

Adult Social Care Outcomes Toolkit Proxy (ASCOT-Proxy) Guidance

Version 2.0

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About ASCOT-Proxy

ASCOT-Proxy is a proxy-report version of the [Adult Social Care Outcomes Toolkit](#) (ASCOT). It is a tool designed to measure the social care-related quality of life (SCRQoL) of people who use adult social care services and are unable to self-report, for example, due to severe cognitive impairment. The ASCOT-Proxy questions are completed by someone who knows the person well (usually, a family member or close friend) on behalf of the person. This is known as 'proxy report', rather than 'self-completion'.

The development of the ASCOT-Proxy is described by Rand et al, 2017. Based on an earlier study by Caiels et al (2019), which found that it was more acceptable to respondents, the ASCOT-Proxy asks for two ratings of SCRQoL for each domain. These two ratings are based on different proxy perspectives (see Table 1).

Table 1. Definitions of proxy perspectives

Proxy perspective	Definition
Proxy-proxy perspective	The proxy respondent is asked to rate what s/he thinks, based on his/her attitudes, preferences and opinion.
Proxy-person perspective	The proxy respondent is asked to rate what s/he thinks that the person thinks, based on the proxy's best estimation of the person's attitudes, preferences and opinion.

This allows proxy respondents to indicate differences between these two perspectives. A comments box allows proxy respondents to add further background information to explain any differences. This approach makes clear that the ratings are not equivalent to self-report, especially as some proxy respondents were hesitant to speak on behalf of the person (Caiels et al, 2019). They are both proxy-report perspectives, based on the proxy's view (**proxy-proxy**) or their estimation of the person's view (**proxy-person**).

ASCOT-Proxy domains

The measure 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 that are sensitive to the outcomes of social care services. They were informed by consultations with policy-makers and experts in the field, literature reviews, interviews 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 service users and policy-makers alike.

The definitions for each of the ASCOT domains are shown in Table 2. These eight domains are used in all of the ASCOT tools for people who are supported by social care, including the ASCOT-Proxy. (ASCOT Carers tools have their own, but related, set of domains.)

Table 2. Definitions of the ASCOT domains

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-Proxy outcome states

There is a question for each ASCOT domain with four response options, which relate to the four outcome states shown in Table 3 below.

Table 3. 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 the ASCOT-Proxy 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 the ASCOT-Proxy is asked a question for each domain and presented with four statements. Each statement relates to one of the outcome states presented above. The 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.

For the ASCOT-Proxy, the respondent is asked to give two ratings for each question. These are based on two proxy-report perspectives: **proxy-proxy** or **proxy-person** (as defined above). There is also a comments box, which allows the respondent to add further background information to explain their answers.

An example from the food and drink domain is shown in Box 1 below.

Box 1. An example question (food and drink domain)

1. Thinking about the food and drink the person you represent gets, which of the following statements best describes his/her situation?

Please say what you think in the first column. Then say how you think the person you are representing would answer in the second column. Please write in the comments box if you wish to add anything to your answer.

The person I am representing...

Please tick (☑) one box for each column

	My opinion	How I think this person would answer
Gets all the food and drink s/he likes when s/he wants	<input type="checkbox"/>	<input type="checkbox"/>
Gets adequate food and drink at OK times	<input type="checkbox"/>	<input type="checkbox"/>
Doesn't always get adequate or timely food and drink	<input type="checkbox"/>	<input type="checkbox"/>
Doesn't always get adequate or timely food and drink, and there is a risk to his/her health	<input type="checkbox"/>	<input type="checkbox"/>

Comments (optional)

Current SCRQoL explained

Social care-related quality of life (SCRQoL) refers to those aspects of a person's quality of life that are relevant to, and the focus of, social care interventions. It is a composite of the eight domains outlined in Table 2.

ASCOT-Proxy measures proxy-reported SCRQoL at the time of completing the questionnaire. We call this *current* SCRQoL. Unless you are using ASCOT-Proxy 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 from the ASCOT-Proxy for each of the two proxy perspectives (**proxy-proxy** and **proxy-person**), as long as they have answered all of the ASCOT-Proxy questions.

Scoring ASCOT-Proxy

All of the questions must be answered to produce an overall current SCRQoL score.

ASCOT is a preference-weighted measure of quality of life. The different outcome states are converted into different numbers, reflecting their relative importance or value to the general population. A full list of these can be found in Table 4, as developed for the ASCOT-SCT4. For example, research has shown that having as much control over your daily life as you want is perceived to be more important than having as much social contact as you want. The weighted scores for ASCOT reflect these preferences. Netten et al (2012) checked whether people 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.

The ASCOT-Proxy generates two measures, based on rating SCRQoL using the **proxy-proxy** and **proxy-person** perspectives. We recommend that both proxy perspectives are collected, as this has been found to be more acceptable to respondents (Caiels et al, 2019; Rand et al, 2017). However, studies of family carer and care staff proxy respondents have found that only the proxy-person perspective forms a valid and reliable measure equivalent to the ASCOT-SCT4 (Silarova et al, 2023; Rand et al, 2024). Therefore, we recommend that the **ASCOT-Proxy proxy-person** is reported and used in analysis, especially for research or evaluation purposes.

It is important to note that the ASCOT-Proxy (at the time of publication) does not have its own set of preference weights. In the interim, we recommend that the standard preference weights are applied (see Table 4 and Netten et al, 2012). These weights are used in the absence of other available data, but may be subject to update in the future. Therefore, caution is advised when interpreting results.

Table 4. 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 to 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
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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-Proxy 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-Proxy

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 x weighted score) – 0.466

0.6027 x 0.203 = 1.223481

1.223481 – 0.466 = 0.757481

Current SCRQoL = 0.76

The formula outlined above can be applied in various data-entry and analysis tools (MS Excel, SPSS, STATA etc.) to calculate an overall current SCRQoL score.

STATA syntax to calculate current SCRQoL for **ASCOT-Proxy proxy-person** is available upon request. (Please contact Dr Stacey Rand: s.e.rand@kent.ac.uk.)

Impact and ASCOT-Proxy

ASCOT-Proxy measures what a person's life is currently like, which we call current SCRQoL. It is not able to measure the impact of care and support, and is limited in what it can tell us about the impact of services if it is collected on its own, at one time-point only. This is because SCRQoL may be influenced by a number of different factors, including health status, severity of impairment and living environment (Forder et al., 2016).

This issue also applies to other similar measures of health or care-related quality of life. To address this, there are a number of different study designs or methods that can be used to help understand the impact of care and support, whilst controlling for other influences. One approach is to use what is known as 'counter-factual self-estimation'. If you are interested in finding out more, please look at the information on the ASCOT-INT4 (www.pssru.ac.uk/ascot).

Using ASCOT-Proxy: Frequently Asked Questions (FAQs)

How do I obtain permission to use ASCOT-Proxy?

To read this guidance and see the ASCOT tools, you or your organisation needs to obtain a licence via the ASCOT website: www.pssru.ac.uk/ascot/not-for-profit.

The person completing the form must agree the terms and conditions (T&C's) on behalf of their organisation. Therefore, they must ensure that they have their organisation's approval. If they do not have the authority to agree the T&C's on behalf of their organisation, then they must seek a person in their organisation who has the authority to do so. Once you have submitted your form, you will receive a confirmation email granting you the ASCOT-Proxy licence and a copy/copies of the ASCOT instruments along with the accompanying guidance.

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: www.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.

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 testing to ensure they are acceptable, valid and reliable. Making changes to the questions could jeopardise the reliability, validity 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-Proxy questions into a longer interview?

Yes. Users sometimes ask other questions alongside the ASCOT-Proxy, as part of a survey or questionnaire. We would strongly advise that you keep the ASCOT questions together, as a

block, and do not change their order. You will be asked to tell us how you plan to use the ASCOT during the registration process.

Do I need to use all the ASCOT-Proxy 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-Proxy?

It is possible to use the ASCOT-Proxy without specific training, although general research skills and knowledge is useful to support its application and interpretation. If you would like more information about the ASCOT, there are freely-available resources and online training materials available on the ASCOT website: www.pssru.ac.uk/ascot.

What support is available to me if I use ASCOT-Proxy?

We are not funded to provide support for ASCOT, beyond what is available on our website. If you need further support, please contact the ASCOT team (ascot@kent.ac.uk) and they will liaise with you about consultancy options.

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