



# Adult Social Care Outcomes Toolkit (ASCOT) INT4 guidance

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

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#### **About ASCOT-INT4**

ASCOT-INT4 is an interview version of the Adult Social Care Outcomes Toolkit (ASCOT). It is designed to measure the social care-related quality of life (SCRQoL) of adults accessing social care services (e.g., homecare, residential care) and can be used in research and evaluation.

The ASCOT-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-INT4 SCRQoL explained**

SCRQoL refers to those aspects of a person's quality of life that are relevant to, and the focus of, social care interventions. INT4 contains two measures of SCRQoL:

- Current SCRQoL: what the person's life is like now, usually as a result of support and services
- **Expected SCRQoL**: what a person's life would be like without the help and support they receive from services.

These two SCRQoL scores can be calculated for each person, as long as they have answered all ASCOT 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** section below.

#### **ASCOT-INT4 Domains**

ASCOT-INT4 SCRQoL 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 can be affected by social care services. The domains were informed by consultations with policy-makers and experts in the field, reviews of the literature in this area, and 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-INT4 domains are therefore relevant to, and the focus of, social care, whilst also being valued by social care recipients and policy-makers alike.

The definitions for each of the eight ASCOT-INT4 domains are shown in Table 1. These eight domains are used in the ASCOT tools for people who are supported by social care services.

Table 1: Definitions of ASCOT domains

**User 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

User SCRQoL Domain	Definition
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

In ASCOT-INT4, each of these domains is rated on two questions with four outcome states (except for dignity – see below).

These two questions relate to:

- 1. The person's quality of life now (current SCRQoL) and
- 2. Their quality of life without the care and support they receive (expected SCRQoL).

Between these two questions is an (optional) filter question that asks the person 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 INT4 outcome states**

Each current and expected SCRQoL question has four response options relating to four outcome states. These are shown in Table 2.

Table 2: 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.

For each domain, we have translated these outcome states into four response options or statements for each domain. The person completing INT4 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 their experience. The interviewer records the person's response by ticking or selecting the box next to the selected option.

Interviewer prompt: When you are thinking about how you spe	end your time,
please include anything you value or enjoy, including leisure ac	tivities, formal
employment, voluntary or unpaid work, and caring for others.	
If needed, please prompt: When answering the question, think a situation at the moment.	about your
Pleas	e 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	ugh
I don't do anything I value or enjoy with my time	
how you spend your time?	
Interviewer prompt: By 'support and services' we mean, << EXAMPLE >> [interviewer should either (a) Insert the name service that is being investigated (for example, home care, pe or (b) (If asking about the service user's full social care package examples of the support and services that the service user is recorded and include help from health professionals, such as CRs and	of the specific rsonal budget); age) give some ceiving]. <i>Please</i>
<< EXAMPLE >> [interviewer should either (a) Insert the name service that is being investigated (for example, home care, pe or (b) (If asking about the service user's full social care packate examples of the support and services that the service user is read on not include help from health professionals, such as GPs and	of the specific rsonal budget); age) give some ceiving]. <i>Please</i>
<< EXAMPLE >> [interviewer should either (a) Insert the name service that is being investigated (for example, home care, pe or (b) (If asking about the service user's full social care packate examples of the support and services that the service user is red do not include help from health professionals, such as GPs and friends and family.	of the specific rsonal budget); age) give some ceiving]. <i>Please</i> nurses, or from
<< EXAMPLE >> [interviewer should either (a) Insert the name service that is being investigated (for example, home care, pe or (b) (If asking about the service user's full social care packate examples of the support and services that the service user is red do not include help from health professionals, such as GPs and friends and family.  Pleas	of the specific rsonal budget); age) give some ceiving]. <i>Please</i>
<< EXAMPLE >> [interviewer should either (a) Insert the name service that is being investigated (for example, home care, pe or (b) (If asking about the service user's full social care packate examples of the support and services that the service user is red do not include help from health professionals, such as GPs and friends and family.	of the specific rsonal budget); age) give some ceiving]. <i>Please</i> nurses, or from
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situation, which of the following would best descri spend your time?	be how you would
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: <i>Please be assured that this is pure</i>	ely 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 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	

# **Dignity**

Unlike the other ASCOT-INT4 domains, there are two questions for Dignity.

- The first question is designed to enable people to express how *having help (at all)* affects how they feel about themselves. It is not used in the scoring, but we have found it is important to ask this question. We refer to this as the 'Dignity filter question'.
- The second question is the ASCOT-INT4 Dignity domain. This question asks about *how* the way you are helped makes you feel. This question is used in the scoring.

When we were developing the ASCOT- INT4 in interviews with people using services, we found that some people wanted to answer the Dignity question based on how having help (at all) affected how they felt. While this is important, it is not what we wish to measure with ASCOT- INT4. Therefore, we added the first question to enable people to express how they felt about having help (at all) before going on to tell us how the way they are helped makes them feel. This helped most people to respond to the Dignity question in the way we had intended it (Netten et al, 2012).

Unlike the other domains in the ASCOT-INT4, the dignity domain also only ask about the person's current SCRQoL. There are no questions which ask the person to reflect on their expected dignity in the absence of services. This is because of how ASCOT defines dignity. While dignity is a broad and wide-ranging concept, ASCOT uses a narrower definition in its measurement of SCRQoL. In ASCOT, dignity refers to the effect of how the person is helped

on their sense of self and significance. Hence, asking a person to make a rating of this in the absence of services is not possible because it assumes that they are receiving care and support.

When calculating the expected SCRQoL score, the dignity domain is scored as 'no needs'. See the scoring section below for further detail.

# Using the questionnaire

The ASCOT-INT4 interview questionnaire provides a script for the interviewer to read to the interviewee coupled with spaces to record responses. It is a tool that requires careful 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 INT4 script begins with two pages of interviewer notes. They cover a number of issues, as outlined in the extract presented in Box 2 below.

#### Box 2. An extract of the Interviewer Notes in ASCOT-INT4

## 1. Definition of Support and Services

The interview is flexible so that the definition of support and services can be tailored to the needs of your particular research study. Where the schedule reads << EXAMPLE>>, the interviewer should either:

- a. Insert the name of the specific service that is being investigated: for example, home care, personal budget; or
- b. (If asking about the service user's full social care package) give some examples of the support and services that the service user is receiving.

The interview is designed to measure the impact of social care services on the social carerelated quality of life (SCRQoL) of service users. We found that a clear definition of what is, or is not, included helps the respondent to answer the questions. It is suggested (although this may be adapted to your particular needs) that:

- a. If there are any specific services you would like to exclude (for example, NHS support and services), the interviewer should use the prompts to exclude NHS support and services when answering the filter (for example, question 2) and expected situation questions (for example, question 3). You may wish to ask respondents to include some NHS services, for example if they are a service user with a mental health problem who has support from a Community Mental Health Team (CMHT) that is joint-funded by Adult Social Care Services and the NHS. In this case, we would strongly recommend that the interviewer makes this clear in the definition of support and services at the start of the interview, as well as in the prompts throughout the interview schedule.
- b. There may be situations where service users may use social care services funded by streams outside of social care. It is recommended that you ask service users to include <u>all social care services</u>, regardless of the funding source, when answering the filter and expected questions.

### 2. Using the Interviewer Prompts

- a. When asking the interviewee about their social care-related quality of life in the absence of services (expected situation questions, for example question 3):
  - i. Emphasise that the respondent does *not base his/her answers on the assumption that any other help steps in.*
  - ii. Reassure them that the question is about a *purely imaginary situation and does* not affect the services they receive in any way.
- b. Make sure that the interviewer prompts are used frequently to define 'support and services', as cognitive interviewing has shown that this helps respondents in answering the questions.
- c. When asking about a service user's current situation, interviewers may add that this question is asking about the service user's present situation, to clarify the timeframe of the question.

## 3. Notes on the Filter Questions (for example, question 2)

When asking the filter questions:

- a. Be very clear about which services you are interested in and use examples to help you.
- b. Emphasise that the question is asking whether the support and services affect a service user with regard to each particular aspect of life (for example, 'do support and services affect how you **spend your time**?'). If needed, explain to the respondent that we are not asking whether support and services make a difference generally, but whether they make a difference (either positive or negative) to that particular aspect of their life.

#### 4. Notes on Sensitive Questions

It should be noted that the set of questions asks respondents to think about their lives and experiences. This may be upsetting to some respondents, particularly if they are currently experiencing difficulties. We would recommend that the interviewer clearly explains the nature of the questions before obtaining informed consent, and emphasises the respondent's right to terminate the interview or to refuse to answer specific questions without further explanation.

The 'expected situation' questions may be particularly sensitive in situations where the respondent has recently experienced cuts to their social care support or services. In this case, we would recommend that the interviewer be especially aware of the potential sensitivity of the questions and be prepared to terminate or pause the interview, if needed.

# **Scoring ASCOT-INT4**

ASCOT-INT4 current SCRQoL cannot be calculated if any of questions, bar the dignity filter question, have been left blank. All survey questions must be answered.

ASCOT-INT4 is a preference-weighted measure that can be used in economic evaluation. The scores are converted into numbers that reflect their relative importance or value based on preference studies with the general population and people accessing services (see Table 3) (Netten et al, 2012).

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

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	0.875
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	0.184
to my health	0.10
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

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 INT4 is:

#### Current SCRQoL = (0.203 x 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). In other words, while a score of 1.00 would mean that the person has reported 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-INT4 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

 $0.6027 \times 0.203 = 1.223481$ 

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).

The *expected SCRQoL* score is calculated using the same formula as the current score. The weighted ratings for the expected questions (questions 3, 6, 9, 12, 15, 18 & 21) are added together, with a fixed rating for dignity. Because the dignity question (23) is about being treated with dignity when you are helped by services, there is no equivalent question about dignity in the absence of services. It is assumed that in the absence of service there is no impact on dignity (the 2nd level). The 'no needs' score (0.637) is used in the calculation of the expected weighted score.

The formula for calculating the expected SCRQoL is:

## Expected SCRQoL = (0.203 x weighted score) - 0.466

An example of this calculation can be found in Box 3.

Box 3. Calculating expected ASCOT-INT4 SCRQoL

For a respondent who rates every expected domain as 4 (high-level needs) Expected SCRQoL

0.00 (control) + 0.195 (cleanliness) + 0.184 (food) + 0.114 (safety) + 0.241 (social) + 0.170 (occupation) + 0.288 (accommodation) + 0.637 (dignity) = 1.829

 $1.829 \times 0.203 = 0.371$ 

0.371 - 0.466 = -0.094

Expected SCRQoL = - 0.09

SCRQoL gain is a score that estimates the impact of a service(s) on SCRQoL as the difference between current SCRQoL and expected SCRQoL. So, for example, if a person had a current SCRQoL score of 0.97 and an expected SCRQoL score of 0.67, SCRQoL gain would be 0.30. Where the expected SCRQoL score is higher than the current SCRQoL score, a negative SCRQoL gain score will be produced, suggesting that services are having a negative impact on SCRQoL. Negative SCRQoL gain scores can reflect the lack of impact of services in any domain, or/and a loss of dignity associated with the way the support is provided.

## **How do I obtain permission to use ASCOT-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 from the University of Kent will contact you.

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