



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

Stacey Rand, James Caiels, Barbora Silarova,
Ann-Marie Towers and Elizabeth Welch

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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 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.

ASCOT-Proxy domains

ASCOT-Proxy 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 ASCOT tools for people who are supported by social care, including ASCOT-Proxy.

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

Each ASCOT-Proxy question has four response options. These are shown in Table 3 below.

Table 3. Definitions of ASCOT outcomes states

Outcome state	Definition
Ideal	The person's wishes and preferences in this aspect of their life are (or would be) fully met
No needs	The person 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 the person'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.

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

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

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

Comments (optional)

Scoring ASCOT-Proxy

The ASCOT-Proxy SCRQoL cannot be calculated if any of questions have been left blank.

ASCOT is a preference-weighted measure of quality of life, which can be used in economic evaluation. The scores are converted into numbers that reflect their relative importance/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 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-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 ASCOT-Proxy SCRQoL

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

Using ASCOT-Proxy to understand the impact of social care

ASCOT-Proxy measures what a person's life is currently like, which we call **current SCRQoL**. It is not able, on its own, to tell us about the impact of services. This is because SCRQoL may also be influenced by other factors, including health status, severity of impairment and living environment (Forder et al., 2016). If you would like to measure the impact of services on people's quality of life and you are not able to or do not wish to apply research study designs and methods (e.g., RCTs), you may want to look at the ASCOT-INT4 tool. This is suitable for use in local service evaluation by care providers or in qualitative/mixed methods research studies.

How do I obtain permission to use ASCOT-Proxy?

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.

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.
- Caiels, J., Rand, S., Crowther, T. *et al.* (2019) Exploring the views of being a proxy from the perspective of unpaid carers and paid carers: developing a proxy version of the Adult Social Care Outcomes Toolkit (ASCOT). *BMC Health Serv Res* 19, 201. <https://doi.org/10.1186/s12913-019-4025-1>
- 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 (ASCOT)*, 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 Petch, 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., McDaid, 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. <http://dx.doi.org/10.3310/hta16160>
- Rand, S., Caiels, J., Collins, G. *et al.* (2017) Developing a proxy version of the Adult social care outcome toolkit (ASCOT). *Health Qual Life Outcomes* 15, 108. <https://doi.org/10.1186/s12955-017-0682-0>
- Rand, S., Towers A-M., Allan S. *et al.* (2024) Exploratory factor analysis and Rasch analysis to assess the structural validity of the Adult Social Care Outcomes Toolkit Proxy version (ASCOT-Proxy) completed by care home staff. *Quality of Life Research* 33, 1555-1567 <https://doi.org/10.1007/s11136-024-03631-1>
- Silarova, B., Rand, S., Towers, A-M. *et al.* (2023) Feasibility, validity and reliability of the ASCOT-Proxy and ASCOT-Carer among unpaid carers of people living with dementia in England. *Health Qual Life Outcomes* 21, 54. <https://doi.org/10.1186/s12955-023-02122-0>
- 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.