

Adult Social Care Outcomes Toolkit (ASCOT)-Carer SCT4 guidance

Version 2.0

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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.

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About the ASCOT-Carer SCT4

The ASCOT-Carer SCT4 is a self-completion version of the Adult Social Care Outcomes Toolkit (ASCOT) designed to measure the social care-related quality of life (SCRQoL) of carers aged 18 years or over. (By 'carer', we mean someone who cares, unpaid, for a friend or family member who needs support in their day-to-day life due to illness, disability, a mental health problem or needs related to addiction.)

If you are unsure if ASCOT-Carer SCT4 is the right tool for your project, see the short video on the ASCOT website (www.pssru.ac.uk/ascot) which compares the different versions of ASCOT-Carer.

ASCOT-Carer SCRQoL explained

ASCOT-Carer SCRQoL refers to those aspects of a carer's quality of life that are relevant to, and the focus of, social care interventions. The ASCOT-Carer SCT4 measures what a carer'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 usually measures 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 the ASCOT-Carer SCT4** section below.

ASCOT-Carer SCT4 domains

The measure of current ASCOT-Carer SCRQoL is comprised of questions covering seven areas of a person's life, which we call domains. In identifying and defining these domains, we focused on areas of quality of life that are important to carers and are also sensitive to the outcomes of social care services. The domains were informed by consultations with carers, policy-makers and experts in the field, review of the literature in this area, and focus groups and cognitive testing with carers (Fox et al., 2010; Malley et al., 2010; Rand et al., 2012; Rand and Malley, 2014; Rand et al., 2015). The ASCOT-Carer domains are therefore relevant to, and the focus of, social care whilst also being valued by carers.

The definitions for each of the seven ASCOT-Carer domains are shown in Table 1 below. These seven domains are used in all of the ASCOT tools for carers. (ASCOT tools for people with needs supported by social care services have their own, but related, set of domains). In the ASCOT-Carer SCT4, the outcomes in each domain are measured by one question with four response options.

Table 1: Definitions of the ASCOT-Carer domains

Carer SCRQoL Domain	Definition
Occupation	The carer is sufficiently occupied in a range of meaningful and enjoyable activities, whether formal employment, unpaid work, caring for others or leisure activities
Control over daily life	The carer can choose what to do and when to do it, having control over his/her daily activities
Self-care	The carer feels that s/he is able to look after him/herself, in terms of eating well and getting enough sleep
Personal safety	The carer feels safe and secure, where concerns about safety include fear of abuse, physical harm or accidents that may arise as a result of caring
Social participation and involvement	The carer is content with his/her 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 carer
Space and time to be yourself	The carer feels that s/he has enough space and time in everyday life to be him/herself, away from the caring role and the responsibilities of caregiving
Feeling encouraged and supported	The carer feels encouraged and supported by professionals, care workers and others, in his/her role as a carer

Understanding the ASCOT-Carer SCT4 outcome states

Each 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-Carer outcomes states

Outcome state	Definition
Ideal	The individual's needs are met to his/her preferred level
No needs	Where needs are met, but not to the preferred level
Some needs	Where there are needs, but these do not have an immediate or longer-term health implication
High-level needs	Where there are needs, and these have an immediate or longer-term health implication

The person completing ASCOT-Carer SCT4 does not need to have an understanding of the four outcome states to answer the questions. The person completing SCT4 is simply asked a question and presented with four statements. The outcome states presented above correspond to the four response options for each domain. The response option statements for 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. Some questions have an additional sentence to aid understanding.

An example from the occupation domain is shown in Box 1 below.

Box 1. An example of question in the occupation domain

Which of the following statements best describes how you spend your time?

When you are thinking about how you spend your time, please include anything you value or enjoy, including leisure activities, formal employment, voluntary or unpaid work, and caring for others.

Please tick (✓) one box

I'm able to spend my time as I want, doing things I value or enjoy	<input type="checkbox"/>
I'm able to do enough of the things I value or enjoy with my time	<input type="checkbox"/>
I do some of the things I value or enjoy with my time, but not enough	<input type="checkbox"/>
I don't do anything I value or enjoy with my time	<input type="checkbox"/>

Scoring the ASCOT-Carer SCT4

The ASCOT-Carer is a preference-weighted measure of quality of life in carers. This means that the ratings of each outcome state are converted into weighted ratings that their relative value to the general population. The list of preference-weighted scores for all domain levels are presented in Table 3. More detail of how these weights were estimated can be found in the article by Batchelder et al. (2019).

The ASCOT-Carer SCRQoL cannot be calculated if any of questions have been left blank. All seven questions must be answered.

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

Domain	Weighted rating
Occupation	
1. I'm able to spend my time as I want, doing things I value or enjoy	0.171
2. I'm able do enough of the things I value or enjoy with my time	0.159
3. I do some of the things I value or enjoy with my time, but not enough	0.082
4. I don't do anything I value or enjoy with my time	-0.009
Control over daily life	
1. I have as much control over my daily life as I want	0.164
2. I have adequate control over my daily life	0.137
3. I have some control over my daily life, but not enough	0.071
4. I have no control over my daily life	-0.012
Looking after yourself	
1. I look after myself as well as I want	0.128
2. I look after myself well enough	0.120
3. Sometimes I can't look after myself well enough	0.017
4. I feel I am neglecting myself	-0.001
Safety	
1. I feel as safe as I want	0.118
2. Generally I feel adequately safe, but not as safe as I would like	0.062
3. I feel less than adequately safe	0.029
4. I don't feel at all safe	0.006

Social participation and involvement

1. I have as much social contact as I want with people I like	0.127
2. I have adequate social contact with people	0.112
3. I have some social contact with people, but not enough	0.066
4. I have little social contact with people and feel socially isolated	0.008

Space and time to be yourself

1. I have all the space and time I need to be myself	0.157
2. I have adequate space and time to be myself	0.137
3. I have some of the space and time I need to be myself, but not enough	0.074
4. I don't have any space or time to be myself	0.000

Feeling supported and encouraged

1. I feel I have the encouragement and support I want	0.134
2. I feel I have adequate encouragement and support	0.126
3. I feel I have some encouragement and support, but not enough	0.066
4. I feel I have no encouragement and support	0.007

Please note that the preference-weighted scores for all domain levels were adjusted such that the SCRQoL scores for carers valued on a 0 to 1 interval. The weights were anchored such that the state of having an 'ideal state' (state 1111111, level 1 of each domain) was given a value of one (1). The state of having 'high-level needs' (state 4444444, level 4 of each domain) was given a value of zero (0). One seventh of the value of the 'ideal state' (state 1111111) was subtracted from all domains. This value was then divided by the difference between 'ideal state' and 'high-level needs' (Coast et al., 2008; Flynn et al., 2015; Huynh, Coast, Rose, Kinghorn, & Flynn, 2017). This was to ensure that there were relative differences between domain levels.

The overall SCRQoL score for carers is calculated by summing the preference-weighted values for the chosen level for each domain.

$$\text{Current SCRQoL} = \text{Weight_Occupation}_L + \text{Weight_Control}_L + \text{Weight_PersonalCare}_L \\ + \text{Weight_Safety}_L + \text{Weight_Social}_L + \text{Weight_Space}_L + \text{Weight_Support}_L$$

This formula produces a summed score ranging between 0 (high-level needs) and 1 (ideal state). Box 2 shows a worked example of the calculation behind the current SCRQoL score for carers.

Box 2. Calculating current SCRQoL for carers in SCT4

For a respondent who reports *no needs* (level 2) in each domain:

Weighted score:

0.159 (occupation) + 0.137 (control over daily life) + 0.120 (personal care) + 0.062 (safety)
+ 0.112 (social participation and involvement) + 0.137 (space and time) + 0.126 (support)

Current SCRQoL for carers = 0.853 (85%)

The simple calculation outlined above can be used with a range of data entry and analysis tools (MS Excel, SPSS, STATA and so forth), however, we provide an MS Excel ASCOT data-entry tool specifically for the ASCOT-Carer SCT4. 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 the ASCOT-Carer SCRQoL score. It also features a sheet that presents the aggregate ASCOT-Carer data. This includes an overall ASCOT-Carer 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 may be used in reports.

Using ASCOT-Carer SCT4 to evaluate the effectiveness (impact) of care

ASCOT-Carer SCT4 measures what a person's life is currently like, which we call current SCRQoL. Like other measures of quality of life, it does not tell us, at least on its own, the impact or effect of care and support on quality of life. This is because quality of life may be influenced by a number of different factors other than social care, including health status, severity of impairment and living environment (Forder et al., 2016).

There are various methods used by researchers to control for these other influences, so that the effect of an intervention may be estimated (for example, randomised control trials). The ASCOT-Carer SCT4 may be used in studies designed to evaluate the effectiveness of a policy or care intervention.

If you would like to measure the impact of services on social care-related quality of life on a smaller scale and/or with limited resources, you may want to look at the ASCOT-Carer INT4 (www.pssru.ac.uk/ascot). This tool provides a pragmatic and easy-to-implement method of estimating the impact of interventions on social care-related quality of life.

Frequently Asked Questions (FAQs)

How do I obtain permission to use the ASCOT-Carer SCT4?

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 Carer SCT4 instrument, this guidance and a link to a purchasable data-entry tool.

Do I have to pay to use the ASCOT-Carer SCT4?

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 the ASCOT website (www.pssru.ac.uk/ascot). 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-Carer SCT4 data-entry tool?

The data-entry tool supplements the ASCOT-Carer SCT4 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-Carer SCT4 questionnaire by the user. 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-Carer SCT4 question (frequencies and percentages) and charts.

Do I have to pay for the ASCOT-Carer SCT4 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 breach of licence and may incur appropriate legal action from the Licensor – the University of Kent. You will be given access to Kent Shop, where you will be able to purchase the tool upon approval of your registration form, which grants the licence to use the ASCOT tool.

Do I have to agree to any conditions when using the ASCOT-Carer SCT4?

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 have 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 terms and conditions of use, to which you be required to agree in order to access ASCOT tools. You can find a guide on how to reference ASCOT on our website: www.pssru.ac.uk/ascot.

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

Yes. Many users sometimes ask other questions alongside the ASCOT-Carer SCT4 to help them understand their data. We would also strongly advise that you keep the ASCOT-Carer SCT4 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-Carer SCT4 questions during the registration process.

Do I need to use all the ASCOT-Carer SCT4 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-Carer SCT4?

While we do run a one-day introduction to ASCOT training course which covers the ASCOT-Carer SCT4, it is possible to administer the self-completion survey without training. Details of training course may be found on our website: www.pssru.ac.uk/ascot.

What support is available to me if I use the ASCOT-Carer SCT4?

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.

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