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Netten, Ann and Beadle-Brown, Julie and Caiels, James and Forder, Julien E. and Malley, Juliette and Smith, Nick and Towers, Ann-Marie and Trukeschitz, Birgit and Welch, Elizabeth and Windle, Karen (2011) ASCOT Adult Social Care Outcomes Toolkit: Main Guidance v2.1 PSSRU Discussion Paper 2716/3, University of Kent. Manual. Personal Social Services Research Unit, University

DOI

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ASCOT

adult social care outcomes toolkit

Main guidance v2.1

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Introduction

The aim of this document is provide both the background to and guidance for using ASCOT 2.1. It provides information relevant to all the ASCOT tools; for those using the care home instrument (CH3) there is a supplementary document specific to observations in care homes:

Beadle-Brown, J. et al. (2011) *Adult Social Care Outcomes Toolkit V2.1: additional care home guidance*, PSSRU Discussion Paper 2716/3 (supplement), Personal Social Services Research Unit, University of Kent, Canterbury.

General principles and definitions

Scope

The ASCOT measure is designed to capture information about an individual's social care-related quality of life (SCRQoL).¹ The aim is for the measure to be applicable across as wide a range of user groups and care and support settings as possible. In identifying and defining the domains (see Table 1), the aim is to ensure the measure is sensitive to outcomes of social care activities. Evidence from consultation with service users, experts and policy-makers, as well as focus group work and interviews with service users, indicated that the measure captures aspects of SCRQoL that are valued by service users (and policy-makers) (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).

Capabilities and functioning

For people with impairments, quality of life is often limited by their ability to pursue the different aspects of SCRQoL, often due to environmental and sometimes to financial barriers. Aligning itself with the social model of disability which foregrounds the contextual barriers over individual impairments, the focus of much policy has been on broadening opportunities for people with disabilities and developing 'independence', 'choice' and 'control' (Cabinet Office, 2005; Department of Health, 2005; Department of Health, 2006). It is argued that it is the flexibility and freedom that people most want and value from services.

This focus on choice and control is consistent with the capabilities framework put forward by Sen (see e.g. Sen, 1985) as an alternative to standard welfare economics (Burchardt, 2004). Sen argues that utility is not the sole object of value; rather, it is capability, understood as the substantive opportunities an individual has to be or do a range of things that is the object of value. Capabilities are contrasted to functionings, which are understood to be states of being (for example, being well-fed or being safe) or activities (for example, shopping). Most health outcome measures, for example the EQ-5D (EuroQol Group, 1990), capture functionings and ask people to value these functioning states. However, if it is capabilities and not functionings that are valued, then each domain should be designed to capture the individual's capability rather than functioning state.

The distinction between capabilities and functionings is of central importance to the development of a measure of social care outcome. On the one hand, evidence from user movements and research implies that it is opportunities or capabilities that are valued. But, from another perspective, functionings are important. For some aspects of SCRQoL, it could be argued that a low level of functioning is indicative of need, whether a person recognises that need or otherwise. For example, someone who is anorexic may choose to have poor nutritional intake, but as a society we deem the level of functioning poor enough to require

¹ Social care-related quality of life (SCRQoL) refers to those aspects of people's quality of life that are relevant to and the focus of social care interventions.

some form of intervention. Similar issues exist for people with disabilities as they may adapt to their circumstances (for example, in a poor-quality care home), adjust their expectations and judge their opportunities within an aspect of their life to be quite good. However, an external observer might identify the potential for much better opportunities for that individual in another care environment. If it is the case that for each SCRQoL aspect of people's lives there is a level of functioning that we as a society judge to be unacceptable, our measure should reflect this.

Early self-report versions of the measure used three levels of need in each domain, and language that focused on functioning. We want to ensure the measure can reflect the increased policy emphasis on capabilities as far as possible, although inevitably, when people have limited cognitive and communication abilities, ratings are more likely to reflect functionings.

In the current version of the toolkit we provide a number of options, including:

- A three-level 'capability-based' self-report version (SCT3)
- A three-level 'functionings-based' observation version for use in communal living settings (CH3)
- A four-level self-report version where the domains are phrased in the language of capabilities at the high quality of life end of the spectrum and in terms of functionings when reflecting low quality of life (SCT4).

Value and attribution of social care interventions to outcome

A major problem in measuring outcomes in social care is reflecting the full value of what has been provided. Most social care is for people with long-term conditions where 'before' and 'after' only reflect the marginal impact of an intervention. For those where the underlying health state deteriorates, a before-and-after measure might reflect no change, where in practice over the period there has been considerable increase in the contribution of the intervention to people's well-being. It is also difficult to distinguish the effect of changes that are attributable to interventions from other factors: for example, life events in the absence of specific research designs such as randomised control trials.

People who use services and support know themselves the contribution that services make and their likely (or occasionally actual) situation in the absence of those services. In order to reflect this in face-to-face interviews, in addition to a question asking about a person's current status within each domain, there is also a 'hypothetical' question that asks people to rate what their quality of life would be like in the absence of services, or their 'expected needs'. These questions can be combined with those asking about current status to provide a measure of the contribution of social care services to SCRQoL. When people do not have the capacity to hypothesise and/or this is very difficult to do, as is the case in a care home setting, we can deduce what their likely SCRQoL is through observation of the way in which the service helps (or hinders) them in each domain. The observational element of the toolkit demonstrates how we do this in practice. 'Expected' SCRQoL which is generated through the responses or ratings has been shown to be highly associated with more usual measures of activities of daily living (Caiels et al., 2010; Netten et al., 2010; Netten et al., 2009).

Domains

The ASCOT measure in all of its versions draws on eight SCRQoL domains. They are listed and described below.

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 he/she 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 he/she has a nutritious, varied and culturally appropriate diet with enough food and drink he/she 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
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, 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 it be 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

Levels

As noted above, some of the ASCOT tools have three-level SCRQoL measures while others have four-level SCRQoL measures. The main difference between the three- and four-level versions is that the latter has more sensitivity in the top SCRQoL states: that is, for people with low needs.

Three-level versions

In the *three-level versions* the levels in each domain are defined as:

No needs

The individuals has 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 needs

High 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 number

Four-level versions

In the *four-level versions* the top level is divided to distinguish no needs from the desired situation:

Ideal state

The individual's wishes and preferences in this aspect of their life are fully met

No needs

The individual has 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 needs

High 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 number

Measures

A number of different measures can be derived from the toolkit. The measures can be displayed graphically in cobweb charts/bar charts when the interest is in individual domains and the overall pattern of outcome. For example, previous work has identified that care homes tend to be better at delivering outcomes in basic aspects of people's lives (such as personal cleanliness, food and drink, and safety) than in 'higher-order' domains (such as control, social participation and occupation) (Netten et al. 2010).

In order to report overall SQRQoL, we need to reflect the fact that the domains and levels within those domains are not necessarily of equal importance to people. Our ASCOT measure is weighted to reflect the preferences of the general population, although recent ASCOT developmental work has shown that service users' preferences do not differ significantly from those found in the general population. For further information on the weighting of measures, see the scoring document in the guidance section of the ASCOT website or the following report:

A Netten, P Burge, J Malley, D Potoglou, A-M Towers, J Frazier, T Flynn, J Forder and B Wall (2012) *Outcomes of social care for adults: developing a preference-weighted measure*, Health Technology Assessment 2012; Vol. 16: No. 16

The toolkit allows the measurement of:

Current SCRQoL

This reflects people's currently experienced SCRQoL and can be obtained through interview (INT4, CHINT3), self-completion questionnaire (SCT3, SCT4) or observation (CHOBS).

Expected SCRQoL

This reflects the social care-related quality of life that would be expected in the absence of the intervention that is of interest. This could be an individual service, package of care, personal budget and include or exclude the help provided by informal carers. This is measured directly through interview or observation. As expected SCRQoL is highly associated with more usual measures of abilities in activities of daily living (ADLs), the overall measure can be estimated from these more simply collected data. The precise relationship depends on the type of service or intervention. The short collection tool (SCT3) includes ADL items that allow the estimation of expected SCRQoL and outcome (see below) for day care services for older people based on previous research (Caiels et al., 2010).

The definition of the Dignity domain (the impact of the way care and support is provided on self esteem) is such that it is only relevant in the presence of this support. This means when scoring SCRQoL we would use the 'no needs' level, which is equivalent to no impact when measuring expected SCRQoL in the absence of the intervention.

Outcome

There are three possible ways of measuring outcome using the instruments in the toolkit:

Change in current SCRQoL

Outcome can be measured as the difference in current SCRQoL (using SCT3, SCT4 or INT4) before and after an intervention. Once other factors affecting changes in SCRQoL have been allowed for, this reflects the marginal benefit of the intervention. Other factors will include changes in individuals' level of impairment, other sources of help, and support and environmental influences such as accessibility of the home and surrounding area.

SCRQoL gain

It can be difficult to allow for other factors affecting SCRQoL, and often social care interventions do not come into play until people are already receiving help from services or family. SCRQoL gain is the difference between current SCRQoL and expected SCRQoL in the absence of the intervention. This reflects the total benefit of the intervention and can be directly measured through interview (INT4) or rated in care homes using multi-methods including observation (CH3).

Change in expected SCRQoL

There is an increasing emphasis on enablement services that reduce or prevent the need for care and support. Changes in expected SCRQoL in the absence of the service before and after the intervention would provide a measure of outcome of such services. This could be done through interview (INT4) or, if a communal establishment had this objective, through multi-methods including observation (CH3). As expected SCRQoL is highly correlated with more routinely-used measures such as abilities in activities of daily living (ADLs), these would provide a less burdensome alternative for routine measurement.

Capacity for benefit (CfB) and quality

An indirect way of measuring outcomes can be used at the level of an intervention. An intervention's capacity *for* benefit is what that intervention could possibly achieve, which is reflected in the domains of SQRQoL affected by the intervention and the degree to which

people using the intervention rely on it.

Individuals have the capacity *to* benefit from an intervention (CtB). CtB is the difference between expected levels of SCRQoL in the absence of the intervention and the maximum that could be achieved by that service or intervention. This maximum is decided on the basis of what the intervention is intended to deliver.

Capacity for benefit (CfB) is the sum of the capacity to benefit of individuals who use that service, and can be estimated by using the average CtB of a representative sample of people using the service multiplied by the total number of users.

In order to reflect what the service actually does deliver, we need an indicator of *quality*, which is the degree to which those outcomes have actually been delivered. This is the measure of current SCRQoL of service users and can be measured using self-completion questionnaires (SCT3 and SCT4) or interview (SCT4). Other potential indicators are quality ratings of care homes, but as these are currently under review we do not include them at present (see [Future Developments](#) section of the ASCOT website)

For further descriptions of this approach, see Netten et al. (2005), Netten and Forder (2010) and Netten et al. (2010).

Which measure should I use?

There are, as noted above, four versions of ASCOT, which are for use in different circumstances and generate different measures.

- SCT4: The four-level self-completion tool is for use with people who live in community settings. It has nine four-level questions from which current SCRQoL can be calculated.
- INT4: The four-level interview tool is for use with people who live in community setting. It has 23 questions from which current SCRQoL and expected SCRQoL can be calculated.
- SCT3: The three-level self-completion tool is for use with people who live in community settings. It has 18 questions which calculate current SCRQoL and can generate predicted SCRQoL gain from indirect indicators based on previous research in a day care setting. These indicators have not been tested in another setting and may not be appropriate for all settings.
- CH3: The tool kit is for use in residential setting. Using a combination of observation (CHOBS3) and interviews with residents, relatives and staff (CHINT3), both current and expected SCRQoL can be calculated.

Using the ASCOT toolkit

Registration/copyright

With the update to version 2.1 only those who register on the ASCOT website may download the ASCOT tools. Registration is completely free and so is the use of ASCOT for non-commercial purposes. By registering you are agreeing not to alter the tools without permission from the ASCOT team, to inform the ASCOT team of your usage and ensure that any use of the ASCOT tools in your research is acknowledged. This may be done by referencing this document in the following way:

A Netten, P Burge, J Malley, D Potoglou, A-M Towers, J Frazier, T Flynn, J Forder and B Wall (2012) *Outcomes of social care for adults: developing a preference-weighted measure*, Health Technology Assessment 2012; Vol. 16: No. 16

Or

Netten, A., Beadle-Brown, J., Caiels, J., Forder, J., Malley, J., Smith, N., Trukeschitz, B., Towers, A., Welch, E. and Windle, K. (2011) *Adult Social Care Outcomes Toolkit v2.1: Main guidance*, PSSRU Discussion Paper 2716/3, Personal Social Services Research Unit, University of Kent, Canterbury.

Users wishing to make commercial use of any of the ASCOT materials should contact the ASCOT team (ascot@kent.ac.uk), who will put them in touch with Kent Innovation & Enterprise.

ASCOT tools

Each version of ASCOT has a number of associated documents and tools. For SCT3 and SCT4, there is both a set of questions and a data-entry tool in the form of an MS Excel spreadsheet. For INT4 we provide an interview schedule and a data-entry tool. Because CH3 draws on different possible approaches to arrive at its measures, the CH3 tool kit includes both interview schedules and an observation tool kit, along with a form for consolidating and recording data at an individual level. Like the other versions of ASCOT, it has its own data-entry tool. Given the greater level of complexity in using CH3 compared to other versions of ASCOT, it has its own guidance manual which supplements the information provided in this document. It is also suggested that before embarking on care home observations, anyone planning to use this section of the ASCOT toolkit (whether researchers, providers or commissioners) undertakes training.

The self-completion tools can either be used on their own or as part of larger survey that asks other questions about services users' experiences of social care. This is equally true for the four-level interview version of ASCOT (INT4). Any use of the tools assumes that an appropriate sample of service users was asked to answer questions, whether via interview or self-completion, and that good surveying practice was adopted.

Data-entry tools and measures

The data-entry tools provided are in the format of MS Excel spreadsheets. They provide space to enter responses for up to 1995 participants. Each spreadsheet contains a front sheet that contains further guidance to aid data entry, a data-entry sheet, and a sheet with summary tables of responses and charts that draw on the data entered. In addition, the data-entry tools can be used to calculate the overall ASCOT well-being score for individuals on the basis of their responses to questions about their current social care-related quality life and their SCRQoL in the absence of services. Investigators can enter details from service

users collected using ASCOT questionnaires (by interview or through self-completion). Current SCRQoL information is collected in either three or four levels across either eight or nine domains of SCRQoL (depending on the service option). The data-entry tools then apply the relative importance or 'preference' weights estimated in the MOPUS² and OSCA³ projects to each level within each domain to obtain the overall current SCRQoL score. This overall score is a number between -0.27 and one which quantifies a service user's well-being in terms of the degree to which they experience a range of care needs. In developing these indicators, the research team experimented with a number of options for these measures which balance sensitivity and validity of the indicators against ease of use and general parsimony. More details about ASCOT scoring, including details of weights and how to calculate ASCOT scores without the data-entry tools, can be found in the additional scoring guidance on the ASCOT website.

The indicators embodied in these data-entry tools were developed in two projects which started in 2007 and investigated the outcomes of people using care home services and those using day care services. The three-level, nine-domain tool was developed for the day care MOPUS project. A four-level, eight-domain tool was subsequently developed in the OSCA project. Currently a working version is available (SCT4), although some aspects of the measure are undergoing further testing and refinement. In particular, the preference weights in the data-entry tools refer to a version with very minor wording differences to the current four-level version. We anticipate this making only minor differences, but new preference weights will be estimated in due course.

There is a great deal of common ground in these two measures. The intention was to assess whether adding a further level within each SCRQoL domain produced a justifiable increase in precision. The main difference between the three- and four-level versions is that the latter has more sensitivity in the top SCRQoL states: that is, for people with low needs. Nonetheless, the difference is small. We therefore advise users of these tools to select the version that best suits their specific needs.

The data-entry tools are designed to calculate the scores for samples of people using care services. In this way, investigators can use these tools to determine the sample average current SCRQoL score and also information summarising the distribution of scores. The potential applications are many. One highly relevant example is where investigators compare the (current) SCRQoL of two samples of people, one where a new service is provided and the other where the current service is used. The difference in mean SCRQoL scores between these groups is an indication of the SCRQoL gain associated with the new service compared with the existing service.

The data-entry tool for the three-level indicator also includes provision for investigators to enter service user condition, service use and background data collected from the day care self-completion questionnaire. These data can be used to predict the SCRQoL score of the person were they not to receive day care. A formula for this purpose was developed as part of the MOPUS project. By taking the difference between the current SCRQoL score and this predicted 'expected' SCRQoL score, predicted SCRQoL *gain* from day care service use can be calculated. This approach is useful because it precludes the need for investigators to compare day care service use with a group of people that did not use the service (as in the above example). Nonetheless, this prediction is an estimate. It is valid only for a sufficiently large and representative sample of people; individual person scores are generated but the mean difference should be used, not individual person differences. The mean SCRQoL gain

² The Measuring Outcomes for Public Service Users (MOPUS) project was funded over three years (2007-2009) by the Treasury under the Invest to Save budget and led by the Office for National Statistics (ONS) National Statistics.

³ The Outcomes of Social Care for Adults (OSCA) project was funded by the NIHR Health Technology Assessment programme (project number 06/96/01).

is calculated in the data-entry tool, along with the current SCRQoL scores.

Further information

Further information on ASCOT can be found on the ASCOT website (www.pssru.ac.uk/ascot). In particular, the frequently asked questions section and the forum will address common questions, and the future developments section will highlight the ongoing work on being carried out on developing ASCOT. The ASCOT team can also be contacted via email (ascot@kent.ac.uk).

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.
- Burchardt, T. (2004). Capabilities and disability: the capabilities framework and the social model of disability. *Disability and Society* 19(07): 735-752.
- Burge, P., Potoglou, D., Kim, C. and Hess, S. (2010) *How do the public value different outcomes of social care? Estimation of preference weights for ASCOT*, RAND working paper, Rand Europe, Cambridge.
- Cabinet Office (2005). *Improving the Life Chances of Disabled People*. London, The Stationery Office.
- Caiels, J., Forder, J., Malley, J., Netten, A. and Windle, K. (2009) *Measuring the outcome of low-level services: Final Report*, PSSRU Discussion Paper, Personal Social Services Research Unit, University of Kent.
- Department of Health (2005). *Independence, Well-being and Choice: Our Vision for the Future of Social Care for Adults in England*. London, The Stationery Office.
- Department of Health (2006). *Our Health, Our Care, Our Say: A new direction for community services*. London, The Stationery Office.
- EuroQol Group (1990) EuroQol - a new facility for the measurement of health-related quality of life, *Health Policy*, 16, 199-208.
- Harris, J., Foster, M., Morgan, H. & 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., Beadle-Brown, J., Trukeschitz, B., Towers, M., Welch, E., Forder, J., Smith, J. and Alden, E. (2010) *Measuring the outcomes of care homes*, PSSRU Discussion Paper 2696/2, Personal Social Services Research Unit, University of Kent, Canterbury.
- Netten, A., Burge, P., Malley, J., Potoglou, D., Brazier, J., Flynn, T. and Forder, J. (2009), *Outcomes of Social Care for Adults (OSCA) Interim findings*, PSSRU Discussion Paper 2648/2, 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. & Wall, B. (Forthcoming). *Outcomes of Social Care for Adults: Developing a Preference Weighted Measure*. HTA project number 06/96/01. London: NIHR Health Technology Assessment Programme.
- Netten A and Forder J (2010) Measuring productivity: an approach to measuring quality weighted outputs in social care, *Public Money and Management*, 30: 3, May, 159-166.

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., 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.

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.

Sen, A. (1985). *Commodities and capabilities*. Oxford, North-Holland.