Adult Social Care Outcomes Toolkit (ASCOT) Carer INT4 guidance

Stacey Rand, Nick Smith, Ann-Marie Towers, Laurie Batchelder and Elizabeth Welch

Version 3.1

August 2026

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Disclaimer and Acknowledgement

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 department.

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.

The ASCOT-Carer INT4 is not simply an interview version of ASCOT-SCT4. It is a tool designed to estimate the effect of social care services on a carer's SCRQoL without having to use study designs and methods (e.g. RCTs, pre-post test).

ASCOT-Carer INT4 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 can be calculated for each person, as long as they have answered all ASCOT-Carer questions. Using these two scores, 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 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 the ASCOT tools for carers.

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

In ASCOT-Carer INT4, each of these domains is rated on two questions with four outcome states.

These two questions relate to:

1. The person's quality of life now (**current SCRQoL**) and
2. Their quality of life without any care and support for themselves (as carers) or for the person they support (**expected SCRQoL**).

Between these two questions is an (optional) filter question that asks the carer to say if the social care services they receive affect their quality of life in that domain. This is rated as yes, no or unsure/don't know. If someone selects 'no' then the expected SCRQoL question for that domain can be skipped.

Understanding the ASCOT-Carer INT4 outcome states

Each current and expected ASCOT-Carer INT4 question has four response options, relating to four outcome states. These are shown in Table 2.

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

For each domain, we have translated these outcome states into four response options or statements for each domain. The person completing the ASCOT-Carer INT4 is simply asked a question and presented with the 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.

An example is shown in Box 1 below.

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 preparation before use. We also advise that those administering the interview have had prior 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').

Box 1. An example of questions in the occupation domain

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	☐
I would be able to do enough of the things I value or enjoy with my time	☐
I would do some of the things I value or enjoy with my time, but not enough	☐
I wouldn't do anything I value or enjoy with my time	☐

Scoring the ASCOT-Carer INT4

The ASCOT-Carer INT4 SCRQoL cannot be calculated if any of questions have been left blank. All questions must be answered.

ASCOT-Carer SCRQoL is a preference-weighted measure of quality of life in carers, which can be used in economic evaluation. The scores are converted into numbers that reflect their relative importance/value to the general population (see Table 3). More detail of how these weights were estimated can be found in the article by Batchelder et al. (2019).

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

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

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

Box 2 below shows a worked example.

Box 2. Calculating current SCRQoL for carers using ASCOT-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

The expected SCRQoL score can be calculated in the same way (see Box 2).

The SCRQoL gain score (impact of services on SCRQoL) is the difference between current and expected SCRQoL scores.

The simple calculation outlined above can be applied using a range of data analysis tools (MS Excel, SPSS, STATA and so forth).

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

You need to complete a licensing form on the web page below. Please complete the correct form, whether **for-profit** or **not-for-profit**.

https://research.kent.ac.uk/ascot/licensing/

ASCOT-Carer INT4 is free of charge for **not-for-profit** use but a licence is required. You will receive the ASCOT tool automatically, once you have submitted your form. If you are applying for a licence to use ASCOT-Carer INT4 in a **for-profit** capacity, the application will be reviewed and someone will contact you.

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