

Carer social care-related quality of life outcomes: estimating English preference weights for the Adult Social
Care Outcomes Toolkit for Carers (ASCOT-Carer)

Laurie Batchelder, PhD^{1*}; Juliette Malley, PhD²; Peter Burge, MSc³; Hui Lu, PhD³; Eirini-Christina Saloniki,
PhD^{1,4}; Ismo Linnosmaa, PhD^{5,6}; Birgit Trukeschitz, PhD⁷; Julien Forder, PhD¹

¹Personal Social Services Research Unit, University of Kent, Kent, UK

²Personal Social Services Research Unit, London School of Economics, London, UK

³RAND Europe, Cambridge, UK

⁴Centre for Health Services Studies, University of Kent, Kent, UK

⁵Centre for Health and Social Economics, National Institute for Health and Welfare, Helsinki, Finland

⁶Department of Health and Social Management, University of Eastern Finland, Finland

⁷Research Institute for Economics of Aging, WU Vienna University of Economics and Business, Vienna,
Austria

*Corresponding author. Email address: laurie.batchelder@gmail.com; Address: Cornwallis Central, University
of Kent, Canterbury, CT2 7NF; Telephone number: +44(0)7552079077

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Highlights:

- There is increased interest to examine the effects of interventions on older people and their informal carers in economic evaluations. This study fills a gap in the literature by producing the first set of preference-based index values for the English version of ASCOT-Carer in a general population sample from England using Best-Worst Scaling.
- This work provides new evidence indicating attributes of social care-related quality of life of informal carers using the ASCOT-Carer are valued differently, highly valuing having time to do things valued and enjoyed, as well as having as much control over daily life as wanted.
- These preference weights for the English version of the ASCOT-Carer can be used for economic evaluation of interventions that support informal carers.

Abstract

Objective: To estimate preference-based index values for the English version of the ASCOT-Carer, a measure assessing social care-related quality of life (SCRQoL) in informal carers, from the general population in England.

Methods: The ASCOT-Carer consists of seven domains, each reflecting aspects of SCRQoL in informal carers. Preferences for the ASCOT-Carer SCRQoL states were estimated using a Best-Worst Scaling exercise (BWS) in an online survey. The survey was administered to a sample of the general adult population in England (n=1,000). Participants were asked to put themselves into the hypothetical state of being an informal carer and indicate which attribute they thought was the best (first and second) and worst (first and second) from a profile list of seven attributes reflecting the seven domains, each ranging at a different level (1-4). Multinomial logistic regression was used to analyse the data and estimate preference weights for the ASCOT-Carer measure.

Results: The most valued aspect by English participants was the 'occupation' attribute at its highest level. Results further showed participants rated having 'no control over their daily life' as the lowest attribute-level of all those presented. The position of the seven attributes influenced participants' best and worst choices, and there was evidence of both scale and taste heterogeneity on preferences.

Conclusions: This study has established a set of preference-based index values for the ASCOT-Carer in England derived from the BWS exercise that can be used for economic evaluation of interventions on older individuals and their informal carers.

Introduction

Informal care is a key part of the total care provided for older individuals and those with long-term conditions. Providing care for another individual can have significant effects on the carer's health and quality of life (QoL) [1–4]. Caregiving can have negative effects on the carer's mental and physical health and QoL [3,5,6], but can also have positive effects, arising from empathy, altruism, and fulfilment [7,8]. Research shows interventions on older individuals and those with long-term conditions can have an effect on a carer's health and QoL, so it is important economic evaluations of these interventions also consider the impact on informal carers [9, 10].

Several studies that have attempted to measure the effects of interventions on informal carers used the quality-adjusted life years (QALYs) metric [9, 10]. In measuring QALYs of informal carers the EQ-5D measure is often used [10]. The EQ-5D focuses on aspects of health status and not on more holistic aspects of QoL or well-being, so it may not be broad enough to capture what matters to informal carers or the impact of caregiving on informal carers for economic evaluations [11]. To overcome this limitation, carer-specific measures assessing QoL and/or well-being have been developed [12–15]. Carer-specific measures typically focus on negative effects of care on carers' QoL, such as care burden, while neglecting positive effects of care [7,16]. Recent measures, such as the Care-related Quality of Life Instrument (CarerQoL) [17] and the Carer Experience Scale (CES) [7,18], have been developed to capture the impact of caregiving on informal carers. However, validation is ongoing.

The Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer)ⁱ is an outcome measure aimed at assessing social care-related QoL for informal carers (SCRQoL) across seven domains [19,20]. These include: occupation, control over daily life, self-care, personal safety, social participation, space and time to be yourself, and feeling supported and encouraged. Each domain is rated on a four-level scale, ranging from the 'ideal state' (level 1) to 'high needs' (level 4). A key feature of this measure, differentiating it from other relevant measures, is its focus on the impact of social care services on informal carers. The ASCOT-Carer was developed using interviews and cognitive testing to capture important aspects of carers' SCRQoL [19,20,21,22]. However, certain attributes of carers' SCRQoL are likely to be more important than others. To account for this in producing a single overall SCRQoL score, we need to determine the relative value or 'weight' for each of the measures' attribute-levels [23,24]. To date, the ASCOT-Carer has not been preference-weighted.

There are different methods available to elicit preferences in informal carers. Previous work has examined the use of the time trade-off technique (TTO) for estimating the value of a carer's well-being [25]. Additional work has estimated preference-based index values for the CES using Best-Worst Scaling (BWS) in carers [7]. BWS is arguably a less cognitively burdensome method compared to other choice methods, such as discrete choice experiments (DCE) or TTO [26,27]. The main advantage of the BWS (profile case) is people consider the attribute-levels that describe a profile, instead of comparing two profiles [27] (for further details on this method, see e.g. Flynn et al. [28]).

The aim of this study was to estimate a set of preference weights for the English version of the ASCOT-Carer instrument gathered from an English sample using BWS. This paper begins by explaining the methods used for the BWS exercise: experimental design, methods of data collection and planned analysis. We report BWS model results relating to the generation of preference weights for the ASCOT-Carer in an English sample for economic evaluations.

Methods

Valuation exercise

During BWS, participants were asked to put themselves in the imaginary state of caring for someone who was unable to care for themselves due to either illness, accident or old age. Participants were presented with eight scenarios. Each scenario included a profile containing seven attributes reflecting the seven SCRQoL domains of ASCOT-Carer [23,28,29]. The attributes each represented one out of four levels, ranging from 'ideal state' (level 1) to 'high needs' (level 4). Participants were asked to select the 'best' choice from the list of attribute-levels in the scenario (type of BWS experiment known as 'profile' case). This selected choice was greyed out. The same process was repeated for the worst, second best and second worst choices. After selecting all four choices in the first scenario, this process was repeated for the remaining seven scenarios of the different attribute-level combinations. In total, each participant made 32 choices (i.e. four choices in each of the eight scenarios).ⁱⁱ

Experimental design

The scenarios for the BWS exercise were developed using an orthogonal main effects plan (OMEP) [30]. All attributes had the same number of levels, so we were able to use a “balanced” OMEP whereby all attributes were statistically independent of one another. The full factorial design plan consisted of 4^7 possible profiles, which would be too many states for presentation [24,31,32]. The fractional-factorial design reduced the full factorial plan to a design matrix of 32 scenarios. The design matrix was blocked into four segments. Thus, each participant received eight BWS scenarios. The blocking procedure retained balance within the blocks and sought to minimise correlations of the levels being presented for the attributes within the block. A foldover design was used to eliminate easy or straightforward choices from each scenario [33]. The blocked scenarios were randomly allocated to participants to minimise selection bias. The order of attributes was randomised between participants to prevent ordering bias and separate the effect of attribute choice from the position of that attribute within a scenario [34,35].

Survey design and sampling

The BWS exercise was part of a self-completion online survey. The survey included some general socio-demographic questions to assess representativeness of the sample and participants’ consent to take part in the study. The survey also included a set of questions regarding participants’ QoL and SCRQoL using the ASCOT-Carer measure, the BWS exercise, some follow-up questions about participants’ understanding of the BWS exercise, some questions concerning the participants’ experiences of social care and caring, and some additional socio-demographic and socio-economic questions. The study was reviewed and approved by the [reference] Research Ethics Committee [reference].

We estimated preferences of a general population sample (rather than a service user or carer sample), which is a common approach in the estimation of preference weights [36,37]. This is because it is the public at large whose views are relevant, where services are publicly-funded and whose data is used to make decisions about resource allocations [38].

The survey was piloted in May 2016 with a total sample of 50 adults from the general population, recruited through an online panel. The pilot data helped inform decisions regarding wording of the BWS exercise. Following the pilot, some questionnaire items and wording of the BWS exercise were refined for clarity.

The main survey was conducted between June and July 2016. The study included 1,000 adults recruited from the general population in England. Participants were recruited from the same online panel as the pilot; those who completed the main survey did not complete the pilot survey. Sampling was targeted to be representative of the English general population in terms of age, gender, and region. Individuals who took less than 4.5 minutes to complete the BWS task were omitted from the sample before the end of data collection, as this was deemed an unrealistically short period of time to complete the task. Sampling continued until the target of 1,000 participants was reached. No further exclusion criteria were applied for the analysis.

Statistical analysis

Analysis of best-worst scaling data

Based on random utility theory, a multinomial logit regression (MNL) [39,40] model was used to estimate preference weights for informal carers' SCRQoL using the ASCOT-Carer. The estimation closely followed Netten et al. [36]. Each attribute was specified as an alternative and given a utility function, which was based on the level at which the attribute was presented within the scenario and the position of the attribute in the scenario. The position effect of the attribute was separated by best (first and second) and worst (first and second) choices. The MNL model assumed all choices were independent and sequential [28,41]. The basic MNL model was estimated as follows:

$$U_{iq} = V_{iq} + \varepsilon_{iq}, \forall J \quad (1)$$

where U_{iq} is the utility function for respondent q derived for an alternative i being chosen from a profile of J alternatives. The utility function has a systematic component, V_{iq} , and a random component, ε_{iq} .

An example of the specification of the basic utility function for the occupation domain is outlined below. Effects coding was used to dissociate best (first and second) and worst (first and second) choices:

$$\begin{aligned}
U_q(\text{occupation}) = & +\beta_1 * (1, \text{if occupation level} = 1)_{iq} * (1, \text{if choice} = \text{best or second best})_{iq} \\
& -\beta_1 * (1, \text{if occupation level} = 1)_{iq} * (1, \text{if choice} = \text{worst or second worst})_{iq} \\
& \vdots \\
& +\beta_4 * (1, \text{if occupation level} = 4)_{iq} * (1, \text{if choice} = \text{best or second best})_{iq} \\
& -\beta_4 * (1, \text{if occupation level} = 4)_{iq} * (1, \text{if choice} = \text{worst or second worst})_{iq} \\
& +\gamma_1^B * (1, \text{if occupation appeared in first row})_{iq} * (1, \text{if choice} = \text{best or second best})_{iq} \\
& \vdots \\
& +\gamma_7^B * (1, \text{if occupation appeared in seventh row})_{iq} * (1, \text{if choice} = \text{best or second best})_{iq} \\
& -\delta_1^W * (1, \text{if occupation appeared in first row})_{iq} * (1, \text{if choice} = \text{worst or second worst})_{iq} \\
& \vdots \\
& -\delta_7^W * (1, \text{if occupation appeared in seventh row})_{iq} * (1, \text{if choice} = \text{worst or second worst})_{iq} \\
& +\varepsilon_{iq}
\end{aligned} \tag{2}$$

Where; $\beta_1 \dots \beta_4$ denotes the coefficient for each attribute-level (1 refers to the ideal state, whereas 4 refers to high needs), $\gamma_1^B, \dots, \gamma_7^B$ ($\delta_1^W, \dots, \delta_7^W$) are the coefficients for the position of the occupation attribute within the best-worst scenario if the choice was best or second best (worst or second worst), ε_{iq} refers to the random component. The attribute ‘control over daily life’ at level 4 was used as a reference level and was set to zero [36].

Each choice in the above was estimated using the MNL model:

$$P_{iq} = \frac{e^{\vartheta V_{iq}}}{\sum_{j \in J} e^{\vartheta V_{jq}}} \tag{3}$$

Where; P_{iq} refers to the probability of each respondent q choosing alternative i from all relevant alternatives j in a profile J . ϑ is the scale parameter and inversely proportionate to the standard deviation of the random component.

The basic MNL model was first estimated. The basic model refers to the MNL model (1) in which $\vartheta = 1$. T-ratios were used to indicate the level of significance of the coefficient compared to the reference levels (‘control over daily life’ at level 4 and first position of the profile list for first and second best and worst choices). A t-ratio of -1.96 or +1.96 was considered statistically significant at the 95% level.

The scale heterogeneity MNL model (S-MNL) [42] was estimated to control for differences in error variance in sub-groups. This allowed us to investigate the consistency of choices and would allow for more valid and reliable utility estimates [28]. Following the work of Netten et al. [36], scale factors were included in the model to test for scale heterogeneity based on previous research (age, education level, best and worst choices, time taken to complete the BWS task, health status) [36]. After testing the hypothesized scale factors, we ended with a model that included three statistically significant scale factors that were sensible and in-line with economic / psychological theory: age, education and time taken to complete the BWS task.

It is also important to control for variation in preferences between sub-groups associated with observable characteristics (taste heterogeneity). Our aim was to account for any additional variation in estimation within the model based on our sampling approach. Taste heterogeneity was modelled by adding interaction terms between attribute-levels and observable characteristics to the systematic component of the model (1) [30]. Several taste factors were included in the model to test for taste heterogeneity on the attribute-levels based on socio-economic and socio-demographic characteristics that were either significantly under- or overrepresented in the sample compared to the general population (see Table 1) [36]. After testing the hypothesized taste factors, we ended with a model that included four statistically significant taste factors that were sensible and in-line with economic / psychological theory: education, marital status, social grade and religion.

Each participant in the BWS task made 32 choices (giving 32,000 observations in total). The full sample was used for the basic MNL model but was reduced to 31,392 observations due to a small number of missing observations for the education variable (608 observations, or 19 participants) in the S-MNL and taste heterogeneity S-MNL models.

The MNL models were developed and estimated first using ALOGIT software [43]. To correct for the repeated nature of the task, robust standard errors were obtained using the sandwich estimator [36] and estimated in Biogeme [44].

Generation of preference-based index values for the ASCOT-Carer in England

Results from the taste heterogeneity S-MNL model were then used to generate sensible preference-based index values by taking into account representativeness of the data. Population proportions were applied to certain coefficients where there was evidence of (taste) variation in the taste heterogeneity S-MNL model to produce revised average values that take into account significant differences that exist between groups. Socio-economic and socio-demographic variables selected to apply population proportions were informed by large differences compared to the general population detected through descriptive statistics (>10 point difference): marital status, education, social grade, religion [41,45]. Population proportions taken from English Census and National population statistics were applied to the selected taste variables to better reflect tastes of the English population (see Table 1 in Appendix for list of sources).

The next step was to rescale the revised average values so that summed state attribute scores varied on a 0-1 interval [31,41,46]. In the QALY, death is typically anchored to zero. For the current study, values were rescaled such that ‘high needs’ or the ‘pits state’ were given a value of zero. This reflected a measure of unmet needs. The benefit of this option is it allowed us to measure and understand the relative value of each SCRQoL state and retain a scale of ‘high needs’ or ‘pits state’ and ‘ideal state’ [31,41,46]. Anchoring values of the ASCOT-Carer to the dead state may be considered in future work.

One seventh of the value of the state 4444444 (‘high needs’ for all seven domains) was subtracted from all attributes. This value was then divided by the difference between value states 1111111 (‘ideal state’ for all seven domains) and 4444444 (‘high needs’ for all seven domains). This was to ensure the lowest possible state (‘pits state’) (‘high needs’ for all seven domains) sums to zero and the highest possible state (‘ideal state’ for all seven domains) sums to one, while maintaining relative differences between the attribute-level coefficients [31,41,46].

Results

Table 1 includes socio-demographic and socio-economic statistics from the sample (n = 1,000) compared to the general population. There was a larger number of respondents in higher education (e.g. having a degree and above (BA/MA/PhD or equivalent)) (38.9%) compared to the general population (27.4%). There was a larger number of respondents in either lower or upper secondary education (40.6%) and a smaller proportion of

respondents below secondary education (4.9%) compared to the general population (15.2% and 35.8%). For religion, there was a larger proportion of respondents who reported no religion (42.6%) compared to the general population (23.4%). The sample also underrepresented those of Christian faith. There was a larger proportion of respondents reported as married/in a civil partnership (58.2%) compared to the general population (46.8%). For social grade, Grades AB (combined) were overrepresented (46.2%) compared to the general population (22.9%). Both Grade C2 and Grades DE (combined) were also underrepresented. The percentage of people with self-reported 'very good' health status also differed. 'Good' and 'fair' health statuses (50.2% and 24.3%) were also overrepresented compared to the general population (34.2% and 13.1%).

{insert Table 1}

Descriptives for the BWS task are reported in Table 2. The median time to complete the BWS task was just under 8 minutes. Nearly all of the participants were able to put themselves into the imaginary situations, either all of the time (45.8%) or some of the time (47.6%). Interestingly, 23.5% of the sample did not think about the length of time in the imaginary situations, whereas 31.4% of participants imagined the length of time in the imaginary situations would be a number of years, and 23.4% thought the length of time would be permanent. The majority of respondents were able to understand the scenarios presented in the BWS task (73.4%), considered all of the scenarios when making decisions (82.7%), and found the BWS task fairly easy to complete (63.5%).

{insert Table 2}

Best-worst scaling model results

Table 3 presents the attribute-level coefficients, the position best (first and second) and worst (first and second) choice variables estimated using the basic MNL model for the ASCOT-Carer. The goodness-of-fit measure (rho-squared) indicated the MNL model fit performed relatively well, with a rho-squared value = 0.226 (a rho-squared value between 0.25 – 0.3 is equivalent to a value between 0.75 and 0.80 of a linear regression model) [36].

{insert Table 3}

All attribute-levels were estimated relative to level 4 of the ‘control over daily life’ attribute. The latter was defined as the reference level because it had the lowest utility. There were statistically significant differences between estimated coefficients compared to level 4 of the ‘control over daily life’ attribute. This indicates all other SCRQoL states were more valued compared to ‘control over daily life’ level 4, indicating these weights were greater and more positive compared to this attribute-level.

The largest coefficient was estimated for the ‘occupation’ attribute at level 1. The second largest coefficient was the ‘control over daily life’ attribute at level 1. The lowest coefficient was estimated for the ‘control over daily life’ attribute at level 4, followed by the second lowest coefficient, ‘occupation’ attribute at level 4.

The parameters of the position variables capturing instances in which an attribute was chosen in a particular position for the best and second best choices were all statistically significant. There was no clear trend for positioning of worst and second worst choices.

A second model was estimated to investigate the potential influence of scaling effects on preferences. Results for the S-MNL model with scale effects are presented in Table 4.

{insert Table 4}

The attribute-level coefficients were all statistically significant compared to ‘control over daily life’ at level 4, similar to the findings from the original MNL model. Participants placed the highest valuation on ‘occupation’ at level 1 and the lowest valuation on ‘control over daily life’ at level 4. Position effects were also consistent with the original MNL model.

The scale parameters revealed significant variations in error variance amongst different groups. Findings showed those who were aged 45 years and older, those who had higher educational qualifications, and those who spent more than six minutes to complete the BWS task, made more deterministic choices and showed less error variance compared to their group counterparts.

A final model was estimated to explore variation in preferences between groups. Results for the taste heterogeneity S-MNL model are presented in Table 5.

{insert Table 5}

The taste heterogeneity S-MNL model showed similar results compared to the original MNL and S-MNL models, where participants placed the highest valuation on ‘occupation’ at level 1 and the lowest valuation on ‘control over daily life’ at level 4.

Those with higher educational qualifications placed a higher value on ‘occupation’ level 1 compared to those with other educational qualifications. Individuals with short-term tertiary educational qualifications also placed a higher value on ‘control over daily life’ level 1. The top level of the ‘space and time to be yourself’ attribute was also valued more highly by those who identify with social grade A (‘higher managerial, administrative or professional’) than those who identify with any other social grade classification. Individuals who identify with social grade B (‘intermediate managerial, administrative or professional’) were less concerned if they were in a situation in which they would ‘have some encouragement and support, but not enough’ than individuals identifying with any other social grade classification. Those of Christian faith (all denominations) also placed a lower value on the bottom level of the ‘support’ attribute. Married individuals valued the ‘control over daily life’ attribute higher and the ‘social participation’ attribute lower compared to their unmarried counterparts.

ASCOT-Carerer preference-based index values

Population proportions were applied to certain coefficients showing evidence of taste heterogeneity and correcting for sample unrepresentativeness. The coefficients were adjusted, and the weighted average values were re-scaledⁱⁱⁱ. The final preference-based index values for all attribute-levels of the ASCOT-Carerer are presented in Figure 1.

{insert Figure 1}

We can calculate the overall SCRQoL informal carer state by summing the preference-based index values for the selected levels across each attribute. For instance, the value for state 333333 (0.405) is the sum of values at level 3 ('some needs') across all attributes of the ASCOT-Carer.

Discussion

The current study produced a set of preference-based index values for the ASCOT-Carer within a general sample from England. Respondents placed the highest value on the 'occupation' attribute-level 1 and a lower value on other attributes, with the lowest valuation on the 'control over daily life' attribute at level 4. These values can be used to assess the impact of interventions on older individuals and their informal carers in England for economic evaluations.

We found the values of the levels within each attribute of the ASCOT-Carer monotonically increased, which was in-line with our expectations given that the levels were placed on an ordinal scale. The largest utility differences were found between the second highest valued level (level 2) compared to the second lowest valued level (level 3) for all attributes except the safety attribute. There were fewer differences between the highest and second highest valued level (levels 1 and 2). The steep drop in perceived utility when moving between level 2 and level 3 may indicate that people tend to place higher value on positively framed outcomes (i.e. ideal state or no needs), and major changes to utility is implemented once reaching a certain state (i.e. some needs or high needs). Interestingly, for the safety attribute, the decrements between the levels were fairly similar.

We further explored position effects on best and worst choices. Results identified the position of the attributes in the list framed how respondents made 'best' (first and second) choices. Respondents were more likely to indicate attributes presented at the top of the list were the 'best', and less likely to choose attributes as the 'best' as they moved down the list, which is consistent with the literature [35,36,45]. This framing was not apparent for worst (first and second) choices. Participants may use different heuristics and psychological processes when evaluating profiles and selecting best and worst choices [47]. For instance, respondents may be more inclined to choose the first or second positioned item for the best choices but examine each item in every position for the worst choices. Choice probability from the MNL model assumes all participants consider the process of

choosing best and worst choices is the same, and this work further confirms the need to randomize the ordering of the attributes to control for the ordering effect in the BWS task.

There were also significant differences in preferences for SCRQoL in informal carers based on socio-economic and socio-demographic characteristics, including education, marital status, social grade and religion. Further results showed variations in error between groups. The significant age and education effects on error variance may relate to cognitive ability, which has been shown to underlie choice behavior [23,31]. Those who took longer time to complete the BWS exercise showed less error variance compared to faster respondents. This finding is in-line with previous work revealing greater error variance for quicker respondents in online stated choice experiments [48]. One explanation is some respondents take longer to understand the cognitive processes underpinning the BWS task, suggesting slower respondents use more cognitive effort and make more deterministic choices [49]. This includes taking into account all of the attributes in each scenario and weighing up the available alternatives [50].

This work further investigates the BWS exercise to assess whether it is a viable technique to value SCRQoL states in a general sample. There was good completion of the BWS exercise, and the majority of participants understood the BWS and were able to put themselves into the hypothetical state as a carer [31]. The majority of participants also found the exercise fairly easy to complete. The BWS exercise was administered through a web-based survey, which allowed participants to easily access and complete the questionnaire. This design also allowed us to achieve a large sample size to give sufficient power to estimate preferences and provide robust results to explore scale and taste heterogeneity [41].

There are some limitations worth noting in the study. It is argued scale and taste heterogeneity should be investigated together but there is some debate about whether estimates from the S-MNL model are biased [51]. S-MNL models are routinely used to estimate preferences [42]; however, others proposed using alternative methods to analyse the data, such as scale-adjusted latent class analysis [31,32]. Future work could further examine BWS data using this method to further investigate the accuracy of the method. Another limitation is some variable sub-groups of the sample were unrepresentative compared to the general population (education, marital status, social grade, religion). We aimed to account for this by adjusting the coefficients to take into account population proportions.

There are a number of implications for social care policy and practice drawn from this work. This study has filled a gap by generating preference weights for the ASCOT-Carer, an outcome measure for informal carers based on attributes that matter most to people. This expands the use of the measure, making it suitable for use in economic evaluations of interventions and support. The ASCOT-Carer was designed to capture broader well-being experiences relevant to caring for other people, rather than simply measuring health effects. This is useful for social care practice [36] in England and could complement the preference-weighted ASCOT service user measure to understand the impact of interventions on older people and people with long-term conditions and their informal carers.

Conclusion

We estimated a set of preference-weighted index values for the English version of the ASCOT-Carer measure from the general population in England using BWS. BWS has shown to be a viable technique to value SCRQoL informal carer states to be used for understanding the impact of social care and interventions on older people and people with long-term conditions and their informal carers in England for economic evaluations.

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ⁱ *The ASCOT measure is disclosed in full herein but ordinarily should not be used for any purposes without the appropriate permissions of the ASCOT team and the copyright holder – the University of Kent. Please visit www.pssru.ac.uk/ascot or email ascot@kent.ac.uk to enquire about permissions.*

ⁱⁱSee *Supplementary Material* for an example of the Best-Worst Scaling task using the ASCOT-Carer measure

ⁱⁱⁱSee *Supplementary Material* for a comparison of re-scaled coefficients (0-1 values) from the basic MNL model, the S-MNL model and the taste heterogeneity S-MNL model

Table 1. Sample characteristics compared to the general population (N = 1,000)

Variable	Sample		General Population	
	Frequency	%	Frequency	%
Gender ¹				
Male	480	48.00	20,262,822	48.62
Female	520	52.00	21,412,674	51.38
Age ²				
18-24 years	106	10.60	4,920,128	11.41
25-34 years	175	17.50	7,485,996	17.37
35-44 years	167	16.70	7,107,372	16.49
45-54 years	182	18.20	7,700,360	17.86
55-64 years	190	19.00	6,183,043	14.34
65 – 79 years	173	17.30	7,089,983	16.45
80+ years	7	0.70	2,621,589	6.08
Ethnicity ¹				
White	900	90.00	36,377,829	87.29
Mixed/Multiple ethnic backgrounds	15	1.50	602,862	1.45
Asian/Asian British	62	6.20	3,007,110	7.22
Black/African/Caribbean/Black	15	1.50	1,284,281	3.08
Other ethnic group	1	0.10	403,414	0.97
Prefer not to say	7	0.70	--	--
Religion ¹				
No religion	426	42.60	9,768,622	23.44
Christian (all denominations)	480	48.00	25,721,735	61.72
Buddhist/Hindu/Jewish/Muslim	64	6.40	3,063,874	7.35
Any other religion/Prefer not to say	30	3.00	3,121,265	7.49
Education (ISCED class) ³				

Below secondary education (ISCED < 2)	49	4.90	15,371,251	35.76
Lower secondary education and upper secondary education (ISCED 2, 3)	406	40.60	6,544,614	15.22
Short-cycle tertiary and post- secondary education (ISCED 4, 5)	140	14.00	6,842,565	15.92
BA/MA/PhD or equivalent (ISCED 6, 7, 8)	389	38.90	11,769,361	27.38
Don't know	3	0.30	--	--
Other	16	1.60	2,461,829	5.73
Marital status³				
Married/In a civil partnership	582	58.20	20,129,657	46.82
Separated (still legally married)	20	2.00	1,141,196	2.65
Divorced	57	5.70	3,857,137	8.97
Widowed	31	3.10	2,971,702	6.91
Single, that is, never married AND never in a civil partnership	299	29.90	14,889,928	34.64
Prefer not to say	11	1.10	--	--
Employment status⁴				
Employed (full-time, part-time, self-employed)	616	61.60	24,143,464	62.10
In education, (not paid for by employer) even if on vacation	38	3.80	3,592,654	9.24
Unemployed	42	4.20	1,702,847	4.38
Permanently sick or disabled	24	2.40	1,574,134	4.05
Retired	224	22.40	5,320,691	13.68
In community or military service	0	0.00	--	--

Doing housework, looking after children or other persons	50	5.00	1,695,134	4.36
Other	3	0.30	852,450	2.19
Don't know	3	0.30	--	--
Social grade ⁵				
A/B	462	46.20	7,737,602	22.94
C1	276	27.60	10,238,039	30.35
C2	122	12.20	7,396,569	21.93
D/E	130	13.00	8,362,138	24.79
Other	10	1.00	--	--
Self-reported health status ⁶				
Very good	196	19.60	25,005,712	47.17
Good	502	50.20	18,141,457	34.22
Fair	243	24.30	6,954,092	13.12
Bad	52	5.20	2,250,446	4.25
Very bad	7	0.70	660,749	1.25

¹ Source: 2011 Census for England, 18+ population from England and Wales-

https://www.nomisweb.co.uk/census/2011/DC1117EW/view/2092957699?rows=c_age&cols=c_sex

² Source: 2015 Analysis Tool, Office for National Statistics

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesanalysistool>

³ Source: 2011 Census for England, population estimates for those aged 16+ from England and Wales-

https://www.nomisweb.co.uk/census/2011/DC5107EWLA/view/2092957699?rows=c_hlqpk11&cols=c_age

⁴ Source: 2011 Census for England, population estimated for those aged between 16 and 74 from England and

Wales https://www.nomisweb.co.uk/census/2011/KS601EW/view/2092957699?rows=cell&cols=c_sex

⁵ Source: 2011 Census for England, all residents for England between 16 and 64

<https://www.nomisweb.co.uk/census/2011/QS613EW/view/2092957699?cols=measures>

⁶ Source: 2011 Census for England, all residents from England and Wales

https://www.nomisweb.co.uk/census/2011/QS302EW/view/2092957699?rows=c_health&cols=rural_urban

Table 2. Descriptives for the BWS task (N = 1,000)

Variable	%
Time taken to complete the BWS task (minutes) – median	7.88
Interquartile range (IQR): 25% - 75%	6.00 – 11.37
Ability to put themselves in the imaginary situation	
Yes, all of the time	45.80
Yes, but only some of the time	47.60
No	6.60
Assumed length of time in imaginary situation	
Didn't think about it	23.50
Temporary – less than a few weeks	2.10
Temporary – a number of weeks	3.80
Temporary – a number of months	7.00
Temporary – about a year	8.80
Temporary – a number of years	31.40
Permanent or rest of my life	23.40
Understanding of the scenarios in the BWS task	
Yes, all of the time	73.40
Yes, but only some of the time	24.00
No	2.60
Whether considered all of the scenarios when making decisions	
Yes, all of the time	82.70
Yes, but only some of the time	15.80
No	1.50
Report of how easy or difficult to complete the BWS task	
Very easy	12.10
Fairly easy	63.50
Fairly difficult	22.80
Very difficult	1.60

Table 3. Estimated parameters for the ASCOT-Carerer measure using general population data from England-
Basic MNL model (N = 1,000)

Attribute level		MNL	
	coefficient	S.E.	t-ratio (robust)
<i>Occupation</i>			
1. I'm able to spend my time as I want, doing things I value or enjoy	4.019	0.112	35.9
2. I'm able do enough of the things I value or enjoy with my time	3.748	0.105	35.6
3. I do some of the things I value or enjoy with my time, but not enough	2.170	0.073	29.6
4. I don't do anything I value or enjoy with my time	0.327	0.049	6.6
<i>Control over daily life</i>			
1. I have as much control over my daily life as I want	3.876	0.109	35.6
2. I have adequate control over my daily life	3.288	0.096	34.3
3. I have some control over my daily life, but not enough	1.825	0.069	26.3
4. I have no control over my daily life	0.000	0.000	Constant
<i>Looking after yourself</i>			
1. I look after myself as well as I want	3.122	0.089	35.2
2. I look after myself well enough	2.957	0.089	33.3
3. Sometimes I can't look after myself well enough	0.839	0.055	15.2
4. I feel I am neglecting myself	0.451	0.053	8.6
<i>Safety</i>			
1. I feel as safe as I want	2.943	0.082	35.7
2. Generally I feel adequately safe, but not as safe as I would like	1.770	0.063	28.3
3. I feel less than adequately safe	1.066	0.057	18.6
4. I don't feel at all safe	0.601	0.054	11.1
<i>Social participation and involvement</i>			
1. I have as much social contact as I want with people I like	3.095	0.093	33.4
2. I have adequate social contact with people	2.780	0.081	34.4

3. I have some social contact with people, but not enough	1.894	0.066	28.6
4. I have little social contact with people and feel socially isolated	0.776	0.054	14.4
<i>Space and time to be yourself</i>			
1. I have all the space and time I need to be myself	3.681	0.103	35.8
2. I have adequate space and time to be myself	3.294	0.092	35.7
3. I have some of the space and time I need to be myself, but not enough	2.008	0.070	28.6
4. I don't have any space or time to be myself	0.517	0.049	10.6
<i>Feeling supported and encouraged</i>			
1. I feel I have the encouragement and support I want	3.255	0.093	35.1
2. I feel I have adequate encouragement and support	3.074	0.088	35.0
3. I feel I have some encouragement and support, but not enough	1.858	0.067	27.8
4. I feel I have no encouragement and support	0.652	0.054	12.1
<i>Attribute position in the BWS task</i>			
Position 1_B	0.000	0.000	Constant
Position 2_B	-0.140	0.041	-3.4
Position 3_B	-0.222	0.041	-5.4
Position 4_B	-0.314	0.042	-7.5
Position 5_B	-0.365	0.043	-8.4
Position 6_B	-0.402	0.045	-9.0
Position 7_B	-0.397	0.045	-8.8
Position 1_W	0.000	0.000	Constant
Position 2_W	0.010	0.043	0.2
Position 3_W	-0.008	0.043	-0.2
Position 4_W	0.023	0.045	0.5
Position 5_W	0.034	0.044	0.8
Position 6_W	-0.022	0.045	-0.5
Position 7_W	0.062	0.045	1.4
No. of observations	32,000		
df	39		

Final log-likelihood	-41693.4
Rho ² (0)	0.226
AIC	83464.9
BIC	83791.5

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Table 4. Estimated parameters for the ASCOT-Carer measure using general population data from England- S-MNL model (N = 981)

Attribute level		S-MNL	
	coefficient	S.E.	t-ratio (robust)
<i>Occupation</i>			
1. I'm able to spend my time as I want, doing things I value or enjoy	2.886	0.189	15.3
2. I'm able do enough of the things I value or enjoy with my time	2.694	0.176	15.3
3. I do some of the things I value or enjoy with my time, but not enough	1.561	0.106	14.7
4. I don't do anything I value or enjoy with my time	0.233	0.037	6.2
<i>Control over daily life</i>			
1. I have as much control over my daily life as I want	2.781	0.185	15.1
2. I have adequate control over my daily life	2.368	0.155	15.3
3. I have some control over my daily life, but not enough	1.304	0.092	14.2
4. I have no control over my daily life	0.000	0.000	Constant
<i>Looking after yourself</i>			
1. I look after myself as well as I want	2.228	0.151	14.7
2. I look after myself well enough	2.113	0.145	14.6
3. Sometimes I can't look after myself well enough	0.610	0.052	11.8
4. I feel I am neglecting myself	0.342	0.041	8.4
<i>Safety</i>			
1. I feel as safe as I want	2.092	0.142	14.7
2. Generally I feel adequately safe, but not as safe as I would like	1.278	0.087	14.7
3. I feel less than adequately safe	0.779	0.059	13.2
4. I don't feel at all safe	0.447	0.045	10.0
<i>Social participation and involvement</i>			
1. I have as much social contact as I want with people I like	2.221	0.146	15.2
2. I have adequate social contact with people	2.008	0.132	15.2

3. I have some social contact with people, but not enough	1.355	0.095	14.2
4. I have little social contact with people and feel socially isolated	0.545	0.050	10.8

Space and time to be yourself

1. I have all the space and time I need to be myself	2.640	0.175	15.1
2. I have adequate space and time to be myself	2.365	0.155	15.3
3. I have some of the space and time I need to be myself, but not enough	1.439	0.100	14.4
4. I don't have any space or time to be myself	0.360	0.041	8.8

Feeling supported and encouraged

1. I feel I have the encouragement and support I want	2.327	0.156	14.9
2. I feel I have adequate encouragement and support	2.201	0.145	15.1
3. I feel I have some encouragement and support, but not enough	1.320	0.092	14.3
4. I feel I have no encouragement and support	0.474	0.046	10.3

Domain position in the BWS task

Position 1_B	0.000	0.000	Constant
Position 2_B	-0.098	0.030	-3.3
Position 3_B	-0.163	0.031	-5.2
Position 4_B	-0.224	0.033	-6.9
Position 5_B	-0.259	0.035	-7.5
Position 6_B	-0.283	0.036	-7.9
Position 7_B	-0.270	0.036	-7.4
Position 1_W	0.000	0.000	Constant
Position 2_W	0.020	0.031	0.7
Position 3_W	0.002	0.032	0.1
Position 4_W	0.025	0.033	0.7
Position 5_W	0.027	0.033	0.8
Position 6_W	-0.016	0.033	-0.5
Position 7_W	0.035	0.033	1.1

Scale parameters

Scale parameter for younger participants: data relates to participants aged 18 years – 44 years	1.000	Base
Scale parameter for older participants: data relates to participants aged 45+ years	1.184	3.1
Scale parameter for time to complete BWS task: duration \leq 6 minutes (360 seconds)	1.000	Base
Scale parameter for time to complete BWS task: duration $>$ 6 minutes (361 seconds+)	1.250	3.3
Scale parameter for participants with lower educational qualifications (below BA/MA/PhD or equivalent)	1.000	Base
Scale parameter for participants with higher educational qualifications (BA/MA/PhD or equivalent)	1.202	3.4

No. of observations	31,392
df	42
Final log-likelihood	-40843.1
Rho ² (0)	0.227
AIC	81770.1
BIC	82121.1

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Table 5. Estimated parameters for the ASCOT-Carer measure using general population data from England-
Taste heterogeneity S-MNL model (N = 981)

Attribute level	Taste S-MNL		
	coefficient	S.E.	t-ratio (robust)
Occupation			
1. I'm able to spend my time as I want, doing things I value or enjoy (BA/MA/PhD or equivalent education)	2.850	0.191	14.9
1. I'm able to spend my time as I want, doing things I value or enjoy (below BA/MA/PhD or equivalent education)	2.784	0.185	15.0
2. I'm able do enough of the things I value or enjoy with my time	2.620	0.172	15.2
3. I do some of the things I value or enjoy with my time, but not enough	1.476	0.103	14.4
4. I don't do anything I value or enjoy with my time	0.132	0.038	3.5
Control over daily life			
1. I have as much control over my daily life as I want (short-term tertiary education)	2.828	0.214	13.2
1. I have as much control over my daily life as I want (education other than short- term tertiary education)	2.573	0.175	14.7
2. I have adequate control over my daily life	2.202	0.148	14.9
3. I have some control over my daily life, but not enough	1.229	0.088	14.0
4. I have no control over my daily life	0.000	0.000	Constant
All levels: respondent living as married	0.174	0.027	6.6
Looking after yourself			
1. I look after myself as well as I want	2.153	0.147	14.6
2. I look after myself well enough	2.033	0.141	14.4
3. Sometimes I can't look after myself well enough	0.511	0.050	10.3
4. I feel I am neglecting myself	0.243	0.041	6.0
Safety			

1. I feel as safe as I want	2.013	0.139	14.5
2. Generally I feel adequately safe, but not as safe as I would like	1.186	0.083	14.2
3. I feel less than adequately safe	0.684	0.056	12.2
4. I don't feel at all safe	0.348	0.044	8.0
<i>Social participation and involvement</i>			
1. I have as much social contact as I want with people I like	2.173	0.145	15.0
2. I have adequate social contact with people	1.949	0.130	15.0
3. I have some social contact with people, but not enough	1.260	0.092	13.8
4. I have little social contact with people and feel socially isolated	0.414	0.046	8.9
All levels: respondent living as married	-0.061	0.026	-2.3
<i>Space and time to be yourself</i>			
1. I have all the space and time I need to be myself (social grade A- high managerial, administrative or professional)	2.742	0.021	13.4
1. I have all the space and time I need to be myself (below social grade A)	2.543	0.169	15.0
2. I have adequate space and time to be myself	2.291	0.151	15.2
3. I have some of the space and time I need to be myself, but not enough	1.350	0.096	14.0
4. I don't have any space or time to be myself	0.260	0.041	6.3
<i>Feeling supported and encouraged</i>			
1. I feel I have the encouragement and support I want	2.251	0.152	14.8
2. I feel I have adequate encouragement and support	2.123	0.142	15.0
3. I feel I have some encouragement and support, but not enough (social grade B- intermediate managerial, administrative or professional)	1.208	0.094	12.9
3. I feel I have some encouragement and support, but not enough (all other social grades)	1.243	0.091	13.6
4. I feel I have no encouragement and support (respondent reported as Christian (all))	0.341	0.055	6.6
4. I feel I have no encouragement and support (everyone else: respondent reported as no religion/Buddhist/Hindu/Muslim/Sikh/Any other religion)	0.411	0.053	7.8

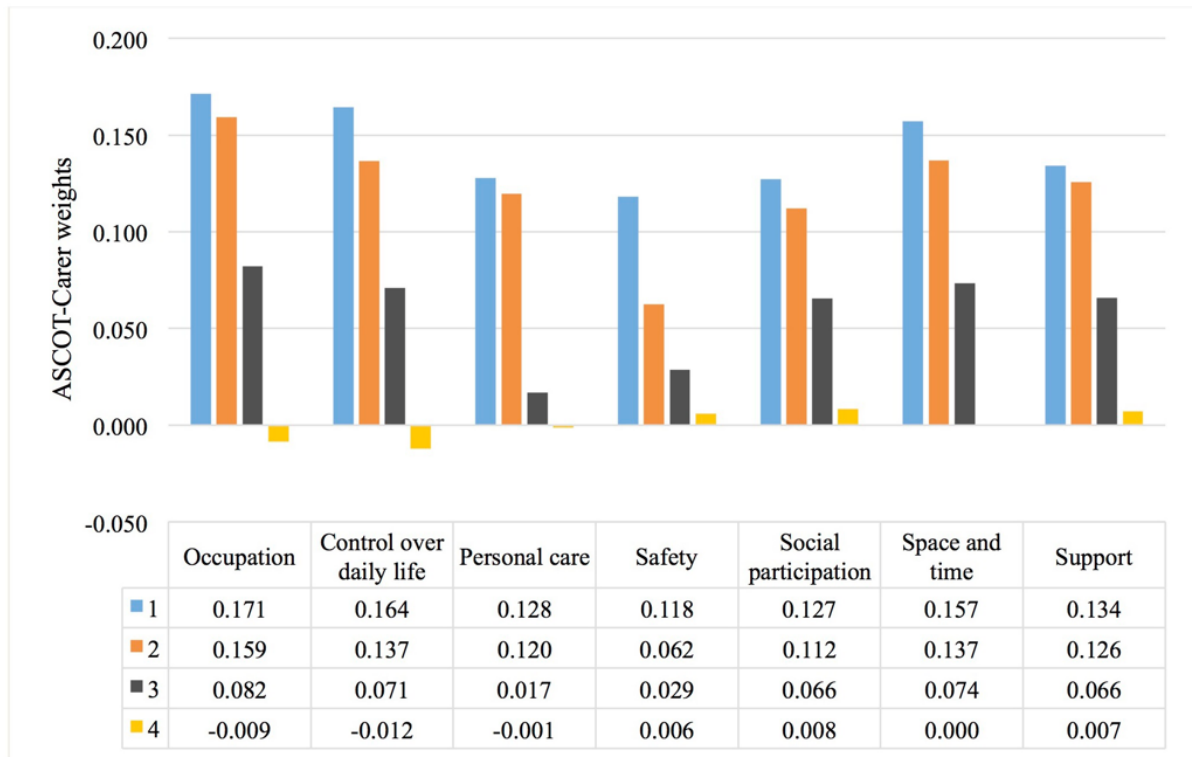
Domain position in the BWS task

Position 1_B	0.000	0.000	Constant
Position 2_B	-0.097	0.030	-3.2
Position 3_B	-0.162	0.031	-5.2
Position 4_B	-0.221	0.033	-6.7
Position 5_B	-0.255	0.035	-7.4
Position 6_B	-0.282	0.036	-7.9
Position 7_B	-0.268	0.036	-7.4
Position 1_W	0.000	0.000	Constant
Position 2_W	0.021	0.031	0.7
Position 3_W	0.000	0.032	0.0
Position 4_W	0.021	0.033	0.6
Position 5_W	0.023	0.033	0.7
Position 6_W	-0.016	0.033	-0.5
Position 7_W	0.033	0.033	1.0
<i>Scale parameters</i>			
Scale parameter for younger participants: data relates to participants aged 18 years – 44 years	1.000	0.000	Base
Scale parameter for older participants: data relates to participants aged 45+ years	1.182	0.060	3.1
Scale parameter for time to complete BWS task: duration \leq 6 minutes (360 seconds)	1.000	0.000	Base
Scale parameter for time to complete BWS task: duration $>$ 6 minutes (361 seconds+)	1.242	0.073	3.3
Scale parameter for participants with lower educational qualifications (below BA/MA/PhD or equivalent)	1.000	0.000	Base
Scale parameter for participants with higher educational qualifications (BA/MA/PhD or equivalent)	1.200	0.058	3.4
No. of observations	31,392		
df	49		
Final log-likelihood	-40781.9		

Rho ² (0)	0.227
AIC	81661.8
BIC	82071.2

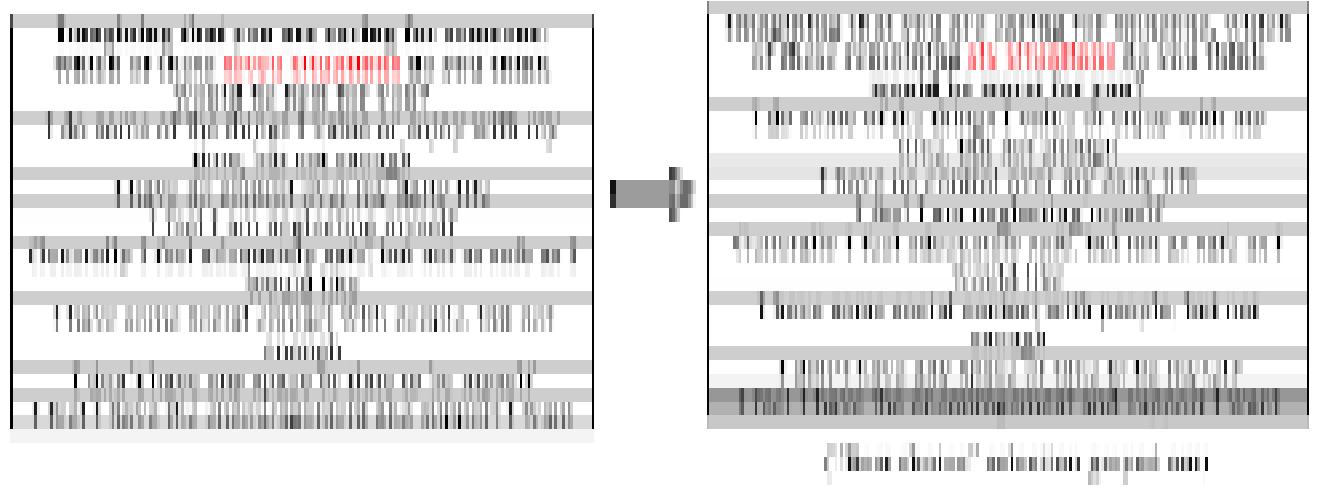
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Figure 1. ASCOT-Carer preference-based index values (N = 981)



Supplementary Material

1. Figure 1 – Best-worst scaling example for the ASCOT informal carer measure



2. Comparison of generated preference-based index values (0-1 scale) using the basic MNL, the S-MNL model and the taste S-MNL model.

	Basic	S-MNL	Taste
	MNL	Model	S-MNL
		Model	Model
Occupation			
1. I'm able to spend my time as I want, doing things I value or enjoy	0.171	0.172	0.171
2. I'm able do enough of the things I value or enjoy with my time	0.158	0.159	0.159
3. I do some of the things I value or enjoy with my time, but not enough	0.082	0.082	0.082
4. I don't do anything I value or enjoy with my time	-0.007	-0.007	-0.009
Control over daily life			
1. I have as much control over my daily life as I want	0.165	0.165	0.164
2. I have adequate control over my daily life	0.136	0.137	0.137
3. I have some control over my daily life, but not enough	0.065	0.065	0.071
4. I have no control over my daily life	-0.023	-0.023	-0.012
Looking after yourself			
1. I look after myself as well as I want	0.128	0.128	0.128
2. I look after myself well enough	0.120	0.120	0.120
3. Sometimes I can't look after myself well enough	0.018	0.018	0.017
4. I feel I am neglecting myself	-0.001	0.000	-0.001
Safety			
1. I feel as safe as I want	0.119	0.118	0.118
2. Generally I feel adequately safe, but not as safe as I would like	0.063	0.063	0.062
3. I feel less than adequately safe	0.029	0.030	0.029
4. I don't feel at all safe	0.006	0.007	0.006
Social participation and involvement			
1. I have as much social contact as I want with people I like	0.127	0.127	0.127
2. I have adequate social contact with people	0.112	0.113	0.112
3. I have some social contact with people, but not enough	0.069	0.068	0.066

4. I have little social contact with people and feel socially isolated	0.015	0.014	0.008
Space and time to be yourself			
1. I have all the space and time I need to be myself	0.155	0.155	0.157
2. I have adequate space and time to be myself	0.136	0.137	0.137
3. I have some of the space and time I need to be myself, but not enough	0.074	0.074	0.074
4. I don't have any space or time to be myself	0.002	0.001	0.000
Feeling supported and encouraged			
1. I feel I have the encouragement and support I want	0.135	0.134	0.134
2. I feel I have adequate encouragement and support	0.126	0.126	0.126
3. I feel I have some encouragement and support, but not enough	0.067	0.066	0.066
4. I feel I have no encouragement and support	0.009	0.009	0.007