

## **Adult Social Care Outcomes Toolkit (ASCOT)-Carer INT4 guidance**

*Version 2.0*

Stacey Rand, Nick Smith, Ann-Marie Powers, Laurie  
Batchelder, Juliette Malley, and Kamilla Razik

December 2019

Discussion Paper 2940

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](mailto:qoru@kent.ac.uk)

[www.qoru.ac.uk](http://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 the ASCOT-Carer INT4 .....	2
ASCOT-Carer SCRQoL explained .....	2
ASCOT-Carer INT4 domains .....	3
Understanding the ASCOT-Carer INT4 outcome states .....	4
Scoring the ASCOT-Carer INT4 .....	6
Frequently Asked Questions (FAQs) .....	10
How do I obtain permission to use the ASCOT-Carer INT4? .....	10
Do I have to pay to use ASCOT? .....	10
What is the ASCOT-Carer INT4 data-entry tool? .....	10
Do I have to pay for the ASCOT-Carer INT4 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-Carer INT4 questions into a longer interview? .....	11
Do I need to use all the ASCOT-Carer INT4 questions? .....	11
Do I need training before I use ASCOT-Carer INT4? .....	11
What support is available to me if I use the ASCOT-Carer INT4? .....	11
References .....	12

## About the ASCOT-Carer INT4

The ASCOT-Carer INT4 is an interview 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 INT4 is the right tool for your project, see the short video on the ASCOT website ([www.pssru.ac.uk/ascot](http://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 INT4 contains two measures of SCRQoL:

**Current SCRQoL:** what the person's life is like now

**Expected SCRQoL:** what a person's life would be like without the help and support they (or the person they care for) receive from services.

These two SCRQoL scores are calculated for each person, as long as they have answered all 21 of the questions that make up the ASCOT-Carer INT4 interview. These questions cover seven areas of a person's life. We call these areas domains.

For each domain, there are three questions:

1. A question asking about the person's life now (**current SCRQoL question**);
2. A question asking whether services (either received by the person or the person they care for) affect that area of their lives (the **filter question**);
3. A question asking what the person's life would be like without the help and support they (or the person they care for) currently receive (**expected SCRQoL question**).

More details about these domains can be found below.

Using these two scores (current and expected), you can also calculate **SCRQoL gain**, which is an estimation of the impact of the service upon the person's SCRQoL. Further information about calculating these SCRQoL scores can be found in the **Scoring the ASCOT-Carer INT4** section below.

## ASCOT-Carer INT4 domains

In identifying and defining the ASCOT-Carer 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).

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 INT4 outcome states

Each current and expected 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-Carer outcomes states

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

The person completing ASCOT-Carer INT4 does not need to have an understanding of the four outcome states to answer the questions. The person completing INT4 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 (current or expected) 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.

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

**Interviewer prompt:** *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.*

If needed, please prompt: *When answering the question, think about your situation at the moment.*

Please tick (☑) one box

I'm able to spend my time as I want, doing things I value or enjoy ☐

I'm able to do enough of the things I value or enjoy with my time ☐

I do some of the things I value or enjoy with my time, but not enough ☐

I don't do anything I value or enjoy with my time ☐

**2. Do the support and services that you and [cared-for person's name] get from <<EXAMPLE>> affect how you spend your time?**

**Interviewer prompt:** *By 'support and services' we mean, for example, <<EXAMPLE>> [interviewer should either (a) Insert the name of the specific service that is being investigated (for example, home care, personal budget, carer support group); or (b) (If asking about the full social care package) give some examples of the support and services being received]. Please do not include help from health professionals, such as GPs and nurses, or from friends and family.*

Please tick (☑) one box

Yes ☐

No ☐

Don't know ☐

**If 2 = yes or don't know, then go to question 3**

**If 2 = no, then go to question 4**

**3. Imagine that you and [cared-for person's name] didn't have the support and services from <<EXAMPLE>> that you do now and no other help stepped in. In that situation, which of the following would best describe how you would spend your time?**

**Interviewer note:** It is important that respondents do not base their answers on the assumption that any other help steps in; please emphasise this to interviewees.

Reassure if necessary: *Please be assured that this is purely imaginary and does not affect the services you receive in any way.*

Please tick (☑) one box

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

Although the ASCOT-Carer INT4 interview schedule is essentially a script for the interviewer to read to the interviewee coupled with spaces to record responses, it is a tool that requires some preparation before use. We also advise that those administering the interview have some experience or training around structured interviewing techniques and have carried out a few practice interviews.

The ASCOT-Carer INT4 includes interviewer notes, which cover a number of issues related to the administration of the interview (e.g. how to define 'support and services').

### Scoring the ASCOT-Carer INT4

The ASCOT-Carer is a preference-weighted measure of quality of life in carers. This means that the ratings of each outcome state can be converted into ratings that reflect their relative value, based on the views of the general population. The list of preference weights 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	Preference Weight
<b>Occupation</b>	
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
<b>Control over daily life</b>	
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
<b>Looking after yourself</b>	
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
<b>Safety</b>	
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

<b>Social participation and involvement</b>	
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
<b>Space and time to be yourself</b>	
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
<b>Feeling supported and encouraged</b>	
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 weights for all domain levels have been adjusted such that the preference-weighted SCRQoL score for carers takes values between 0 (the 'pits' state where high-level needs is chosen for each domain) to 1 (maximum SCRQoL where the 'ideal' response options are chosen for each domain).

The overall SCRQoL score for carers is calculated by summing the relevant preference weights (determined by the response given to the ASCOT-Carer) across domains.

$$\text{Current SCRQoL} = \text{Weight\_Occupation}_L + \text{Weight\_Control}_L + \text{Weight\_PersonalCare}_L \\ + \text{Weight\_Safety}_L + \text{Weight\_Social}_L + \text{Weight\_Space}_L + \text{Weight\_Support}_L$$

Box 2 shows a worked example of the calculation behind the current SCRQoL score for carers.

Box 2. Calculating current SCRQoL for carers in INT4

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 do provide an MS Excel ASCOT data-entry tool specifically for the ASCOT-Carer INT4. 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.

## Frequently Asked Questions (FAQs)

### How do I obtain permission to use the ASCOT-Carer INT4?

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](http://www.pssru.ac.uk/ascot), download and complete the registration form, and submit to [ascot@kent.ac.uk](mailto: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 INT4 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 the ASCOT website: [www.pssru.ac.uk/ascot](http://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 the ASCOT website ([www.pssru.ac.uk/ascot](http://www.pssru.ac.uk/ascot)) and submit to [ascot@kent.ac.uk](mailto:ascot@kent.ac.uk).

### What is the ASCOT-Carer INT4 data-entry tool?

The data-entry tool supplements the ASCOT-Carer INT4 instrument. The data-entry tool is an MS Excel file that generates the current, expected and gain social care-related quality of life (SCRQoL) scores for each individual. These scores are calculated from data entered from the ASCOT-Carer INT4 questionnaire by the user.

Upon entering data, the SCRQoL scores for each participant are automatically calculated. The tool also produces a summary of the distribution of responses to each ASCOT-Carer INT4 question (frequencies and percentages) and charts.

### Do I have to pay for the ASCOT-Carer INT4 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. 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 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](http://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 are 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](http://www.pssru.ac.uk/ascot).

### **Can I put the ASCOT-Carer INT4 questions into a longer interview?**

Yes. Users sometimes ask other questions alongside the ASCOT-Carer INT4 to help them understand their data. We would also strongly advise that you keep the ASCOT-Carer INT4 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 INT4 questions during the registration process.

### **Do I need to use all the ASCOT-Carer INT4 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 all the scores (current, expected and gain). Please inform us if you plan to use only a selection of the questions when completing the registration form.

### **Do I need training before I use ASCOT-Carer INT4?**

While we do run a one-day introduction to ASCOT training course which covers the ASCOT-Carer INT4, it is possible to administer the interview without specific ASCOT training. Details of our training courses can be found on the ASCOT website: [www.pssru.ac.uk/ascot](http://www.pssru.ac.uk/ascot). If you have never administered a research interview or a structured interview before, we would recommend attending an appropriate training course to familiarise yourself with the various techniques.

### **What support is available to me if I use the ASCOT-Carer INT4?**

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](mailto:entcontracts@kent.ac.uk)). Please include **ASCOT** in the subject line of your email to ensure it reaches the correct person.

## References

- Batchelder, L., Malley, J., Burge, P., Lu, H., Saloniki, E., Linnosmaa, L., Trukeschitz, B., Forder, J. (2019) Carer Social Care-Related Quality of Life Outcomes: Estimating English Preference Weights for the Adult Social Care Outcomes Toolkit for Carers, *Value in Health*, 22 (12), 1427-1440.
- Forder, J., Malley, J., Rand, S., Vadean, F., Jones, K., and Netten, A. (2016) *IIASC report: Interpreting outcomes data for use in the Adult Social Care Outcomes Framework (ASCOF)*, PSSRU Discussion Paper 2892, University of Kent, Canterbury.
- Fox, D., Holder, J., and Netten, A. (2010) *Personal Social Services Survey of Adult Carers in England – 2009-10: Survey Development Project. Technical Report*, PSSRU Discussion Paper 2643/2, University of Kent, Canterbury.
- Malley, J., Fox, D., and Netten, A. (2010) *Developing a Carers' Experience Performance Indicator*, PSSRU Discussion Paper 2734, University of Kent, Canterbury.
- Rand, S., Malley, J., and Netten, A. (2012) *Measuring the Social Care Outcomes of Informal Carers: An Interim Technical Report for the Identifying the Impact of Adult Social Care (IIASC)*, PSSRU Discussion Paper 2833, University of Kent, Canterbury.
- Rand, S., and Malley, J. (2014) Carers' quality of life and experiences of adult social care support in England, *Health and Social Care in the Community*, 22 (4), 375-385.
- Rand, S., Malley, J., Forder, J., and Netten, A. (2015) Factor structure and construct validity of the Adult Social Care Outcomes Toolkit for Carers (ASCOT-Carer), *Quality of Life Research*, 24 (11), 2601-2614.