

**Adult Social Care Outcomes Toolkit
(ASCOT) SCT4 Easy Read guidance**

Version 1.0

James Caiels, Nick Smith, Ann-Marie Towers and Kamilla Razik

Subject to licence © University of Kent
all rights reserved

November 2017

Discussion Paper 2939

The Policy Research Unit in Quality and Outcomes of person-centred care (QORU) is a collaboration involving researchers in health and social care from the Universities of Kent, Oxford and the London School of Economics (LSE) funded by the Department of Health and Social Care.

Our aim is to improve the quality of health and social care of people with long-term conditions through generating high-quality evidence about need, quality and outcomes of person-centred care.

CONTACT

QORU

Personal Social Services Research Unit

University of Kent

Canterbury

CT2 7NF

Email: qoru@kent.ac.uk

www.qoru.ac.uk

This report is based on independent research commissioned and funded by the NIHR Policy Research Programme, Policy Research Unit in Quality and Outcomes of person-centred care (QORU). The views expressed in the publication are those of the author(s) and not necessarily those of the NHS, the NIHR, the Department of Health and Social Care or its arm's length bodies or other government departments.

Table of Contents

About ASCOT SCT4 Easy Read.....	2
SCRQoL explained	2
ASCOT SCT4 ER domains	2
Understanding the ASCOT SCT4 ER outcome states	3
The safety domain	6
Scoring ASCOT SCT4 ER.....	6
Impact and ASCOT SCT4 ER.....	9
Using ASCOT SCT4 ER: Frequently Asked Questions (FAQs).....	10
How do I obtain permission to use ASCOT SCT4 ER?	10
Do I have to pay to use ASCOT?.....	10
What is the ASCOT SCT4 ER data-entry tool?	10
Do I have to pay for the ASCOT SCT4 ER data-entry tool?	10
Do I have to agree to any conditions when using ASCOT?	10
Can I make changes to the question order or wording?	11
Can I add my own questions to yours and call this a new measure?.....	11
Can I put the ASCOT SCT4 ER questions into a longer interview?.....	11
Do I need to use all the ASCOT SCT4 ER questions?	11
Do I need training before I use ASCOT SCT4 ER?.....	11
What support is available to me if I use ASCOT SCT4 ER?	11
References	12

About ASCOT SCT4 Easy Read

ASCOT SCT4 Easy Read (ER) is a self-completion version of the Adult Social Care Outcomes Toolkit (ASCOT), specifically designed for use by adults with intellectual and developmental disabilities. It contains illustrations and different wording of questions to aid understanding. It is a tool designed to measure the social care-related quality of life (SCRQoL) of the individual completing the questionnaire. If you are unsure if SCT4 ER is the right tool for your project, see the short video on our website (www.pssru.ac.uk/ascot) that compares the different versions of ASCOT.

SCT4 ER is a self-completion questionnaire, which means that it is designed to be completed by the person whose SCRQoL you are measuring. If completing the easy read questionnaire is likely to be difficult, for example due to severe cognitive impairment, other versions of ASCOT are available. These include a face-to-face interview version (INT4), and a Braille version of SCT4.

Please contact the ASCOT team (ascot@kent.ac.uk) if you are interested in using the Braille version of ASCOT. The other tools are available on our website (please note that to access and use the tools a licence is required – the licensing process includes registration and consent to the terms and conditions).

SCRQoL explained

SCRQoL refers to those aspects of a person's quality of life that are relevant to, and the focus of, social care interventions. SCT4 ER measures what a person's SCRQoL is like at the time of completing the questionnaire. We call this current SCRQoL. Unless you are using ASCOT as a baseline measure *before* a service is put in place, current SCRQoL is usually the person's quality of life with services and support. A current SCRQoL score can be calculated for each person, as long as they have answered all of the ASCOT questions. Further information about the current SCRQoL score can be found in the **Scoring ASCOT** section below.

ASCOT SCT4 ER domains

The measure of current SCRQoL is comprised of questions covering eight areas of a person's life, which we call domains. In identifying and defining these domains, we focused on areas of quality of life sensitive to the outcomes of social care services. The domains were informed by consultations with policy-makers and experts in the field, reviews of the literature in this area, and cognitive testing and focus groups with people using social care services (Qureshi et al., 1998; Bamford et al., 1999; Netten et al., 2002; Harris et al., 2005; Netten et al., 2005; Malley et al., 2006; Miller et al., 2008). The ASCOT domains are therefore relevant to, and the focus of, social care, whilst also being valued by social care recipients and policy-makers alike.

The definitions for each of the eight ASCOT domains are shown in Table 1 below. These eight domains are used in all of the ASCOT tools for people who are supported by social care (ASCOT Carers tools have their own, but related, set of domains). In ASCOT SCT4 ER, outcomes in each domain are measured by either one or two questions with four outcome states.

Table 1. Definitions of the ASCOT domains

User SCRQoL Domain	Definition
Control over daily life	The service user can choose what to do and when to do it, having control over his/her daily life and activities
Personal cleanliness and comfort	The service user feels s/he is personally clean and comfortable and looks presentable or, at best, is dressed and groomed in a way that reflects his/her personal preferences
Food and drink	The service user feels s/he has a nutritious, varied and culturally appropriate diet with enough food and drink s/he enjoys at regular and timely intervals
Personal safety	The service user feels safe and secure. This means being free from fear of abuse, falling or other physical harm and fear of being attacked or robbed
Social participation and involvement	The service user is content with their social situation, where social situation is taken to mean the sustenance of meaningful relationships with friends and family, and feeling involved or part of a community, should this be important to the service user
Occupation	The service user is sufficiently occupied in a range of meaningful activities, whether formal employment, unpaid work, caring for others or leisure activities
Accommodation cleanliness and comfort	The service user feels their home environment, including all the rooms, is clean and comfortable
Dignity	The negative and positive psychological impact of support and care on the service user's personal sense of significance

Understanding the ASCOT SCT4 ER outcome states

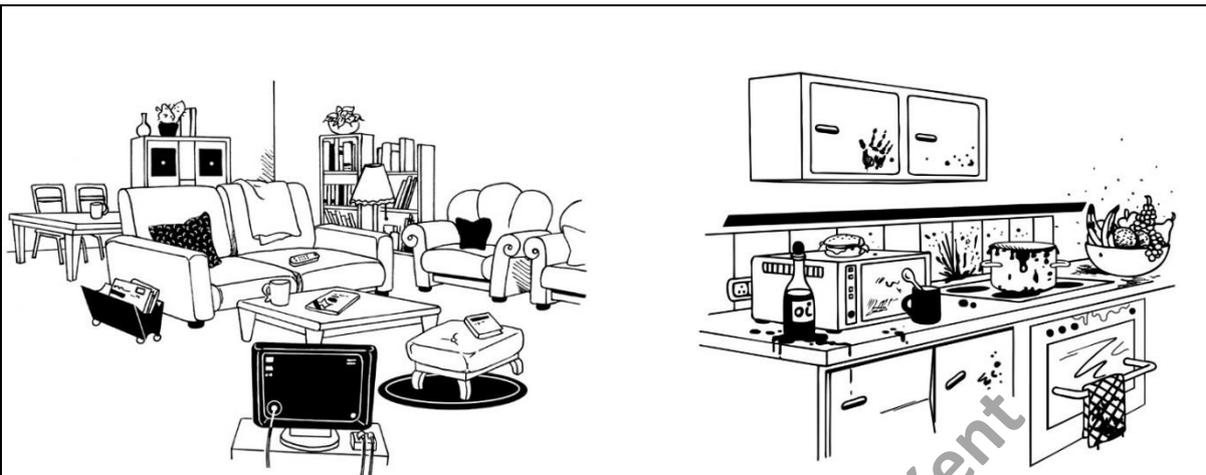
Each current SCRQoL question has four response options, relating to four outcome states. The outcome states are shown in Table 2 below (from best to worst).

Table 2. Definitions of ASCOT outcomes states

Outcome state	Definition
Ideal	The individual's wishes and preferences in this aspect of their life are (or would be) fully met
No needs	The individual has (or would have) no or the type of temporary trivial needs that would be expected in this area of life of someone with no impairments.
Some needs	Some needs are distinguished from no needs by being sufficiently important or frequent to affect an individual's quality of life.
High-level needs	High-level needs are distinguished from some needs by having mental or physical health implications if they are not met over a period of time. This may be because of severity or frequency.

The person completing SCT4 ER does not need to have an understanding of the four outcome states to answer the questions. We have conceptualised these states into response options for each domain. The person completing SCT4 ER is simply asked a question and presented with four statements. Each statement relates to one of the outcome states presented above. The statements in each question are always ordered with the best outcome state (ideal) at the top and high-level needs at the bottom. The person completing the questionnaire is asked to choose the statement that best fits their experience by ticking the box next to that option. Before each question there are one to three illustrations relating to the question theme, as well as a brief explanation of what it is about, to aid understanding. An example from the accommodation domain is shown in Box 1 below.

Box 1. An example question (accommodation domain)



This question is about how clean and comfortable your home is.

Having a clean home means that the kitchen, bathroom, bedrooms and all other rooms are clean and tidy.

Having a comfortable home means that you like how your home looks and feels.

How clean and comfortable is your home?

Please tick (✓) 1 box

My home is as clean and comfortable as I want.

My home is quite clean and comfortable.

My home is not clean and comfortable enough.

My home is not clean and comfortable at all.

The safety domain

The safety domain in the ASCOT SCT4 ER comprises two questions to reflect safety inside and outside of the home. During development, it was found that people had difficulty responding to a single question about safety because they differed between feeling safe inside and outside of their home (Turnpenny et al., 2016). The safety domain is therefore split into two questions to capture safety inside and outside of the home.

Scoring ASCOT SCT4 ER

Current SCRQoL cannot be calculated if any of questions, other than **only one** of the safety questions, have been left blank. Other than this, all survey questions must be answered to produce a SCRQoL score.

ASCOT is a preference-weighted measure of quality of life. This means that the raw scores used in the data-entry spreadsheet for the different outcome states (0,1, 2, 3) are converted into different numbers, reflecting their relative importance/value to the general population. A full list of these can be found in Table 3. For example, research has shown that having as much control over your daily life as you want is seen as being more important than having as much social contact as you want. The weighted scores used in the calculation of ASCOT reflect these preferences. We checked whether people being supported by services had different preferences to the general population and found that, overall, they did not. The final weights reported below were derived from a series of studies. More details of these studies can be found in the report by Netten et al. (2012).

When scoring the safety question, only the response of one of the two questions should be taken into account – the response that captures the higher level of need. If you are using the data-entry tool, you can enter all responses as normal and the higher level of need response will be automatically calculated for you.

It is important to note that the ASCOT SCT4 ER uses (at the time of publication) the standard preference weights pertaining to the general population as per the ASCOT SCT4. These weights are used in the absence of other available data but may be subject to change/update. Therefore, caution is advised when interpreting results.

Table 3. A list of the weights for each ASCOT domain level

Domain	Weighted rating
Control over daily life	
1. I have as much control over my daily life as I want	1.000
2. I have adequate control over my daily life	0.919
3. I have some control over my daily life but not enough	0.541
4. I have no control over my daily life	0.000
Personal cleanliness and comfort	
1. I feel clean and am able to present myself the way I like	0.911
2. I feel adequately clean and presentable	0.789
3. I feel less than adequately clean or presentable	0.265
4. I don't feel at all clean or presentable	0.195
Food and drink	
1. I get all the food and drink I like when I want	0.879
2. I get adequate food and drink at OK times	0.775
3. I don't always get adequate or timely food and drink	0.294
4. I don't always get adequate or timely food and drink and I think there is a risk to my health	0.184
Personal safety	
1. I feel as safe as I want	0.880
2. Generally I feel adequately safe, but not as safe as I would like	0.452
3. I feel less than adequately safe	0.298
4. I don't feel at all safe	0.114
Social participation and involvement	
1. I have as much social contact as I want with people I like	0.873
2. I have adequate social contact with people	0.748
3. I have some social contact with people, but not enough	0.497
4. I have little social contact with people and feel socially isolated	0.241
Occupation	
1. I'm able to spend my time as I want, doing things I value or enjoy	0.962
2. I'm able do enough of the things I value or enjoy with my time	0.927
3. I do some of the things I value or enjoy with my time but not enough	0.567
4. I don't do anything I value or enjoy with my time	0.170

Domain **Weighted rating**

Accommodation cleanliness and comfort

1. My home is as clean and comfortable as I want	0.863
2. My home is adequately clean and comfortable	0.780
3. My home is less than adequately clean or comfortable	0.374
4. My home is not at all clean or comfortable	0.288

Dignity

1. The way I'm helped and treated makes me think and feel better about myself	0.847
2. The way I'm helped and treated does not affect the way I think or feel about myself	0.637
3. The way I'm helped and treated sometimes undermines the way I think and feel about myself	0.295
4. The way I'm helped and treated completely undermines the way I think and feel about myself	0.263

The weighted scores are added together and entered into a formula to give a current SCRQoL score. The formula for calculating current SCRQoL in ASCOT SCT4 ER is:

$$\text{Current SCRQoL} = (0.203 \times \text{weighted score}) - 0.466$$

This formula produces a score of between 1.00 and -0.17 (final ASCOT scores are rounded to two decimal places). The formula is based on a Time Trade Off (TTO) exercise with members of the public, with the final score being anchored to 0.00 (being dead) and 1.00 (ideal state). Thus, while a score of 1.00 would mean that the person has reported the ideal state in all domains, a score of 0.00 is, in the view of the general population, the same as being dead. Scores, and the states that they represent, between -0.01 and -0.17 are seen as being worse than death. Box 2 shows a worked example of the calculation behind the current SCRQoL score.

Box 2. Calculating current SCRQoL in ASCOT SCT4 ER

For a respondent who reports *no needs* in each domain

Weighted score

0.919 (control) + 0.789 (personal cleanliness and comfort) + 0.775 (food and drink) + 0.452 (personal safety) + 0.748 (social participation and involvement) + 0.927 (occupation) 0.780 (accommodation cleanliness and comfort) + 0.637 (dignity) = 6.027

Current SCRQoL = $(0.203 \times \text{weighted score}) - 0.466$

$0.6027 \times 0.203 = 1.223481$

$1.223481 - 0.466 = 0.757481$

Current SCRQoL = 0.76

The formula outlined above can be used with a range of data-entry and analysis tools (MS Excel, SPSS, STATA and so forth); however, we do provide an MS Excel ASCOT data-entry tool specifically for SCT4 ER. The tool can be purchased via a dedicated link shared upon obtaining a licence (approval of registration form). The tool costs a one-off fee of £50 per ASCOT user. Users with multiple settings, such as care home providers, should buy one for each care home. The spreadsheet includes guidance on how to use it, and space to enter data from up to 20,000 cases. For each case, where there are no missing data, it automatically calculates a current SCRQoL score. It also features a sheet that presents the aggregate ASCOT data. This includes an overall current SCRQoL score, which is an average (mean) of all of cases entered, and frequencies and percentages for each questions. There are also a number of visual representations of the data, which can be helpful in reports.

Impact and ASCOT SCT4 ER

ASCOT SCT4 ER measures what a person's life is currently like, which we call current SCRQoL. It is not able, at least on its own, to measure the impact of care and support, and is limited in what it can tell us about the impact of services. This is because social care-related quality of life may be influenced by a number of different factors, including health status, severity of impairment and living environment (Forder et al., 2016). If you would like to measure the impact of services, you may want to look at other ASCOT tools, such as INT4 (www.pssru.ac.uk/ascot). Another option would be to measure current SCRQoL before a social care intervention and then again after the intervention (controlling for confounding variables, such as deterioration in health status).

Using ASCOT SCT4 ER: Frequently Asked Questions (FAQs)

How do I obtain permission to use ASCOT SCT4 ER?

To read this guidance and see the ASCOT tools, you or your organisation needs to be registered via the ASCOT website. If you or your organisation has not registered, please go to www.pssru.ac.uk/ascot, download and complete the registration form, and submit to ascot@kent.ac.uk. You will be asked to agree to the terms and conditions during the registration process. The registration form will be reviewed by the ASCOT team. If approved, the registration form and the terms and conditions will form the licence for the use of the ASCOT measure, as specified in the registration form. Upon approval, you will receive a confirmation email with a copy of the SCT4 ER instrument, this guidance and a link to a purchasable data-entry tool.

Do I have to pay to use ASCOT?

The licence to use ASCOT is free for not-for-profit organisations. For definitions of not-for-profit use and for-profit use, please see our website: pssru.ac.uk/ascot/licensing. For-profit users, including consultants, may be charged a licence fee. To enquire about a for-profit licence, download and complete the for-profit licence enquiry form on our website (www.pssru.ac.uk/ascot/) and submit to ascot@kent.ac.uk.

What is the ASCOT SCT4 ER data-entry tool?

The data-entry tool supplements the ASCOT SCT4 ER instrument. The data-entry tool is an MS Excel file that generates social care-related quality of life (SCRQoL) scores for each individual. These scores are calculated from data entered from the ASCOT SCT4 ER questionnaire by the user. The ASCOT SCT4 preference weights are programmed into the file. Upon entering data, a SCRQoL score for each participant is automatically calculated. The tool also produces a summary of the distribution of responses to each ASCOT SCT4 ER question (frequencies and percentages) and charts.

Do I have to pay for the ASCOT SCT4 ER data-entry tool?

Yes, the data-entry tool is chargeable at £50 per user or site (e.g. care home). A service provider who wishes to use ASCOT and the data-entry tools in their care homes will be required to purchase a data-entry tool for each site (care home). Using one data-entry tool at multiple sites will be treated as a breach of the licence, and may incur appropriate legal action from the Licensor – the University of Kent. Upon approval of your registration form, you will be given access to Kent Shop where you will be able to purchase the tool online.

Do I have to agree to any conditions when using ASCOT?

Yes. Terms and conditions are part of the registration process, and you will be required to agree to them when completing the registration form. The terms and conditions can be found on the ASCOT website: www.pssru.ac.uk/ascot

Can I make changes to the question order or wording?

No. The wording of the questions and responses has undergone extensive cognitive testing to ensure they are reliable. Making changes to these will jeopardise the reliability and integrity of the tool.

Can I add my own questions to yours and call this a new measure?

No. Any use of the ASCOT questions or tools must acknowledge our copyright and intellectual property. If you include the ASCOT in a questionnaire with other questions, you are required to reference this accordingly. This requirement forms part of the terms and conditions of use, to which you will be required to agree in order to access ASCOT tools. You can find a guide on how to reference ASCOT on the ASCOT website: www.pssru.ac.uk/ascot.

Can I put the ASCOT SCT4 ER questions into a longer interview?

Yes. Users sometimes ask other questions alongside SCT4 ER to help them understand their data. We would strongly advise that you keep the ASCOT questions as a block of questions and do not change their order. You will be asked to tell us how you plan to use the ASCOT questions during the registration process.

Do I need to use all the ASCOT SCT4 ER questions?

No. You are free to use only the questions that are of use to you. However, without a full set of questions it is not possible to calculate a full score for current SCRQoL. Please inform us if you only plan to use a selection of the questions when completing the registration form.

Do I need training before I use ASCOT SCT4 ER?

While we do run a one-day introduction to ASCOT training course which covers SCT4 (and includes SCT4 ER), it is possible to administer the self-completion survey without training. Details of training courses can be found on our website (www.pssru.ac.uk/ascot/). Alternatively, take a look at our PowerPoint presentations on the ASCOT website: www.pssru.ac.uk/ascot.

What support is available to me if I use ASCOT SCT4 ER?

We are not funded to provide support for ASCOT, beyond what is available on our website and the training courses advertised. If you need further support, please contact the University of Kent's Innovation and Enterprise team about your requirements and they will liaise with the appropriate member of the ASCOT team regarding consultancy options (entcontracts@kent.ac.uk). Please include **ASCOT** in the subject line of your email to ensure it reaches the correct person.

References

- Bamford, C., Qureshi, H., Nicholas, E. and Vernon, A. (1999) *Outcomes of Social Care for Disabled People and Carers*, Outcomes in Community Care Practice Number 6, Social Policy Research Unit, University of York: York.
- Forder, J., Malley, J., Rand, S., Vadean, F., Jones, K. and Netten, A. (2016) *IASC report: Interpreting outcomes data for use in the Adult Social Care Outcomes Framework (ASCOF)*, PSSRU Discussion Paper 2892, University of Kent, Canterbury.
- Harris, J., Foster, M., Morgan, H. and Jackson, K. (2005) *Outcomes for Disabled Service Users*, Research Report, Social Policy Research Unit, University of York, York.
- Malley, J., Sandhu, S. and Netten, A. (2006) *Younger adults' understanding of questions for a service user experience survey*, Report to The Health and Social Care Information Centre, PSSRU Discussion Paper 2360, Personal Social Services Research Unit, University of Kent, Canterbury.
- Miller, E., Cooper, S-A., Cook, A. and Perzin, A. (2008) Outcomes Important to people with intellectual disabilities, *Journal of Policy and Practice in Intellectual Disabilities*, 5, 3,150-158.
- Netten, A., Ryan, M., Smith, P., Skatun, D., Healey, A., Knapp, M. and Wykes, T. (2002) *The development of a measure of social care outcome for older people*, PSSRU Discussion Paper 1690, Personal Social Services Research Unit, University of Kent, Canterbury.
- Netten, A., McDain, D., Fernández, J-L., Forder, J., Knapp, M., Matosevic, T. and Shapiro, J. (2005) *Measuring and understanding social services outputs*, PSSRU Discussion Paper 2132/3, Personal Social Services Research Unit, University of Kent, Canterbury.
- Netten, A., Burge, P., Malley, J., Potoglou, D., Towers, A., Brazier, J., Flynn, T., Forder, J. and Wall, B. (2012) Outcomes of Social Care for Adults: Developing a Preference-Weighted Measure, *Health Technology Assessment*, 16, 16, 1-165, DOI: <http://dx.doi.org/10.3310/hta16160>
- Qureshi, H., Patmore, C., Nicholas, E. and Bamford, C. (1998) *Overview: Outcomes of social care for older people and carers*, Outcomes in Community Care Practice Number 5, Social Policy Research Unit, University of York, York.
- Turnpenny, A., Caiels, J., Crowther, T., Richardson, L., Whelton, R., Beadle-Brown, J. and Rand, S. (2016) Developing an Easy Read version of the Adult Social Care Outcomes Toolkit (ASCOT) *Journal of Applied Research in Intellectual Disabilities*, DOI: <http://dx.doi.org/10.1111/jar.12294>