions.

# Counterfactual self-estimation of outcomes

In their exposition of CSEPP, Mueller et al. (2014) set out how intervention effects are estimated using the potential outcomes framework (Rubin, 1974). Since there are no non-participants in the CSEPP method, the relevant concept from impact evaluation is the treatment-on-the-treated (TOT) effect. This is an estimate of the impact of the treatment on those who receive treatment. Following Mueller et al. (2014), the TOT effect under CSEPP can be calculated as

$$TOT_{CSEPP} = E[Y(1)|D = 1] - E[Y_{EST}(0)|D = 1],$$
(1)

where  $TOT_{CSEPP}$  is the counterfactual self-estimation of the effect of treatment on the treated; D is the binary treatment variable, where D = 1 is treatment participation and D = 0 is non-participation; E[Y(1)|D = 1] is the expected mean value in the outcome of the participants; and  $E[Y_{EST}(0)|D = 1]$  is the expected mean value in the outcome estimated by the counterfactual self-estimation method.

Importantly, since the CSEPP method asks the *same* individual to report their outcome under both conditions of treatment and no treatment at the *same* time, there is no problem of selection bias. All individuals are in both the treatment and control groups. Rather than selection bias, the CSEPP method suffers from what Mueller et al. (2014) refer to as selfestimation bias (SEB), which they formalise as

$$SEB = E[Y(0)|D = 1] - E[Y_{EST}(0)|D = 1],$$
(2)

where SEB is the deviation of the true counterfactual due to overestimation or underestimation of the counterfactual by self-estimation.

The extent of SEB will depend on the decision-making process people use to estimate the counterfactual situation. Since the feasibility and validity of the CSEPP method rest on the ability of people to estimate the counterfactual situation reliably and without bias, it is important to understand the cognitive processes involved in estimating the counterfactual situation in the LTC setting. We discuss these in the later section on estimating the counterfactual.

#### The ASCOT 'expected' method

ASCOT is a set of multi-attribute utility measures developed primarily for use in the evaluation of long-term care interventions, which in the UK are mainly provided through the social care system (Netten et al., 2011; Netten et al., 2012a). The measures have two components: a standardised multi-attribute descriptive system for classifying states of social care-related quality of life (SCRQoL), and a scoring algorithm derived from people's valuations of different SCRQoL states (Netten et al., 2012a; Potoglou et al., 2011). The descriptive system for the service user version of ASCOT, with which we are concerned here, consists of eight QoL attributes that are relevant to the assessment of the impact of LTC (for more details of the descriptive system see Malley et al., 2012). Ratings for each attribute, and respond using one of four response options, broadly capturing an ideal state in which all needs and preferences are met, a state of no need, some needs and high-level needs.

To estimate the impact of LTC interventions, the interview version of ASCOT (ASCOT-INT4), includes a further two questions, which we refer to as the 'filter' question and the 'expected' SCRQoL question. Figure 1 illustrates the question process for the control over daily life attribute. The respondent is asked about their 'current' situation and then to reflect on whether the services that they are receiving affect that aspect of their life. If the answer is yes the following 'expected' question asks users to imagine their situation in the absence of services and, assuming no other forms of help step in, evaluate their QoL in that situation. It provides an estimate of the counterfactual. The dignity attribute does not have an associated 'expected' question as it asks about people's experience of the process of care, so in the absence of services the condition can be scored at the 'no needs' level.

<sup>&</sup>lt;sup>1</sup> There is a version of ASCOT for use in care homes that triangulates evidence from an observational schedule, self-report and proxy-reports (see e.g. Netten et al., 2012b; Towers et al., 2016), but this version is not considered in this article.

#### [insert Figure 1]

These questions were refined during the development of the measure to address two challenges associated with evaluating the effect of LTC (Netten et al., 2012a). First, LTC interventions tend to be 'tailored' to meet the needs of the user, in terms both of the type and quantity of care provided. It is, therefore, important to define the intervention in order to have clarity over the counterfactual (absence of the intervention) condition. Consequently, the 'expected' situation is described with reference to the current service package, which may comprise multiple components, by listing each component. The second challenge is the problem of substitution, in which alternatives for the intervention exist and are used in the control condition (Heckman & Smith, 1995). There are many close substitutes for LTC interventions. For example, where a person receives a meals service, this aspect could be replaced by internet-based delivery companies. Other aspects of home care could be replaced with help from family and friends. Where respondents have knowledge of the availability of close substitutes they may assume they use these in the counterfactual situation, so leading to an underestimate of the intervention effect. The issue is not that the counterfactual is no longer the 'untreated' condition (many controlled experiments compare the new intervention with the best existing alternative). The difficulty is that the alternative is neither homogeneous across individuals, nor is it articulated. For this reason, the ASCOT-INT4 includes instructions and prompts for respondents to assume that 'no other help steps in'.

The parallels between the 'current' and 'expected' SCRQoL questions mean that (i) for each person a SCRQoL gain score can be estimated for each question, (ii) the scoring algorithm can be applied to both the 'current' and 'expected' SCRQoL questions, and (iii) a SCRQoL gain utility score, which is equivalent to  $TOT_{CSEPP}$ , can be generated by subtracting the 'expected' from the 'current' SCRQoL utility score. More formally, this can be expressed as,

$$Y_{gain} = \frac{\sum_{n=1}^{N} (Y_{current} - Y_{expected})}{N},$$
(3)

where  $Y_{current}$  is the utility score for the 'current' items,  $Y_{expected}$  is the utility score for the 'expected' items, and  $Y_{gain}$  is the average gain in utility over the sample of N people. Equation (3) is the equivalent of (1) expressed using ASCOT terminology.

# Estimating the counterfactual in the LTC context: cognitive processes, feasibility and sources of bias

When we ask people to estimate their own counterfactual, we assume that they mentally develop potential scenarios about what their QoL would have been like without LTC services. Although in the context of survey research it is unusual to ask people to imagine what their life would be like in a hypothetical situation, psychologists argue that counterfactual thinking is a common feature of our mental landscape (Roese & Olson, 1997). That counterfactual thinking is an everyday process and that most LTC interventions are of an ongoing nature support the credibility of this method for estimating effectiveness. Service users may have already imagined what their life would be like in the absence of the help and support upon which they rely; for example, in response to fears about care not being forthcoming because a care worker is delayed or because of cuts in public provision. This provides us with a significant advantage in the application of the CSEPP method to LTC compared to other settings.

Nevertheless, we must take seriously the problem of self-estimation bias (SEB). The cognitive processes involved in estimating the counterfactual situation are as follows:

- 1. To imagine a situation without the LTC intervention
- 2. To imagine that nothing else about your current situation would change: i.e. that there is no substitution with close alternatives to the intervention.
- 3. To judge your SCRQoL in that imagined situation.
- 4. To rate SCRQoL at one of four ASCOT outcome levels.

The difference between the 'current' and 'expected' ASCOT questions lies in the first two steps; SEB may arise during these steps. By contrast, steps three and four are common to all evaluative questions, substituting 'imagined' for real. They reflect the processes through which respondents evaluate their QoL (real or imagined) and provide an appropriate response – for which the challenges are well-rehearsed (see for example Schwartz & Rapkin, 2004; Schwartz & Sprangers, 1999).

Several questions therefore need to be addressed if we are to have confidence in using the 'expected' method to estimate the effectiveness of interventions.

*First, can LTC service users estimate their own counterfactual?* This question is concerned with the practical feasibility of the method and with understanding whether the method is suitable for all groups of LTC users. Previous in-depth work with small samples of older service users had explored their understanding of and capacity to answer the questions. This study sought to build on these findings with a larger sample including younger adults.

Second, does the 'expected' method provide a valid measure of the counterfactual situation? In asking this question, we are particularly concerned with the construct validity of the 'expected' SCRQoL measure, in terms of whether it measures what it is intended to represent, which in this case is the QoL of the person in the counterfactual situation of the absence of services. *Third, does the 'expected' method produce unbiased estimates of the impact of LTC?* This final question is critical to the interpretation of results and their validity.

# Methods

We explored the three research questions using data from the study 'Identifying the Impact of Adult Social Care' (Forder et al., 2016). This study was designed to provide estimates of the impact of LTC interventions on ASCOT and is described in detail elsewhere (Forder et al., 2016). Here we focus on key details of the data collection, before providing details of the statistical analyses conducted to answer the three research questions.

# Data collection

Twenty-two local authorities in England with adult social care responsibilities participated in the study. They identified eligible participants from their care records and invited them to participate in the study. Criteria for study inclusion were receipt of publicly-funded community-based LTC services (e.g. home care), not in nursing or residential care, aged ≥18 years, having mental capacity to consent to and participate in the study, and a primary reason for support of physical disability/sensory impairment or mental health condition. A fieldwork organisation contacted respondents to arrange an interview either face-to-face or by telephone. In total, 770 face-to-face or telephone interviews were conducted between June 2013 and March 2014. Written or verbal informed consent was obtained before each interview. This study uses a sub-sample of 748 cases, excluding cases where someone answered all of the ASCOT questions on behalf of the respondent without consultation.

Participants completed a structured interview that included the ASCOT-INT4 instrument (Netten et al., 2011; Netten et al., 2012a). The interview also covered the respondents' understanding of the 'expected' questions, through two questions that asked respondents to rate on a five-point scale (i) how easy or difficult they found the 'expected' questions overall, and (ii) how easy or difficult they found it to assume that no other help would step in. Interviewers were asked to rate on a five-point scale the degree to which the respondent understood what s/he was being asked to do and how much consideration the respondent gave to answering the questions. The interviewers also recorded their general comments in a free-text field at the end of the interview.

We used an adapted version of a standardised set of questions to capture information on functional ability (activities of daily living, ADLs, and IADLs (instrumental activities of daily living)) and receipt of formal and informal care and support<sup>2</sup> (NatCen et al., 2010). These

<sup>&</sup>lt;sup>2</sup> These questions asked about a range of LTC services: home care, personal assistant or support worker, day centre, direct payments, personal budgets, voluntary helper (e.g. sitting or befriending services), meals services, equipment (including lifeline alarms), handyman service, and professional

questions were asked before the ASCOT questions so that their responses could be used in the ASCOT 'expected' questions to help respondents to imagine the counterfactual situation, in the absence of services. Additionally, the interview included socio-demographic and socio-economic questions (e.g. age, sex, educational attainment, household finances) and questions concerning health conditions, self-reported general health, suitability of home design, and accessibility of the local area. Respondents were also asked to rate whether they had experienced a situation where they did not have LTC in the last 12 months.

A subset of the sample took part in follow-up interviews, with inclusion dependent on the primary care need being physical disability or sensory impairment. A total of 100 interviews were completed between two and 43 days after the initial interview (mean=10.3, SD=5.19). The follow-up interview included the ASCOT-INT4 with revised 'expected' questions that omitted the instruction to assume that 'no other help would step in'. The respondents were asked after each 'expected' question whether they assumed help would step in or not; if yes, then to provide the assumed source(s) of help. The follow-up interview also included the same I/ADL questions to assess functional ability and items to ask respondents to rate any perceived change in overall health, QoL or service receipt since the initial interview. This study uses a sub-sample of 96 cases, excluding cases where someone answered all of the ASCOT questions on behalf of the respondent without consultation.

Ethical approval was obtained from the English Social Care Research Ethics Committee (12/IEC08/0049).

# Statistical analysis

All analyses were conducted in Stata version 13. We used different analytical methods to assess each research question, as we detail below.

# Feasibility

To assess the feasibility of the 'expected' method and answer the question of whether LTC service users can estimate their own counterfactual, we examined missingness statistics for the ASCOT questions ('current' and 'expected') and descriptive statistics for the two self-assessed and two interviewer-assessed understanding of the 'expected' questions items. To explore whether there were any differences in feasibility between groups of LTC users, we examined associations between these items about understanding of the 'expected' questions.

In the models, we tested for associations between the feasibility questions and characteristics hypothesised to be associated with self-estimation bias (SEB). Characteristics

support from care managers or social workers, sheltered housing managers, community mental health teams and/or occupational therapists.

included severity of disability (measured by being unable to complete alone the I/ADLs of washing hands and face, bathing, and completion of paperwork and bills), complexity of care (with four or more different types of service) and perceptions of household finances. All of these factors may make it more difficult – emotionally and/or conceptually – to imagine the counterfactual situation. Additionally, we tested for associations with indicators of educational level and cognitive/intellectual impairment (completion of the interview with help and the IADL of completion of paperwork and bills, a predictor of early stages of dementia (Barberger-Gateau et al., 1993; De Lepeleire et al., 2004; Sikkes et al., 2011)), which may affect people's ability to engage with the 'expected' questions. Since earlier work suggested that respondents who had experience of situations with no support may find it easier to answer the 'expected' questions (Rand et al., 2012), we tested for an association with the respondents' report of whether they had experienced a situation without services in the last 12 months. We also explored whether the administration mode (telephone or face-to-face interview) affected the ability of respondents to complete and understand the 'expected' questions, because this may inform future applications of the method.

Given the importance of the instruction to assume that no help steps in, we explored how people responded to the questions when this instruction was omitted in the follow-up interviews as part of the feasibility analysis. We examined responses to the questions asking whether people assumed help would step in and, if so, who they assumed would provide it. We also looked at whether respondents' assumptions about help stepping in were associated with their responses to the 'expected' questions, using Fisher's exact test due to small cell counts (Mehta & Patel, 1986).

#### **Construct validity**

To assess whether the 'expected' method provides a valid measure of the counterfactual situation, we tested the construct validity of the 'expected' score ( $Y_{expected}$ ) as a measure of the QoL of the person in the absence of services. We assumed that the 'expected' score will have a strong ( $f^2$ >.35) negative relationship with social care need (Cohen, 1988), such that the greater the social care need the lower a person's 'expected' score. We therefore regressed Y<sub>expected</sub> on a set of social care need variables using OLS estimation. Since the purpose of social care assessment is to assess social care need, we drew on the criteria used by social workers when carrying out assessments to select variables for inclusion in the model. During assessment, social workers consider a person's underlying health and disabling conditions (e.g. chronic illnesses, impairments and disability), immediate environment (e.g. layout of the home, distance to shops), and resources (e.g. monetary and social support networks that provide informal help) (Department of Health, 2010). Therefore, we included ability to complete and difficulty with I/ADLs, which is considered to be the core driver of need for LTC (Wanless et al., 2006), overall self-rated health, and physical or mental health conditions as indicators of underlying conditions. As indicators of the immediate environment, which may compound or alleviate underlying functional impairments (Shakespeare, 2017), we included variables capturing whether the home or

local environment limited the individual. As indicators of resources that may be drawn upon to meet needs and substitute for LTC (Netten & Davies, 1990), we included variables capturing the availability of financial resources, whether the person lived alone, and whether they received unpaid care. Survey-administration factors may be potential sources of response bias and may confound observed relationships, so variables capturing these characteristics (help to complete the survey, interview mode) were also considered for inclusion in the model. These were entered in a hierarchical manner into the statistical model in four theoretically-informed blocks. Model specification and goodness of fit tests were carried out and all were found to be satisfactory.

#### Comparing estimates of the impact of LTC

To address the question of whether the 'expected' method produces unbiased estimates of effectiveness, we compared the average treatment effect estimated by the 'expected' method with those obtained using a production function method on the same dataset. Based in the economic theory of production relations, production functions have been used to estimate the relationship between care outcomes and levels of treatment (hours of care) from observational data in order to provide estimates of the effectiveness of care services (Davies et al., 2000; Fernandez, 2005). The earlier applications address selection bias by controlling for observable differences in the needs-related characteristics of the sample. Forder et al. (2016; 2014), extend the method by applying a spatial lag strategy to specify instrumental variables to tackle selection on unobservables (Jones & Rice, 2011). The details of this approach are outlined in Forder et al. (2016) and a more detailed technical exposition is given in Forder et al. (2018).

To compare the average estimated treatment effect obtained using the 'expected' and production function method for the same sample we use a t-test. We make adjustments for differences in the variance of the two indicators and look at whether the differences between the two estimates of the treatment effect vary according to factors posited to influence SEB. These factors include: the person's level of disability (I/ADLs), the complexity of the service package, receipt of unpaid help from family and friends, the potential availability of informal care from other people in the household, household finances, help to complete the interview, educational level, experience of a situation without formal long-term care services in the past 12 months and mode of interview administration.

#### Results

The sample characteristics are shown in Table 1. The age, sex and overall health of the sample are as 'expected' for a survey of social care users (Health and Social Care Information Centre, 2014). The follow-up subsample comprised only adults whose primary support reason was physical health conditions. All except one case received unpaid care

from family or friends. The level of care needs in this subsample, as indicated by the number of I/ADLs undertaken with difficulty, was higher than the overall sample, with no cases finding difficulty with fewer than three I/ADLs.

[insert Table 1]

# Feasibility

Table 2 presents distributional statistics for the 'current' and 'expected' SCRQoL scores, overall and by attribute. While the overall 'current' score is positively skewed (mean=0.73, median=0.76), the overall 'expected' score is closer to a normal distribution (mean=0.34, median=0.32). There is a low proportion of missing values (all <1.0%) across the seven SCRQoL attributes where the respondent was asked to answer both 'current' and 'expected' questions.

[insert Table 2]

The self and interviewer ratings of the feasibility of the 'expected' questions are shown in table 3. Over half of the respondents reported that it was very or quite easy to answer the 'expected' questions. Interviewers rated that the majority of respondents understood the questions completely or a great deal, and gave the questions very careful or careful consideration. These positive findings were reflected in the comments provided by the interviewers. For example, comments included: 'no problems with hypotheticals', 'able to imagine the hypotheticals well', 'seemed to find it very easy to imagine'. One interviewer also noted that 'the respondent was able to imagine her situation of help was not available because of being in that situation in the past', suggesting that experience may be valuable for imagining the counterfactual situation.

Although interviewers generally recorded positive experiences, they did note some problems. A few people needed the questions to be repeated, and some people with mental health conditions felt that the fluctuating nature of their condition made it difficult to answer the questions. They did not want to imply that their support had little impact on their QoL by evaluating the counterfactual situation in the present when they felt well.

[insert Table 3]

The characteristics influencing the feasibility of the 'expected' questions were systematically explored in ordinal logistic regressions, which are shown in table 4. Despite differences in

the wording of the self-reported and interviewer-reported feasibility questions, there was some agreement on the characteristics associated with feasibility. Across the three questions pertaining to the feasibility of the 'expected' questions as a whole, administration of the survey by telephone rather than face-to-face interview, poorer cognitive ability (as assessed through the difficulty with the IADL of paperwork and bills), and help to complete the interview were all significantly associated with lower self- or interviewer-reported feasibility in answering the 'expected' questions. The complexity of the care package, availability and receipt of informal care, experience of being without formal support and being unable to wash their face and hands were not associated with feasibility.

#### [insert Table 4]

There were some differences, however, between the self-reported and the interviewerreported questions in the characteristics that were associated with feasibility of the 'expected' questions. Respondents' perceptions of financial difficulties were significantly associated with greater self-reported difficulty in answering the 'expected' questions. Higher educational attainment and the respondent being unable to bathe him/herself were both significantly associated with interviewer ratings of respondents having a better understanding of the questions and giving them more consideration.

From the comments recorded by the interviewers, the most difficult aspect of the 'expected' questions appeared to be related to imagining the counterfactual state under the constraint that no other help would step in. This is reflected in the survey responses, where approximately two-fifths of respondents reported that they found it very or quite easy to imagine no other help would step in. The comments suggested that the difficulty was related to an unwillingness, rather than an inability, to imagine themselves in the counterfactual situation due to their degree of dependence on services. Interviewers commented that the 'expected' questions elicited responses such as 'I don't think my family would let me starve would they?'. Analysis of the characteristics associated with self-reported difficulty in assuming no other help would step in lends some support to this interpretation, as difficulty with this aspect of the 'expected' method was only significantly related to the complexity of the care package.

People who expressed initial unwillingness to imagine the counterfactual situation were usually still able to answer the questions. In some instances, however, it seemed to lead respondents to inaccurately report their 'expected' QoL. For example, the interviewers reported some respondents claiming that their QoL in the counterfactual situation would not be affected as they 'would "get by", "make it work", "find a way" and "soldier on". One respondent even claimed, 'I would make my own wheelchair out of spare parts'!

The results from the follow-up interviews, in which the 'expected' questions did not include the prompt to assume that no other help would step in, are shown in table 5. Of the service

users who completed the 'expected' questions, a large proportion based their response on a counterfactual situation that assumed someone would step in to help them if existing sources of formal support were no longer available. Most commonly, service users assumed that unpaid carers would provide additional support in the 'expected' situation. Less frequently, they assumed that paid care or other paid or unpaid sources of help, such as volunteers or cleaners, would substitute for publicly-funded formal care. Importantly, ratings of 'expected' control over daily life and accommodation were significantly associated with whether or not the respondent assumed someone else would step in. Respondents who said they assumed no other help would step in were more likely to rate high-level needs in these two attributes in the counterfactual situation compared to respondents who assumed someone else would help. A similar pattern of response was observed across the six other attributes, but the associations did not reach significance at the 5% level.

[insert Table 5]

# **Construct validity**

Table 6 presents the results of the hierarchical OLS regression of factors associated with 'expected' SCRQoL score. At least one variable from each of the groups of factors was significantly associated with 'expected' SCRQoL and Cohen's  $f^2$  for all models was >.35, providing good evidence for construct validity. Self-reported physical and mental health conditions, the I/ADL score, and poor or very poor self-rated health were all significantly associated with worse 'expected' SCRQoL from the set of underlying health and disabling conditions indicators. Of the immediate environment set of variables, the rating of local area accessibility was significantly negatively associated with 'expected' SCRQoL. Whether the person lived alone, which can be conceptualised as an indicator of the availability of unpaid care, was significantly negatively associated with 'expected' SCRQoL from the set of resources indicators. Finally, from the survey administration variables, the respondents who completed the interview by telephone had significantly lower ratings of 'expected' SCRQoL. In the final model, as anticipated, by far the most important variable for predicting 'expected' SCRQoL was the I/ADL indicator of functional ability.

[insert Table 6]

# Comparing estimates of the impact of LTC

Estimates of the treatment effect from both the 'expected' and the production function methods are shown in in table 7. The treatment effect estimates are close in value overall: 0.39 for the 'expected' method compared with 0.34 for the production function approach.

However, this is a statistically significant difference suggesting that either the production function approach underestimates the impact of services or that in the 'expected' approach people overestimate the effect of the absence of services on their QoL. Interestingly, the magnitude of the difference between the treatment effects estimated by the two methods varies by sub-group. Differences between the methods are greater than average where people were unable to undertake various I/ADLs, had a complex service package, had an informal carer, had higher educational attainment, or completed the survey by telephone. By contrast, the magnitude of differences are much smaller (in some cases close to zero) and often statistically insignificant where people were able to undertake various I/ADLs, had a less complex service package, had no informal carer, had lower educational attainment, or completed the survey by face-to-face interview.

[insert Table 7]

#### Discussion

The 'expected' method is a novel approach for evaluating LTC interventions. It seeks to solve a crucial evaluation problem by asking individuals receiving the intervention to imagine their own counterfactual in the absence of the intervention, and estimate what their situation would be like in that counterfactual situation. The difference between their imagined situation in the absence of the intervention and their actual situation provides an estimate of the effect of the intervention. Previous work with small samples had explored older service users' understanding of the questions and relevance of their responses. The purpose of the present study was to investigate with a larger and more diverse sample (i) whether LTC service users can estimate their own counterfactual, (ii) whether the 'expected' method provides a valid measure of the counterfactual situation, and (iii) whether the 'expected' method produces unbiased estimates of the impact of LTC. In addressing these questions, this study has expanded on the investigation by Netten et al. (2012a) of the feasibility of the 'expected' method by exploring completion rates for the 'expected' questions, and selfreported and interviewer-reported comprehension of the 'expected' questions. This study is the first to explore, in the LTC context, the validity of the counterfactual outcome score produced using the 'expected' method and to compare the treatment effect estimated by the 'expected' method to estimates using an alternative method.

Overall, the evidence presented confirms previous findings about the feasibility of the 'expected' questions and suggests that many LTC service users are able to estimate their own counterfactual. The 'expected' questions had good response rates, and respondents and interviewers both reported that the questions were in general answered well. In addition, the 'expected' ASCOT score (i.e. for the counterfactual situation) had good construct validity. Regression analysis uncovered the anticipated relationships with the

three groups of indicators of need for LTC support (underlying health and disabling conditions, immediate environment and resources available to meet needs) and a particularly strong relationship with functional (I/ADL) ability. This study, therefore, provides good support for the feasibility of the 'expected' method and the validity of self-estimated counterfactual outcome scores.

Having said this, the study did raise some questions about the feasibility of the 'expected' method for those with poorer cognitive ability, as indicators of cognitive ability were associated with lower ratings of both self-reported and interviewer-reported feasibility of the 'expected' questions. This is not surprising as answering any structured question is likely to be more difficult for this group of people and the hypothetical nature of the question is particularly challenging. The study also raised questions about the feasibility of using a telephone interview to administer the method, as this mode of administration was similarly associated with poorer self-reported and interviewer-reported feasibility of the 'expected' questions. Additionally, there is the suggestion from interviewers' recorded comments that those with fluctuating mental health conditions may find the questions more difficult. It would be helpful to explore the relationship between these aspects and feasibility further, to gain a better understanding of the applicability of the 'expected' method to different groups of LTC users. In any such study it would also be helpful to include questions to provide a baseline comparison for the difficulty of the 'expected' items.

A further point of interest was the differences in the characteristics of users that explained user- and interviewer-assessed feasibility of the 'expected' questions. This could be explained by differences in the perspectives of service users and interviewers. Interviewers are likely to use cues that signal mental effort and confusion, which may explain the relationship between interviewer ratings of feasibility and educational attainment, as people with lower educational attainment are known to need text with lower readability scores and less abstract questions (Holbrook et al., 2006). By contrast, perceived acceptability of the counterfactual situation was an important consideration for service users. This may explain the association between self-reported difficulty with the 'expected' questions and perceptions of household finances, as those with financial difficulty have fewer resources available to address the situation by other means and are consequently more dependent on the public provision of services.

A central concern with the CSEPP/'expected' method is the possibility that estimates suffer from self-estimation bias (SEB) (Mueller & Gaus, 2015; Mueller et al., 2014). One interpretation of the statistically significant difference in the treatment effect estimates from the between-methods comparison is that SEB is present in the 'expected' estimates. If this interpretation is correct then analysis of the differences in the estimates by sub-group suggested that SEB, which manifests itself as over-estimation of the effect of LTC, may be greatest where people are unable to complete various I/ADLs, have a complex service package, have an informal carer, have higher educational attainment, or are interviewed by telephone.

It is also possible that people who report finding the 'expected' questions more difficult will display more SEB. In this respect it is notable that the characteristics that are most important for explaining differences in the between-methods comparison of the average treatment effect are not always consistent with those that predict (self- or interviewer-) reported feasibility. For example, lower educational status is associated with problems with the 'expected' questions (as judged by the interviewer) but with a smaller difference in the estimates of the average treatment effect from the two methods. It is not clear whether there is a relationship between self-judged or interviewer-judged feasibility of the 'expected' questions and SEB. There is, however, some suggestion from interviewers' comments that, where respondents were initially unwilling to imagine the counterfactual situation, there may be a degree of SEB.

# Strengths and limitations of the study

A strength of this study was the ability to investigate the performance of the 'expected' method in LTC from a variety of perspectives. Nevertheless, the opportunistic nature of the study meant there were limitations in the methods used, which means there is some uncertainty around the study conclusions. There was limited information about mental health and no information on attitudes and personality, meaning it was not possible to investigate the impact of such factors on self-estimation bias. This could be an important omission as we might well expect people with depression, particularly long-term depression, to envisage a different counterfactual to others in the same situation. Moreover, since respondents chose whether to have a telephone or face-to-face interview, there is likely to be selection bias in the estimate of the effect of mode of administration on ratings of feasibility. Although we controlled for needs-related factors that are likely to be associated with this choice, it is possible that unobserved differences in the characteristics of people choosing the telephone and face-to-face modes explain the observed differences in perceptions of feasibility. More data about respondents' problems in answering structured questions in general would also provide a useful baseline for interpreting reported difficulties with the 'expected' questions. This might provide useful insight into the greater divergence in estimated outcomes for people who have higher levels of need.

The most important methods limitation relates to the assumption underlying the betweenmethods comparison: namely, that the production function method delivers largely unbiased estimates of the effect of LTC and, therefore, represents a robust benchmark for the 'expected' estimate. The validity of this assumption depends on how well the statistical model controls for selection bias on observable and unobservable confounders. In the production function approach, the latter is addressed through the instrumental variables estimation of the intensity of service input and the former through controlling for the types of needs-related characteristics already mentioned, i.e. underlying conditions, immediate environment, and resources. If the instrumental variables estimation fails to fully account for unobserved confounders then the model will underestimate the impact of LTC for this population. It is arguable that this may be most relevant for those with the highest and most complex needs. Either explanation – failure to fully account for selection bias or SEB – could account for the small difference in estimates of the treatment effect.

It is possible to develop plausible explanations for the observed sub-group variations in the magnitude of the difference of the treatment effect that support both the failure to account for selection bias and influence of SEB interpretations of the findings. For example, people with complex packages and more severe disability may overestimate the effect of LTC services, perhaps precipitated by an emotional reaction to the thought of losing services on which they are highly dependent -a constant concern given the tightening of eligibility criteria to address demand pressures (Fernandez et al., 2013). In the case of those with support from family and/or friends, they may attribute some of the input from these unpaid carers to formal care services, hence the overestimate. Educational attainment is a socioeconomic indicator and may be capturing people who are purchasing some of their care through private means. The 'expected' method, as it was implemented in this study, did not ask respondents to distinguish between sources of funding, so the impact of care is likely to include the effect of both privately and publicly-funded care services. An alternative explanation is that these are groups of LTC users for whom the production function method fails to completely address selection bias. This is an equally plausible explanation given the difficulty of estimating outcomes for those with the greatest levels of need (Davies et al., 2000; Forder et al., 2014; Malley, 2017).

A further strength of the study was the insight it provided into the presentation of the questions for deriving the counterfactual estimates. The results confirmed our expectation that the instruction to assume that no other help steps in is important, since without this instruction a large proportion of respondents assumed other help would step in to compensate for the loss of LTC services. This illustrates how significant the problem of substitution is for evaluation in the LTC context (Byford & Sefton, 2003; Knapp, 1984). The findings also suggest how substitution confounds the estimation of the treatment effect, leading to its underestimation, particularly with respect to control over daily life and accommodation. While it is arguable that we should allow respondents to assume that other help would step in, with such an assumption the knock-on implications for carers are not taken into account and users may have unrealistic expectations of what their carers would be able (or willing) to provide.

There is, however, some uncertainty around the effect of the instruction to assume no help steps in. This was the aspect of the method that presented most problems to respondents, but there were limitations to our ability to investigate the impact of this due to the nonexperimental design of this element of the follow-up study, and small numbers. The latter limitation meant we could not control for differences in observed characteristics of those who chose to assume that help stepped in and those who chose not to make this assumption. Randomisation of people to questionnaires with and without the instruction about help stepping in could address the limitation of this study and provide better evidence about the role of substitution on estimates of the treatment effect derived using the 'expected' method.

# Reflections on the 'expected' method and future directions

Evaluation of outcomes is particularly challenging in LTC, giving greater force to the arguments in favour of the CSEPP/'expected' method given by Mueller et al. (2014). Compared with experimental or quasi-experimental designs, the method is less resourceintensive, since evaluators need only collect data from the intervention participants. It is also a much simpler method, requiring no sophisticated sampling techniques or complicated statistical analysis to address selection bias, as the participants provide their own counterfactual. A further value of the 'expected' method is that, like non-experimental approaches, it is capable of answering a range of policy-relevant questions, and is not limited to establishing the average effect of treatment (Heckman & Smith, 1995). This is particularly relevant in the LTC setting, since common interventions – like home care or day centres, for example – tend both to differ in intensity according to the care 'needs' characteristics of users, and to show differences in the marginal productivity of services for different groups of care users (Davies et al., 2000; Fernandez, 2005; Knapp, 1984). The relationship between resource inputs and outcomes for different groups of users is of critical interest to practitioners and policymakers, who want to know what works for whom and to what extent to help guide the allocation of finite resources.

A number of questions remain about the 'expected' method. First, there is evidence from this study that the question instructions may influence how people construct their counterfactual. More careful exploration of how variations in the instructions affect the counterfactual rating and the sensitivity of estimates of the treatment effect to such differences is warranted, including the problems associated with and methodological implications of assuming no other help would step in. Second, further investigation is needed of how mental health (in particular long-term depression), attitude and personality affect people's ratings of the counterfactual. Third, the literature around counterfactual thinking suggests that the emotional significance of an issue affects counterfactual thinking (Mandel et al., 2007; Roese & Olson, 1997). There is evidence from this study that the counterfactual situation was emotionally charged for a number of participants. A more detailed examination of how the emotional significance of the counterfactual situation affects people's ability to engage with the questions and their responses would be beneficial. Fourth, there appeared to be differences in the feasibility of the 'expected' method depending on the mode of administration of the survey. Future research should investigate the suitability of telephone administration for the 'expected' method.

Finally, we have only been able to investigate SEB in a limited way in this study, by exploring the factors influencing feasibility of the 'expected' questions and whether the difference between the 'expected' method and production function method estimates for the effect of LTC differ according to sub-groups of the population. The findings from this aspect of the study are not conclusive given that perceptions of infeasibility may not lead to SEB and that the treatment effect estimates from the production function method may also be subject to selection bias. Despite this, the comparison with the production function method is still useful as it is often the only feasible option in the LTC context (Byford & Sefton, 2003; Forder et al., 2014) and is a well-established method in the econometric literature (Angrist et al., 1996; Newhouse & McClellan, 1998). Future applications of the CSEPP/'expected' method should attempt to determine the extent of SEB and to investigate its determinants (Mueller & Gaus, 2015). In the LTC setting we speculate that SEB may arise from three sources: systematic differences between individuals in the aspects of the LTC intervention they exclude from the counterfactual situation; systematic differences between individuals in the assumptions they make about substitution for current formal services with other forms of provision; and systematic differences in the *length of time people imagine* themselves in the counterfactual situation without services. This study identified some groups of service users for whom SEB may be an issue. It may be possible to explore SEB further among such groups of service users using verbal protocol analysis to uncover the strategies that people use to construct their counterfactual situation (Ericsson & Simon, 1980, 1993). Our previous research suggests that such an approach would be feasible with LTC users (Netten et al., 2012a). Comparison of the estimates from the 'expected' method with a more robust benchmark would also enable a more detailed investigation of SEB.

# Conclusion

Overall, the evidence suggests that the CSEPP/'expected' method, as implemented within ASCOT, could be a useful tool for use in LTC. It is an easy-to-implement method that can be used to generate results quickly. Importantly, the results from this study suggest that the 'expected' method produces estimates of effectiveness of LTC that are plausible and provide relevant inferences for policy development, when compared with the available alternative. Although a promising method, the potential for bias and, in particular, over-estimation of the effect of LTC services means that evidence about the effectiveness of interventions obtained using the 'expected' method should be supported by evidence from other studies conducted using alternative research designs. Further work is needed to investigate the impact of factors such as depression and other fluctuating needs, attitude and personality as this might suggest the need to routinely include questions that could assist in interpretation of responses. Nevertheless, the 'expected' method may be particularly useful for small-scale, exploratory studies that seek primary evidence about the effectiveness of LTC interventions.

As with any method, the 'expected' method will not be suitable for all groups of service users. There was no indication from this study that the people who completed the questionnaire could not complete these questions, but the method may be less feasible for people with reduced cognitive ability and fluctuating conditions. There was also evidence that the method is less well-suited for use in telephone interviews, as opposed to face-toface interviews, although this finding would benefit from further exploration. This study has provided some insight into potential sources of SEB, but a better appreciation of the role of SEB would provide greater confidence in the estimates of effectiveness and make it possible to expand the uses of the method. Future research should seek to understand the role of SEB in estimates of effectiveness obtained using this method.

# References

- Angrist, J.D., Imbens, G.W., & Rubin, D.B. (1996). Identification of causal effects using instrumental variables. *Journal of the American Statistical Association*, *91*(434), 444– 455. doi: 10.1080/01621459.1996.10476902
- Barberger-Gateau, P., Dartigues, J.-F., & Letenneur, L. (1993). Four Instrumental Activities of Daily Living Score as a predictor of one-year incident dementia. *Age and Ageing*, 22(6), 457–463. doi: 10.1093/ageing/22.6.457
- Byford, S., & Sefton, T. (2003). Economic evaluation of complex health and social care interventions. *National Institute Economic Review*, 186(1), 98–108. doi: 10.1177/002795010300100114
- Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences* (2nd ed.). Hillsdale, NJ: Lawrence Erlbaum Associates.
- Davies, B., Fernandez, J., & Nomer, B. (2000). *Equity and Efficiency Policy in Community Care: Needs, Service Productivities, Efficiencies, and their Implications*. Aldershot: Ashgate.
- De Lepeleire, J., Aertgeerts, B., Umbach, I., Pattyn, P., Tamsin, F., Nestor, L., & Krekelbergh, F. (2004). The diagnostic value of IADL evaluation in the detection of dementia in general practice. *Aging & Mental Health, 8*(1), 52–57. doi: 10.1080/13607860310001613338
- Department of Health. (2010). Prioritising need in the context of 'putting people first'. A whole system approach to eligibility for social care guidance on eligibility criteria for adult social care, England 2010. London: Department of Health.
- Ericsson, K.A., & Simon, H.A. (1980). Verbal reports as data. *Psychological Review*, 87(3), 215–251. doi: 10.1037//0033-295x.87.3.215
- Ericsson, K.A., & Simon, H.A. (1993). *Protocol Analysis: Verbal Reports as Data*. Cambridge, MA: MIT Press.
- Evans, D. (2003). Hierarchy of evidence: a framework for ranking evidence evaluating healthcare interventions. *Journal of Clinical Nursing*, *12*(1), 77–84. doi: 10.1046/j.1365-2702.2003.00662.x
- Fernandez, J.-L. (2005). Utilisation and Service Productivities in Community Social Care for Older People: Patterns and Policy Implications. Unpublished doctoral dissertation, London School of Economics and Political Science, London.
- Fernandez, J.-L., Snell, T., & Wistow, G. (2013). Changes in the Patterns of Social Care Provision in England: 2005/6 to 2012/13. PSSRU Discussion Paper 2867. London: PSSRU, London School of Economics.
- Forder, J., Malley, J., Rand, S., Vadean, F., Jones, K., & Netten, A. (2016). IIASC report: Interpreting outcomes data for use in the Adult Social Care Outcomes Framework (ASCOF). Discussion Paper 2892. Canterbury, Kent: QORU, University of Kent.
- Forder, J., Malley, J., Towers, A.-M., & Netten, A. (2014). Using cost-effectiveness estimates from survey data to guide commissioning: an application to home care. *Health Economics, 23*(8), 979–992. doi: 10.1002/hec.2973

- Forder, J., Vadean, F., Rand, S., & Malley, J. (2018). The impact of long-term care on quality of life. *Health Economics*, 27, e43–e58. doi: 10.1002/hec.3612
- Health and Social Care Information Centre. (2014). Personal Social Services Adult Social Care Survey, England 2013-14, Final release. Leeds: Health and Social Care Information Centre.
- Heckman, J.J., & Smith, J.A. (1995). Assessing the case for social experiments. *The Journal of Economic Perspectives*, 9(2), 85–110.
- Holbrook, A., Cho, Y.I.K., & Johnson, T. (2006). The impact of question and respondent characteristics on comprehension and mapping difficulties. *Public Opinion Quarterly*, 70(4), 565–595. doi: 10.1093/poq/nfl027
- Jones, A., & Rice, N. (2011). Econometric evaluation of health policies. In S. Glied & P. Smith (Eds.), *The Oxford Handbook of Health Economics*. Oxford: Oxford University Press.
- Knapp, M. (1984). The Economics of Social Care. Basingstoke: Macmillan.
- Malley, J. (2017). Adjusting for Unobserved and Observed Heterogeneity in Survey-Based Performance Indicators: An Application to Adult Social Care in England. Unpublished doctoral dissertation, London School of Economics and Political Science, London.
- Malley, J.N., Towers, A.-M., Netten, A.P., Brazier, J.E., Forder, J.E., & 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*(1), 1–14. doi: 10.1186/1477-7525-10-21
- Mandel, D.R., Hilton, D.J., & Catellani, P. (2007). *The Psychology of Counterfactual Thinking*. London: Routledge.
- McKee, M., Britton, A., Black, N., McPherson, K., Sanderson, C., & Bain, C. (1999). Interpreting the evidence: choosing between randomised and non-randomised studies. *British Medical Journal, 319*(7205), 312–315. doi: 10.1136/bmj.319.7205.312
- Mehta, C.R., & Patel, N.R. (1986). Algorithm 643: FEXACT: a FORTRAN subroutine for Fisher's exact test on unordered *r* x *c* contingency tables. *ACM Transactions on Mathematical Software*, *12*(2), 154–161. doi: 10.1145/6497.214326
- Mueller, C.E., & Gaus, H. (2015). Assessing the performance of the "counterfactual as selfestimated by program participants": results from a randomized controlled trial. *American Journal of Evaluation, 36*(1), 7–24.
- Mueller, C.E., Gaus, H., & Rech, J. (2014). The counterfactual self-estimation of program participants: impact assessment without control groups or pretests. *American Journal of Evaluation*, 35(1), 8–25.
- NatCen, PSSRU LSE, PSSRU University of Kent, & University of East Anglia. (2010). Social care for older people aged 65+: questionnaire documentation.
- Netten, A., Beadle-Brown, J., Caiels, J., Forder, J., Malley, J., Smith, N., . . . Windle, K. (2011).
   ASCOT Adult Social Care Outcomes Toolkit: Main Guidance v2. 1. PSSRU Discussion
   Paper, 2716/3. Canterbury, Kent: University of Kent, Personal Social Services
   Research Unit.

- Netten, A., Burge, P., Malley, J., Potoglou, D., & Towers, A. (2012a). Outcomes of social care for adults: developing a preference weighted measure. *Health Technology Assessment, 16*(16), 165. doi: 10.3310/hta16160
- Netten, A., & Davies, B. (1990). The social production of welfare and consumption of social services. *Journal of Public Policy*, *10*(3), 331–347.
- Netten, A., Trukeschitz, B., Beadle-Brown, J., Forder, J., Towers, A.-M., & Welch, E. (2012b). Quality of life outcomes for residents and quality ratings of care homes: is there a relationship? *Age and Ageing*, *41*(4), 512–517. doi: 10.1093/ageing/afs050
- Newhouse, J.P., & McClellan, M. (1998). Econometrics in outcomes research: The use of instrumental variables. *Annual Review of Public Health, 19*(1), 17–34. doi: 10.1146/annurev.publhealth.19.1.17
- Nutley, S., Walter, I., & Davies, H.T.O. (2003). From knowing to doing: A framework for understanding the evidence-into-practice agenda. *Evaluation*, 9(2), 125–148. doi: 10.1177/1356389003009002002
- Petticrew, M., & Roberts, H. (2003). Evidence, hierarchies, and typologies: horses for courses. *Journal of Epidemiology and Community Health*, *57*(7), 527–529. doi: 10.1136/jech.57.7.527
- Potoglou, D., Burge, P., Flynn, T., Netten, A., Malley, J., Forder, J., & Brazier, J.E. (2011).
   Best–worst scaling vs. discrete choice experiments: An empirical comparison using social care data. *Social Science & Medicine*, 72(10), 1717–1727. doi: 10.1016/j.socscimed.2011.03.027
- Rand, S.E., Malley, J., & Netten, A. (2012). Measuring the Social Care Outcomes of Informal Carers. An Interim Technical Report for the Identifying the Impact of Social Care (IIASC) Study. PSSRU Discussion Paper 2833. Canterbury, Kent: Personal Social Services Research Unit, University of Kent.
- Roese, N.J., & Olson, J.M. (1997). Counterfactual thinking: The intersection of affect and function. Advances in Experimental Social Psychology, 29, 1–59. doi: 10.1016/S0065-2601(08)60015-5
- Rubin, D.B. (1974). Estimating causal effects of treatments in randomized and nonrandomized studies. *Journal of Educational Psychology, 66*(5), 688–701. doi: 10.1037/h0037350
- Schwartz, C.E., & Rapkin, B.D. (2004). Reconsidering the psychometrics of quality of life assessment in light of response shift and appraisal. *Health and Quality of Life Outcomes, 2*(1), 1–11. doi: 10.1186/1477-7525-2-16
- Schwartz, C.E., & Sprangers, M.A.G. (1999). Methodological approaches for assessing response shift in longitudinal quality of life research. *Social Science and Medicine*, 48, 1531 – 1548.
- Shakespeare, T. (2017). The social model of disability. In L.J. Davis (Ed.), *The Disability Studies Reader* (Fifth ed., pp. 195–203). London: Routledge.
- Sikkes, S.A., Visser, P.J., Knol, D.L., de Lange-de Klerk, E.S., Tsolaki, M., Frisoni, G.B., . . . Uitdehaag, B.M. (2011). Do instrumental activities of daily living predict dementia at 1- and 2-year follow-up? Findings from the Development of Screening Guidelines and

Diagnostic Criteria for Predementia Alzheimer's Disease study. *Journal of the American Geriatrics Society, 59*(12), 2273–2281. doi: 10.1111/j.1532-5415.2011.03732.x

- Towers, A.-M., Smith, N., Palmer, S., Welch, E., & Netten, A. (2016). The acceptability and feasibility of using the Adult Social Care Outcomes Toolkit (ASCOT) to inform practice in care homes. *BMC Health Services Research*, *16*(1), 523. doi: 10.1186/s12913-016-1763-1
- Wanless, D., Forder, J., Fernández, J.L., Poole, T., Beesley, L., Henwood, M., & Moscone, F. (2006). Wanless Social Care Review: Securing Good Care for Older People: Taking a long-term view. London: King's Fund.

#### **Table 1. Sample characteristics**

	Overall sample	Follow-up subsample
	(n=748)	(n=96)
	Frequency (%), or	Frequency (%), or
	Mean (SD, range)	Mean (SD, range)
Age, ≥65 years	395 (52.8%)	54 (56.3%)
Sex, male	312 (41.7%)	39 (40.6%)
Physical health condition(s), (self-reported)	495 (66.2%)	96 (100.0%)
Mental health condition(s), (self-reported)	322 (43.1%)	n/a
I/ADLs with difficulty <sup>†</sup>	8.10 (4.01, 0-13)	9.32 (3.09, 3-13)
Unable to wash hand/face	126 (16.8%)	16 (16.7%)
Unable to have a bath/shower †	391 (52.4%)	66 (68.9%)
Unable to complete paperwork	395 (52.8%)	49 (51.0%)
Self-rated health <sup>+</sup>		
Very good/good	223 (29.8%)	33 (34.4%)
Fair	298 (39.8%)	38 (39.6%)
Very poor/poor	226 (30.2%)	25 (26.0%)
Lives alone	379 (50.7%)	30 (31.3%)
Suitability of home design <sup>+</sup>		
Meets needs very well	371 (49.6%)	50 (52.1%)
Meets most needs	229 (30.6%)	28 (29.2%)
Meets some needs / inappropriate	147 (19.7%)	18 (18.7%)
Accessibility of local area †		
Able to get to all places	237 (31.7%)	32 (33.3%)
At times, difficult to get to all places	261 (34.9%)	34 (35.4%)
Unable to get to all places / does not leave home	248 (33.2%)	30 (31.3%)
Educational level to A-Level equivalent, or higher +	273 (36.5%)	33 (34.4%)
Household financial situation <sup>+</sup>		
Very/quite well	303 (40.5%)	42 (43.8%)
Alright	263 (35.2%)	32 (33.3%)
Some/severe difficulties	175 (23.4%)	20 (20.9%)
Unpaid care	561 (75.0%)	95 (99.0%)
Experienced situation without formal care in the last 12 months +	223 (29.8%)	71 (74.0%)
Complex package of social care support +, ++	151 (19.6%)	25 (26.0%)
Interviewed with help from someone else	87 (11.6%)	18 (18.8%)
Interview by telephone	191 (25.5%)	35 (36.5%)

+ Missing values (overall sample): I/ADLs with difficulty (64); Unable to have a bath/shower (2); Self-rated health (1); Suitability of home design (1); accessibility of local area (2); Educational level (5); Household financial situation (7); Experienced situation without formal care in last 12 months (21); Complex package of social care support (13).

Missing values (follow-up subsample): I/ADLs with difficulty (12); Unable to have a bath/shower (1); Household financial situation (2);

Experienced situation without formal care in last 12 months (4); Complex package of social care support (2).

++ Complex package of social care support: The service user reported receiving support from four or more different types of service.

# Table 2. ASCOT social care-related quality of life (n=748)

Frequency (%), or mean (SD, range) 0.73 (0.21, -0.13 to 1.00) 11 (1.5%) 208 (27.8%) 264 (35.3%) 219 (29.3%) 55 (7.4%) 2 (0.2%) 422 (56.4%) 267 (35.7%) 49 (6.6%) 9 (1.2%) 1 (0.1%)	Frequency (%), or mean (SD, range) 0.34 (0.29, -0.09 to 0.96 18 (2.4%) 69 (9.2%) 71 (9.5%) 236 (31.6%) 370 (49.5%) 2 (0.2%) 156 (20.9%) 126 (16.8%) 199 (26.6%) 266 (35.6%) 1 (0.1%)
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9 (1.2%) 1 (0.1%)	266 (35.6%)
1 (0.1%)	
	1 (0.1%)
522 (60.8%)	
522 (60.8%)	
322 (09.878)	288 (38.5%)
171 (22.9%)	123 (16.4%)
36 (4.8%)	118 (15.8%)
16 (2.1%)	216 (28.9%)
3 (0.4%)	3 (0.4%)
449 (60.0%)	219 (29.3%)
224 (30.0%)	143 (19.1%)
63 (8.4%)	156 (20.9%)
12 (1.6%)	230 (30.7%)
0 (0%)	0 (0%)
387 (51.8%)	133 (17.8%)
248 (33.2%)	157 (21.0%)
81 (10.8%)	161 (21.5%)
	296 (39.6%)
	1 (0.1%)
	. ,
249 (33.3%)	134 (17.9%)
	136 (18.2%)
	189 (25.3%)
	285 (38.1%)
	4 (0.5%)
0 (0/0)	. (0.370)
188 (25 1%)	107 (14.3%)
	107 (14.5%)
	271 (36.2%)
	255 (34.1%) 6 (0.8%)
	36 (4.8%) 16 (2.1%) 3 (0.4%) 449 (60.0%) 224 (30.0%) 63 (8.4%) 12 (1.6%) 0 (0%) 387 (51.8%) 248 (33.2%)

Table 3. Self-rated or interviewer-rated feasibility of expected SCRQoL questions (n=748)

	Frequency (%)
How easy or difficult to answer the expected question	ıs? †
Very easy	201 (26.9%)
Quite easy	241 (32.2%)
Neither difficult nor easy	58 (7.8%)
Quite difficult	99 (13.2%)
Very difficult	132 (17.7%)
Ease of imagining no other help would step in †	
Very easy	108 (14.4%)
Quite easy	168 (22.6%)
Neither difficult nor easy	123 (16.4%)
Quite difficult	128 (17.1%)
Very difficult	191 (25.5%)
Interviewer-rating of respondent comprehension of e	xpected questions
Understood completely	359 (48.0%)
Understood a great deal	240 (32.1%)
Did not understand at all / very much	149 (19.9%)
Interviewer-rating of respondent effort in answering e	expected questions
Very careful consideration	357 (47.7%)
Careful consideration	242 (32.4%)
No, little or some consideration	149 (19.9%)

+ Missing values: Ease or difficulty of answering expected questions (17); Ease of imagining no other help would step in (30).

#### Table 4. Ordinal logistic regressions

	Difficulty of answering expected questions	Difficulty of imagining no other help steps in	Understanding of the expected questions (interviewer-rated)	Consideration given to expected questions (interviewer-rated)
	OR (SE)	OR (SE)	OR (SE)	OR (SE)
Unable to wash hand/face	0.982 (0.204)	1.020 (0.212)	0.845 (0.187)	0.704 (0.157)
Unable to have a bath/shower	0.985 (0.153)	1.198 (0.184)	1.750 (0.292) **	1.654 (0.276) **
Unable to complete paperwork or bills	1.505 (0.233) **	1.332 (0.206)	0.507 (0.085) ***	0.489 (0.081) ***
Complex package of social care support	1.311 (0.227)	1.513 (0.264) *	0.844 (0.158)	0.800 (0.147)
Unpaid help from family/friends	1.186 (0.206)	1.245 (0.220)	1.114 (0.214)	1.423 (0.271)
Lives alone	1.267 (0.190)	1.213 (0.181)	0.823 (0.134)	0.828 (0.135)
Household finances: Alright	1.186 (0.189)	1.144 (0.180)	1.153 (0.194)	1.251 (0.212)
Household finances: Some or severe difficulties	1.734 (0.317) **	1.301 (0.240)	1.175 (0.231)	1.004 (0.198)
Had help to complete the interview	2.024 (0.467) **	1.289 (0.297)	0.189 (0.048) ***	0.193 (0.048) ***
Educated to A-Level equivalent or higher	1.243 (0.182)	1.045 (0.154)	1.782 (0.286) ***	2.007 (0.323) ***
Experienced situation without formal care in the last 12 months	1.161 (0.178)	1.206 (0.186)	0.908 (0.148)	1.009 (0.165)
Interview by telephone	1.952 (0.315) ***	1.312 (0.208)	0.638 (0.112) *	0.690 (0.121) *
McFadden's pseudo R <sup>2</sup>	0.03	0.01	0.07	0.08
<b>Κ</b> <sup>2</sup>	53.0 ***	28.5 **	99.8 ***	109.0 ***
N	690	680	702	702

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001

#### Table 5. Follow-up interviews (*n*=96)

	Answered expected	Assumed that help	Additional help from	Additional help from	Additional help from	Association with the
	question	would step in	unpaid carer	paid carer	other source	assumption that help
	Frequency	Frequency	Frequency	Frequency	Frequency	Fisher's Exact
	(% of sample)	(% of respondents) <sup>+</sup>	(p-value)			
Control over daily life	82 (85.4%)	27 (32.9%)	18 (22.0%)	8 (9.8%)	4 (4.9%)	0.010*
Personal comfort and cleanliness	79 (82.3%)	28 (35.4%)	18 (22.8%)	8 (10.1%)	4 (5.1%)	0.114
Food and drink	45 (46.9%)	20 (44.4%)	13 (28.9%)	6 (13.3%)	3 (6.7%)	0.630
Accommodation comfort and cleanliness	50 (52.1%)	24 (48.0%)	16 (32.0%)	5 (10.0%)	4 (8.0%)	0.004**
Personal safety	78 (81.3%)	26 (33.3%)	20 (25.6%)	6 (7.7%)	3 (3.8%)	0.204
Social participation	50 (52.1%)	18 (36.0%)	12 (24.0%)	4 (8.0%)	6 (12.0%)	0.469
Occupation	60 (62.5%)	17 (28.3%)	12 (20.0%)	3 (5.0%)	4 (6.7%)	0.498

<sup>+</sup> Missing values: Control over daily life (2); Personal comfort and cleanliness (1); Food and drink (1); Personal safety (1); Social participation (3); Occupation (3).

\*p<0.05, \*\* p<0.01

#### Table 6. Hierarchical regression analysis

Outcome variable: Expected SCRQoL	Model	1	Model	2	Model	3	Model	14
	В	SE	В	SE	В	SE	В	SE
Physical health condition(s) (self-reported)	-0.051*	0.022	-0.044*	0.021	-0.047*	0.022	-0.043*	0.022
Mental health condition(s) (self-reported)	-0.046*	0.020	-0.040*	0.020	-0.037	0.020	-0.042*	0.020
Number of I/ADLs with difficulty or unable to complete alone	-0.034**	0.003	-0.031**	0.003	-0.031**	0.003	-0.032**	0.003
Self-rated health: Fair <sup>+</sup>	-0.043	0.024	-0.031	0.024	-0.030	0.024	-0.029	0.024
Self-rated health: Poor or very poor +	-0.088**	0.027	-0.063*	0.028	-0.057*	0.028	-0.057*	0.028
Home design: Meets most needs <sup>+</sup>			0.022	0.022	0.026	0.022	0.025	0.022
Home design: Meets some needs/inappropriate <sup>+</sup>			-0.045	0.027	-0.039	0.027	-0.038	0.027
Local area: Difficult or unable to get to all places or not leave home †			-0.085**	0.023	-0.080**	0.023	-0.079**	0.023
Household finances: Alright <sup>+</sup>					0.005	0.023	-0.002	0.022
Household finances: some or severe difficulties <sup>+</sup>					-0.029	0.026	-0.030	0.026
Live alone					-0.049*	0.021	-0.051*	0.021
Unpaid care					-0.022	0.025	-0.020	0.025
Interviewed with help from someone else							-0.025	0.031
Interview by telephone							-0.086**	0.023
Constant	0.718**	0.027	0.734**	0.028	0.775**	0.035	0.807**	0.036
Ν		653		652		648		648
Adjusted R <sup>2</sup>		0.293		0.311		0.311		0.324
F (df), change in R <sup>2</sup>		n/a	(	5.7**(3 <i>,</i> 64)		0.3 (4,35)		7.0**(2,63)
Cohen's f <sup>2</sup> (all explanatory variables)		0.414		0.451		0.451		0.479
Cook-Weisberg test for heteroscedasticity, X <sup>2</sup> (1)		0.01		0.07		0.19		0.04
Ramsey-Reset test, F (df) misspecification	3	3.2*(3,644)	3	3.6*(3,640)	:	2.7*(3,632)		1.3 (3,630)
Link test, hat <sup>2</sup>		0.35**		2.96**		2.53*		1.81
VIF		1.31		1.31		1.32		1.30

**Base category**: Health, good or very good; home design, meets needs very well; accessibility of local area, able to get to all areas; household finances, very or quite well.
 \*p<0.05; \*\* p<0.01</li>

Table 7. Comparison of effectiveness estimates between the CSEPP/expected and production function methods

	Mean (Std. Dev, N)	Mean (Std. Dev, N)	Unpaired t-test with unequal variances
	CSEPP/expected	Production function	(p value)
Overall	0.390 (0.281, 711)	0.340 (0.173, 714)	<0.001**
By subgroup			
Able to wash hands and face alone / with difficulty	0.364 (0.270, 587)	0.336 (0.168, 590)	0.029*
Unable to wash hands and face	0.508 (0.306, 124)	0.363 (0.194, 124)	<0.001**
Able to bath or shower alone / with difficulty	0.300 (0.263, 335)	0.315 (0.155, 337)	0.381
Unable to bath or shower	0.471 (0.273, 374)	0.364 (0.185, 377)	<0.001**
Able to sort out paperwork or bills alone / with difficulty	0.353 (0.279, 336)	0.323 (0.166, 336)	0.090
Unable to sort out paperwork or bills	0.422 (0.280, 375)	0.356 (0.178, 378)	<0.001**
Complexity of services: <4 services	0.378 (0.278, 554)	0.346 (0.168, 557)	0.025*
Complexity of services: 4+ services	0.448 (0.286, 145)	0.316 (0.193, 146)	<0.001**
Without unpaid help from family/friends	0.308 (0.299, 176)	0.310 (0.166, 180)	0.944
With unpaid help from family/friends	0.416 (0.270, 535)	0.351 (0.175, 534)	<0.001**
Lives with others	0.395 (0.286, 348)	0.349 (0.175, 350)	0.011*
Lives alone	0.384 (0.277, 363)	0.332 (0.171, 364)	0.002**
Household finances: Good	0.418 (0.286, 287)	0.366 (0.146, 293)	0.007**
Household finances: Alright	0.386 (0.278, 251)	0.341 (0.181, 250)	0.032*
Household finances: Bad	0.345 (0.271, 167)	0.297 (0.192, 165)	0.062
No help to complete the interview	0.387 (0.285, 629)	0.341 (0.174, 632)	<0.001**

Had help to complete the interview	0.411 (0.251, 82)	0.336 (0.165, 82)	0.027*
Educated up to GCSE or equivalent	0.379 (0.280, 445)	0.348 (0.175, 449)	0.049*
Educated to A-Level equivalent or higher	0.403 (0.283, 262)	0.328 (0.170, 261)	<0.001**
Not experienced situation without formal care in the last 12 months	0.407 (0.283, 482)	0.363 (0.160, 484)	0.003**
Has experienced situation without formal care in the last 12 months	0.356 (0.270, 215)	0.291 (0.191, 216)	0.004**
Completed by face-to-face interview	0.370 (0.012, 529)	0.340 (0.008, 533)	0.031*
Completed by telephone interview	0.446 (0.022, 182)	0.342 (0.013, 181)	<0.001**

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

Please tick  $(\Box)$  one box

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

2. Do the support and services that you get from <<<u>EXAMPLE</u>>> affect how much control you have over your daily life?

Please tick (☑) one box

Yes	
No	
Don't know	

If 2 = yes or don't know, then go to question 3 If 2 = no, then go to question 4

3. Imagine that you didn't have the support and services from <<<u>EXAMPLE</u>>> that you do now and no other help stepped in. In that situation, which of the following would best describe the amount of control you would have over your daily life?

Please tick (☑) one box

I would have as much control over my daily life as I want	
I would have adequate control over my daily life	
I would have some control over my daily life, but not enough	
I would have no control over my daily life	

Figure 1. Illustration of the question process for the CSEPP/expected method in ASCOT [©PSSRU University of Kent]