QORU | quality and outcomes of person-centred care policy research unit

Adult Social Care Outcomes Toolkit (ASCOT) INT4 guidance

Version 1.0

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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.

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About ASCOT INT4

ASCOT INT4 is the interview version of the Adult Social Care Outcomes Toolkit (ASCOT). It is designed to measure the social care-related quality of life (SCRQoL) of the individual responding to the interview. If you are unsure if INT4 is the right tool for your project, see the short video on the ASCOT website (www.pssru.ac.uk/ascot) which compares the different versions of ASCOT.

INT4 is designed to be administered face-to-face. The interview script has not yet been tested for use in either telephone or video interviews. If completing an interview is likely to be difficult for the person whose SCRQoL you are measuring, you may want to consider alternatives.   The ASCOT toolkit includes a mixed-methods version that can be used in residential settings (e.g. care homes) (CH3), an easy read version of the self-completion tool (ASCOT SCT4 Easy Read), and a Braille version of the self-completion tool (ASCOT SCT4).

Please contact the ASCOT team (ascot@kent.ac.uk) if you are interested in using the Braille version of ASCOT. The other tools are available on our website (please note that to access and use the tools a licence is required – the licensing process includes registration and consent to the terms and conditions. In addition, to use the CH3 there is a requirement to complete training provided by the ASCOT team).

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 of 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 of the 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.

Using INT4 to measure SCRQoL

The SCRQoL scores outlined above are populated by the answers to twenty-three questions that make up the INT4 interview. These questions cover eight areas of a person's life. We call these areas domains. More details about these domains can be found below.

For each domain (except dignity) there are three questions: a question asking about the person's life now (current SCRQoL), a question asking whether services affect that area of

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their lives (the filter question), and a question asking what the person's life would be like without the help and support they currently receive (expected SCRQoL).

ASCOT INT4 Domains

In identifying and defining the ASCOT domains, we focused on areas of quality of life which are sensitive to the outcomes of 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 cognitive testing 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 recipients and policy-makers alike.

The definitions for each of the eight ASCOT domains are shown in Table 1 below. These eight domains are used in all of the ASCOT tools for people who are supported by social care (ASCOT Carers tools have their own, but related, set of domains).

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

Understanding the INT4 outcome states

Each current and expected SCRQoL question has four response options (and a 'don't know' option) relating to four outcome states. The outcome states are shown in Table 2 below (from best to worst).

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.

The person participating in the INT4 interview does not need to have an understanding of the four outcome states to answer the questions. We have translated these states into response options for each domain. The person participating in the interview is simply asked a question and presented with a number of statements. In the questions asking about either current or expected SCRQoL there are four statements, each of which 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. Some questions, including the example below, have an additional sentence for the interviewer to read out to aid understanding. An example of a set of questions from the occupation domain is shown in Box 1 below.

Box 1. An example of set of questions in the occupation domain

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16. 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	☐

17. Do the support and services that you 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); 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]. *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 17 = yes or don't know, then go to question 18
If 17 = no, then go to question 19

18. Imagine that you 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 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	☐

The dignity domain

Each domain of SCRQoL is explored by three questions in the INT4 interview, with the exception of the dignity domain. This domain has two questions. The first dignity question asks about how *having* help makes you feel, while the second asks about how *the way you are helped* makes you feel. It is only the second question, how the *way* you are helped makes you feel, that reflects the ASCOT definition of dignity and is included in the current SCRQoL score. The other question is a filter question and is not included in the current SCRQoL score. There is, however, a very good reason for including this filter question in the interview. During the development and testing of ASCOT, we found that when there was just one question asking about the *way* you are helped, people often wanted to answer it by telling us how they felt about needing or receiving that help. While this is important, it is not the focus of ASCOT. We added the filter question to enable people to express how they felt about getting help before going on to tell us how the way they were helped made them

feel. Testing found that the addition of this extra question helped respondents answer the second question in the way that we intended.

The questions in the dignity domain also only ask about the person's life at it currently stands. 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 negative and positive psychological impact of support and care on the service user's personal sense of significance. Hence, asking a person to make a rating of this in the absence of services is not possible. When calculating the expected SCRQoL score, we use a dummy code for expected needs in the absence of services for the dignity domain. In absence of services (expected), we assume that there are no needs in the dignity domain and the domain is always rated accordingly using the no needs weight. See the scoring section for a discussion of preference weights.

Using the questionnaire

Although the INT4 interview 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 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

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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 <<<mark>EXAMPLE</mark>>>, 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 care-related 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 _all social care services_, regardless of the funding source, when answering the filter and expected questions.

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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.

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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

Creating ASCOT scores for a person requires them to have answered all of the relevant questions. The current SCRQoL score is populated by all of the current SCRQoL questions (Questions 1, 4, 7, 10, 13, 16, 19, 23) bar the dignity filter question. The expected SCRQoL score is populated by all of expected SCRQoL questions (Questions 3, 6, 9, 12, 15, 18, 21). When you have both a current and an expected SCRQoL score, SCRQoL gain can also be calculated.

ASCOT is a preference-weighted measure of quality of life. This means that the raw scores used in the data-entry spreadsheet for the different outcome states (0, 1, 2, and 3) are converted into different numbers, reflecting their relative importance/value to the general population. For example, research has shown that having as much control over your daily life as you want is seen as being more important than having as much social contact as you want. The weighted scores used in the calculation of ASCOT reflect these preferences. We checked whether people being 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. More details of these studies can be found in the report by Netten et al. (2012).

A full list of the weights can be found in Table 3 below. The current and expected scores use the same weights.

Table 3. 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

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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

In order to calculate the current SCRQoL score, the weighted ratings for the current questions (questions 1, 4, 7, 10, 13, 16, 19 & 23) are added together and entered into a formula. 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 SCRQoL in INT4

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 *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) and this (0.637) is used in the calculation of the expected weighted score. The weighted score is used in the formula below:

Expected SCRQoL = (0.203 x weighted score) – 0.466

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

Box 3. Calculating expected SCRQoL in ASCOT INT4

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 x 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.

The formulas 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 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 user or site (e.g. a care home). The spreadsheet includes guidance on how to use it, and space to enter data from up to 2,000 cases. For each case, where there is no missing data, it automatically calculates a current and expected SCRQoL score, as well as a score for SCRQoL gain. It also features a sheet that presents the aggregate ASCOT data. This includes an overall current 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 can be helpful in reports.

Using ASCOT INT4: Frequently Asked Questions (FAQs)

How do I obtain permission to use ASCOT 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, download and complete the registration form, and submit to 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 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 our website: 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 our website www.pssru.ac.uk/ascot and submit to ascot@kent.ac.uk.

What is the INT4 data-entry tool?

The data-entry tool supplements the ASCOT INT4 instrument. The data-entry tool is an MS Excel file that generates social care-related quality of life (SCRQoL) scores for each individual. These scores are calculated from data entered from the ASCOT INT4 interview by the user. The ASCOT INT4 preference weights are programmed into the file. Upon entering data, a current SCRQoL score for each individual is automatically calculated. The tool also calculates the expected SCRQoL score (the individual's quality of life in the absence of the service(s) studied) and the gain in SCRQoL (the impact of the service(s) on the individual's quality of life). The tool also produces a summary of the distribution of responses to each ASCOT INT4 question (frequencies and percentages) and charts.

Do I have to pay for the ASCOT 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 breach of 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.

Can I make changes to the question order or wording?

No. The wording of the questions and responses has 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 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 INT4 questions into a longer interview?

Yes. Many people sometimes ask other questions alongside INT4 to help them understand their data or to measure other aspects of people's lives. This is fine but you should pilot the longer interview schedule first to check how long it takes to complete. We would also strongly advise that you keep the ASCOT 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 questions during the registration process.

Do I need to use all the ASCOT 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 INT4?

While we do run a one-day introduction to ASCOT training course which covers INT4, it is possible to administer the interview without specific ASCOT training. Details of our training courses can be found on our website: 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 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). Please include **ASCOT** in the subject line of your email to ensure it reaches the correct person.

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